Frailty in Tanzania: a longitudinal mixed methods study

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Abstract

Background

Population ageing is occurring globally and sub-Saharan Africa has the most rapidly growing older population. Frailty in old age is likely to become of increasing importance therefore. Several biomedical models of frailty have been proposed, including the frailty phenotype which defines frailty as a syndrome of age-related physical changes meeting a standard criteria. An alternative model is the frailty index, which conceptualises frailty as the product of accumulating age-related "deficits", these being diseases, disabilities, signs or symptoms.

Aims

The quantitative aspect of this study sought to operationalise both of these frailty models, comparing them with expert consensus, applied through the Comprehensive Geriatric Assessment. The aim was to investigate the prevalence characteristics and outcomes of frailty in rural Tanzania. The qualitative aspect of the study aimed to investigate how frailty is understood in the study's setting, as well as the lived-experience of frailty from the perspectives of older people and their communities.

Methods

Quantitative methods included screening adults aged ≥60 years from five randomly selected villages in rural Hai District, Northern Tanzania. Survey questionnaires and anthropometric measurements were conducted, alongside comprehensive geriatric assessments on a frailty-weighted cohort. Qualitative methods involved semi-structured interviews and focus group discussions with a purposive sample of older people, their family members, and community representatives. Transcripts were transcribed, translated and analysed thematically.

Results

Results showed that frailty by biomedical models detected frailty, and replicated the expected epidemiological patterns. Six qualitative themes were developed that demonstrated frailty to be experienced and understood as either a natural conclusion to a long life, or an aberrant form of ageing due to a scarcity of resources and care.

Discussion

Findings were synthesised dialectically in order to arrive at a deeper understanding of frailty, its characteristics and outcomes in this rural African context.

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Chapter 1 Introduction

1.1 The research questions

The research presented is a mixed methods longitudinal study investigating frailty in rural Tanzania. The overall question was kept broad and exploratory: “What is frailty in rural Tanzania?”

The question suggests, by its very asking, that frailty might differ in different contexts, suggesting that perhaps one definition cannot be applied in all settings. In order to investigate frailty, and explore it in context, a mixed methods design was required. Quantitative and qualitative methods were used to answer the following separate sub-questions.

1.1.1 Quantitative component research question

- Can the biomedical models of frailty be applied to measure and characterise frailty and its outcomes in this context?

The associated aim of which was to measure the prevalence, characteristics, and outcomes of frailty using biomedical measurements. These biomedical measurements are underpinned by theoretical models of frailty, thus this approach would allow these models to be investigated for their applicability cross-culturally, and the extent to which practical adaptations are required.

1.1.2 Qualitative component research questions

- How is frailty conceptualised?
- What is the lived-experience of frailty?
- How are frail older people cared for?

Having assumed that frailty may differ in different cultural settings, the qualitative component aimed to investigate how frailty is understood in the study’s setting, as well as the lived-experience of frailty from the perspectives of older people and their communities. The last qualitative research question also assumes that older people living with frailty may be treated differently in different social contexts.

1.2 The thesis organisation

1.2.1 A narrative review of the literature

Given the dearth of research in this field, a narrative approach was taken, allowing for inclusion of all literature deemed relevant in providing the background to this thesis. A traditional ‘systematic review’ with pre-defined inclusion criteria would have been too limiting in scope and breadth. The literature review presented incorporates biomedical and

interpretive social sciences literature relevant to the thesis, and highlights the current knowledge gaps.

1.2.2 Research methodology and methods

The study conceptualisation and design, followed by a detailed description of the quantitative and qualitative methods will be provided in this chapter. Given that this was a cross-cultural and cross-language study, particular attention has been paid to issues raised by this, including the ethics of conducting such work.

1.2.3 The prevalence of frailty in rural Tanzania

Each results chapter includes a focused discussion, often putting the results presented into context through comparisons with other key literature. These focused discussions, as part of each results chapter also permit a more detailed discussion of the strengths and limitations of each component of the results presented. The thesis was organised in this manner given that the discussion chapter aims to discuss and integrate the findings by topic, rather than by chapter. The first quantitative results chapter presents the results from the application of biomedical models to measure and characterise frailty, and provides a comparison of these operational measures.

1.2.4 Qualitative results, Parts One and Two

The first qualitative results chapter presents data from four themes which are relevant to answering the first two qualitative sub-questions. Thus providing insights into the conceptualisation and lived-experience of frailty. Part two, answers the last qualitative sub-question regarding the care of frail older people, presenting two further themes.

1.2.5 The biomedical outcomes associated with frailty at follow-up

The second quantitative results chapter presents the longitudinal follow-up data in an attempt to characterise the outcomes associated with frailty in this context.

1.2.6 Discussion chapter

This chapter seeks to bring together the two datasets in order to answer the research questions set out above. A summary of the key quantitative findings will be presented, followed by the qualitative results. Areas of agreement and overlap between the datasets will be presented, followed by areas of conflict. The implications of the findings, as well as important areas for future research will be discussed before concluding by answering the research questions by balancing and integrating the two datasets.

1.3 Defining and naming old age

In Tanzania, where life expectancy at birth is 65 for females and 63 for males, it may be surprising to know that average life expectancy *at* age 65 is 14 years (Kassebaum et al., 2016). It can be concluded, that long old age is already a reality for those who survive through childhood and young adulthood. Older people comprise 4.6% of the population now, which is expected to reach 7.2% by 2050 (United Nations Department of Economic and Social Affairs Population Division, 2019). Frailty is primarily a concept pertaining to older age, however there were particular challenges in defining and naming old age in this study. A chronological age of ≥60 years was decided upon for the purposes of conducting the quantitative component, on the basis that 60 is the statutory retirement age for Tanzanian government employees (National Social Security Fund, 2018). In practice, this applies only to a minority of Tanzanians as older people are rarely able to retire, given the absence of a universal social pension, which currently exists only in Zanzibar (HelpAge International, 2016). For approximately 80% of the population, including older adults, agriculture provides the majority with livelihoods on smallholder farms (UNDP, 2015). For many older people in rural Tanzania, particularly for those without formal education, their chronological age is unknown. Far more relevant, are the social markers of old age, such as becoming grandparents. Cattell chose a cultural age as the start-point for defining the "Samia elderly" in western Kenya, before afterwards determining their age chronologically (Cattell, 1990, p379). This approach was taken for the qualitative investigation of frailty, whereby older people were identified as "older" or living with frailty by the participant themselves or others close to them.

Given the current discomfort with the term "elderly" within UK medical and academic spheres, the term has been generally avoided throughout the thesis, in preference for the term "older people" (Quinlan and O'Neill, 2008). Yet, the Swahili term *"wazee"* might be best translated as "elders"; a respectful term, also conveying the social role of "elderhood" (McIntosh, 2017). Thus, it should be borne in mind that the English translation and general use of the term "older people", in its emphasis on conveying a neutrality towards older people, fails to express the particular Tanzanian *meaning* attributed to *"wazee"*, which is imbued with particular values and expectations.

1.4 Tanzanian Historical and Political context

This section seeks to set out the historical and political context of the age-cohort which was studied. The youngest of my study participants would have been born in the few years leading up to Tanganykian independence from British colonial rule in 1961, unification with Zanzibar, and the formation of the United Republic of Tanzania in 1962. However, many

older participants will remember these events and will have lived their young adulthood during this period. The first president of Tanzania, Julius Nyerere was leader from this time until 1985, and was also known as *"Baba wa Taifa"* (Father of the Nation) and *"Mwalimu"* (Teacher). His ideas have strongly influenced Tanzanian identity and values, leaving an important legacy, particularly in rural areas.

Firstly Nyerere's presidency succeeded in unifying the country behind nationalism, with the focus being development through "African socialism" (Brown and Brown, 1995). After independence, the country's unity was promoted by making Swahili the national language, endorsing its use over local tribal languages, thus facilitating a sense of belonging to the Tanzanian nation (Moore, 1996, Brown and Brown, 1995). This age-cohort will have been brought up with their local languages, ('Kichagga' and 'Kimasaai' mainly), but with Swahili being the language of education and institutions, and increasingly of their children and grandchildren.

Secondly, Nyerere placed rural development at the heart of his policies and ideologies (Brown and Brown, 1995). Many of this age-cohort of participants would have reached young adulthood by the time of Nyerere's policy paper in September 1967 entitled *"Ujamaa Vijijini"*, or "Socialism and Rural Development" (Komba, 1995). The *Ujamaa*[1] ideology put forward can be understood as Nyerere's attempt to combine the benefits of modern technology, for improving agricultural scale and efficiency, with African traditional society. Nyerere believed that Africans by tradition had been socialists in the sense that their culture encouraged them to think of themselves as members of a group, or a community, who live, work and share together for their collective good. Nyerere conceptualised of this *"Ujamaa"* socialist rural development as a process coming from the community's initiative, with external modernising assistance, but essentially led by a self-determining and co-operating community. The rural subsistence farmer might have been filled with optimism, in this period, hoping that these policies would lead to improved standards of living. In spite of the ultimate failure of implementation of Nyerere's *"Ujamaa"* scheme, co-operatives have not died out in rural villages, and the ethos of communal self-help is still important (Komba, 1995).

[1] The term *"Ujamaa"* means familyhood. In Nyerere's view this form of "African socialism" was required to build on the founding principles of traditional African life. KOMBA, D. 1995. Contribution to Rural Development: Ujamaa & Villagisation. *In:* LEGUM, C. & MMARI, G. (eds.) *Mwalimu: The influence of Nyerere.* London: James Currey Ltd.

1.4.1 Tanzanian population characteristics

Tanzania is categorised as a low income country by the World Bank, and is also in the low human development group, (ranked 154th from 189 countries) (UNDP, 2018). Despite a growing economy in gross domestic product terms, this has not translated into better living standards for the majority of Tanzanians (UNDP, 2015). A minority of 16.9% of the rural population have access to electricity, and only half of the population use improved drinking water sources (UNDP, 2018). The Multidimensional Poverty Index (an aggregate designed to capture the multiple overlapping deprivations that people in low income countries face in the areas of health, education and living standards) estimates that 55.6% and 26.1% of the population are multidimensionally poor, or severely multidimensionally poor respectively. In terms of income poverty, 49.1% are living under the international poverty line of less than $1.90 per day (UNDP, 2018). When the Human Development Index (HDI) (an aggregate of life expectancy at birth, education and income indices) is disaggregated by region however, three regions of Tanzania have higher HDI scores that are comparable to countries of medium human development; these regions are Arusha, Kilimanjaro, and Dar es Salaam (UNDP, 2015). This thesis is set in rural Kilimanjaro region, which is wealthier compared with the majority of Tanzania. Much of this wealth is due to tourism to Mount Kilimanjaro and the national parks, and good conditions for agriculture (the major commercial crops being coffee, maize and sunflower oil). This thesis, investigated rural-dwelling older people (68% of the population in 2016 lived rurally), so it should be noted that rural poverty rates are higher compared with urban areas (UNDP, 2015).

1.4.2 The local rural organisational systems

Hai District, in Kilimanjaro region, where this study is based, consists of 17 wards and 80 villages, distributed across high, middle, and lower altitude zones. The villages in Hai District are spread over an area of 902 km² producing a population density of 233.3 residents per km² compared with 2,907 residents per km2 in Moshi municipal (the nearest town) (Brinkhoff, 2017). These villages are separated administratively into hamlets, which in turn are broken into groups of ten-cells, or ten households. Each ten-cell has an appointed leader, a person chosen by those residents to represent them at village meetings. In the absence of road names, house numbers or post-codes, the ten-cell leader forms a means of locating an individual within the village, as well as a point of contact. The ten-cell leaders are called upon in the event of disputes, crime or antisocial behaviour, such as drunkenness. These ten-cell leaders are coordinated by the hamlet leader, who is under the authority of the village chairman and secretary, both government employees working at village offices, and who lead each village

committee. Official communications between the government and village members occur via these appointed representatives. These systems of organisation were put in place shortly after Tanzanian independence as a means of the ruling party maintaining control and communication with the largely rural and illiterate population (Finucane, 1974). The village committees consisting of around 25 people, select individuals to form sub-committees for health, education, economics, security, and infrastructure development (Ingle, 1972).

1.4.3 An introduction to the Tanzanian healthcare system

Tanzania spends $49 per capita/year on health, which equates to 7.3% of GDP, above the average for low-income countries (5.3%) (Health Policy Project, 2016). From independence until the early 1990s healthcare was free as part of Nyerere's policy for universal access to basic services (Green, 1995). Afterwards user fees were introduced, alongside waivers for vulnerable groups, including adults aged ≥60 years (Maluka, 2013). While these exemption schemes are in theory pro-poor, their ineffective implementation disadvantage vulnerable groups (Mtei et al., 2012). Today a wide range of private and faith-based healthcare providers as well as traditional healers are utilized, these providers charge their own user-fees and do not follow the government waiver system (Brinda et al., 2014, Mtei et al., 2012).

This background and context will be helpful throughout the thesis.

Chapter 2 A Narrative Review of the Literature: Frailty in sub-Saharan Africa

2.1 Introduction to the chapter

This chapter introduces the topic of frailty in ageing, according to both biomedical and interpretive social sciences literature. The controversies and remaining knowledge gaps relating to the present study will be discussed in order to provide a rationale and context to the research questions of this thesis.

The first section includes a narrative review of biomedical literature which synthesises and describes the concept of frailty according to its key characteristics. There is currently no consensus definition of frailty, so the next sections will describe the controversies and questions posed by the different, and sometimes opposing dominant biomedical models. Throughout this chapter the term "model" is used to describe the underlying conceptual framework for frailty, while the terms "measurement", "tool" or "instrument" are used where the theoretical model is being applied. Overall, the biomedical conceptualisation sees frailty as a pre-disability state of vulnerability, which is dynamic, involving multiple body systems, and usually associated with chronic multimorbidity. The value and use of the concept from the perspective of the biomedical literature will also be discussed.

Next, the narrative review will focus on studies of frailty in low and middle income countries (LMICs), then in sub-Saharan Africa (SSA). Given the paucity of research from SSA, the search was broadened to include the related concept of functional disability in older community-dwelling adults. Other closely-associated concepts; falls and HIV-associated frailty were included. Two questions will be answered through the review of this literature body; firstly, how has frailty been conceptualised according to biomedicine, and secondly the extent to which the biomedical models have been applied in LMIC settings.

The interpretive social sciences literature review was used to provide a counter-perspective and to challenge the dominant biomedical models of frailty. This narrative review of the interpretive social sciences literature focused on qualitative investigations of the lived-experience of frailty in different community contexts. Included are relevant work from anthropology, gerontology and health policy backgrounds, which have investigated ageing, frailty and care for older people in SSA. The interpretive social sciences literature will be examined with reference to the biomedical literature in order to provide further rationale for taking a mixed-methods approach in this thesis.

2.2 Approach to the literature review

A narrative approach was taken to investigating the literature relevant to both the quantitative and qualitative components of the present study (Cronin et al., 2008). The overall aim was to bring together the literature relevant to the current study, and to synthesise the literature by topic. A narrative approach was seen as more appropriate than a systematic review, given that it allowed more flexibility, and provided scope for exploration across a wide range of academic work. The review of the interpretive social sciences literature was initially scoping and broad, and was followed by a continuous, iterative review of literature driven by data generated during fieldwork, and its analysis. In contrast, the biomedical literature presented in this chapter, despite not conforming to the rigours of a systematic literature review, was approached more systematically by topic.

2.3 Biomedical literature search strategy

Studies were of interest, if they discussed the construct and definition of frailty, or if they included cohort, cross-sectional or observational studies of frailty, its associations, characteristics, or outcomes from older populations in community settings. Papers that focused on specific sub-groups of older people were excluded. Studies which solely focused on the hospital prevalence or incidence of frailty, or that were interventional (e.g. trials or service evaluations), were also not deemed relevant to the present study's research questions. No limits were placed on geographical location, and studies that included institutional community settings were deemed appropriate. No specific age cut-off was used to define the population of interest in order to be as inclusive as possible of frailty studies in LMICs, (although authors usually defined the population as "older adults"). Medline and Embase databases were chosen as key repositories of biomedical and healthcare literature. They were searched using the term frail* in title or abstract, and the subject heading "frail elderly". Systematic review articles were used to provide an up-to-date introduction of certain sub-topics, such as frailty and HIV. Outlier and contradictory findings were sought-out and examined, particularly where the existing literature was sparse. Given the lack of frailty research in older people in SSA, a broader search was conducted for the related concepts of functional disability and falls. These were searched in Medline and Embase databases as truncated keywords (disab*, fall*). These terms were searched without specific geographical limitations, and were also combined with searches of countries classified as SSA countries according to the World Bank[2] or with the search term "Africa South of the Sahara".

[2] Research coming from any of the following countries were included: Angola, Benin, Botswana, Burkina Faso, Burundi, Cabo Verde (Cape Verde), Cameroon, Central African Republic, Chad, Comoros, Dem. Rep. Congo, Rep. Congo, Cote d'Ivoire, Equatorial Guinea, Eritrea, Eswatini (Swaziland), Ethiopia, Gabon, The Gambia,

2.4 Interpretive social sciences literature search

An initial scoping review of the literature was conducted prior to starting fieldwork, primarily in order to confirm the gap in present knowledge. During the process of data co-construction, an iterative, data-driven literature review was conducted with continuous reflection and comparison between the data, developing themes, and existing literature. This practice is consistent with a constructivist epistemology, which acknowledges that knowledge is constructed through social interactions and lived-experiences (Lincoln et al., 2018). Thus the author's interactions with the literature, and the thinking which developed as a result were part of the enquiry process which contributed to the construction and analysis of the qualitative data.

The three primary questions which guided the literature searches were; how has frailty been conceptualised cross-culturally, and what is the lived-experience of frailty according to current literature, and what is known currently about the care of older people in SSA? The databases Scopus, Medline, and PsycINFO, were searched using the term frail* combined with search terms such as "care" "ageing" "dependency", "experience" and "qualitative", in title or abstract. Key journals such as Ageing & Society and The Journal of Cross-Cultural Gerontology were searched, screening for relevant articles by title and abstract and reference-chaining was often employed.

2.5 Biomedical frailty literature

The literature synthesised in the first half of this chapter attempts to draw out some of the broadly agreed-upon characteristics of frailty. Following this, the key biomedical models of frailty will be introduced and discussed, these being the frailty phenotype (FP) model and the deficit accumulation model, used to produce the frailty index (FI). The comprehensive geriatric assessment (CGA) will also be discussed, as an important clinical tool for the identification and management of frailty. Topics which are closely related to frailty will be introduced; sarcopenia, cognitive frailty and social frailty. From the many frailty screening tools, developed for use in clinical and research settings, the two which were chosen for use in the present study will be introduced with justification. The epidemiology of frailty in LMICs will be discussed, followed by the studies investigating frailty in SSA to date. Next, the closely-related and often overlapping concept of disability in older people will be synthesised

Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Liberia, Madagascar, Malawi, Mali, Mauritania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Rwanda, Sao Tome and Principe, Senegal, Seychelles, Sierra Leone, Somalia, South Africa, South Sudan, Sudan, Tanzania, Togo, Uganda, Zambia, Zimbabwe.

by SSA country. The other topics limited to research conducted in SSA were falls, and frailty in HIV/AIDS.

2.5.1 Frailty: A vulnerable state

This chapter will start by examining the biomedical literature which has sought to describe and define the construct of frailty, however there is currently a lack of consensus on an agreed definition of frailty (Bergman et al., 2007). Frailty doesn't fit with the typical model of a disease which has characteristic clinical signs or biomarkers permitting a neat diagnosis, prognostication, and a target for therapy. Neither a disease state nor a health state, the state of frailty, has been called a state of vulnerability to poor health (Junius-Walker et al., 2018).

Clegg's comprehensive review of frailty illustrates this concept of vulnerability effectively using the example of a minor urinary tract infection (*Figure 2-1*) (Clegg et al., 2013). A short deterioration in health status and full recovery occurs in a non-frail and independent person (illustrated by the green line), however the same minor infection in a frail individual leads to a worse and more prolonged deterioration in health status, and a failure to recover to their previous level of health and independence (red line) (Clegg et al., 2013). These factors which lead to "adverse health outcomes" are usually termed "stressors" and may be acute or chronic, endogenous or exogenous (Junius-Walker et al., 2018). "Adverse health outcomes" which have been associated with frailty include institutional and hospital admissions, increasing disability and dependency, and impaired mobility and falls (Clegg et al., 2013). As a result, frailty has often been seen as a pre-disability state (Rodriguez-Manas et al., 2013). Frailty is also associated with a lower self-reported quality of life, compared with non-frail individuals (Kojima et al., 2016).

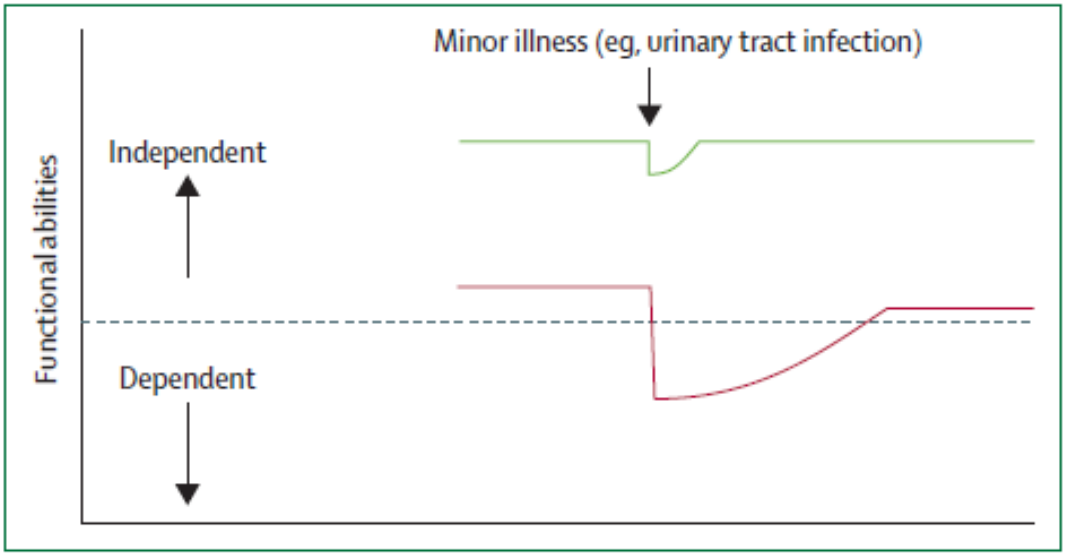
Frailty, by all measures and conceptualisations is also highly predictive of death (Clegg et al., 2013). The increased risk of death is sometimes discussed as "premature death" and thought of as one of the "adverse outcomes" of frailty (Junius-Walker et al., 2018). However it is largely also acknowledged that frailty is in fact on the continuum of, and difficult to distinguish from the "normal" ageing process (Bergman et al., 2007), rather than being due to a separate pathophysiology. While frailty may be based on underlying mechanisms of ageing (such as cell senescence), it is not an inevitable consequence of ageing. Although rare, it is possible to reach old age in good health. Illustrating this, a longitudinal prospective cohort study of 1,292 older American men followed-up over 21 years, found that from 77% who survived to 85 years, 34% were healthy, and from 24% surviving to 95 years, <1% were

healthy (Bell et al., 2014). Healthy survival was defined by Bell et al. as being free from six common chronic diseases and not having physical or cognitive impairment.

It is as yet unknown whether this conceptualisation can be usefully applied in the Tanzanian context, where the underlying health state of an older person may be affected by life-long disadvantages of multidimensional poverty, and where poverty may lead to a reduced ability to withstand adverse social, psychological or physical stressors (McDonough et al., 2005). Taking the life course approach to ageing these disadvantages are present from early development, where nutrition, disease, access to healthcare and other resources, influence the peak of health attained in adulthood, which in turn influences the trajectory of old age (Hanson et al., 2016). Importantly, the life course trajectory differs between high and low-resource settings; illustrated by cross-country comparisons of hand grip strength (HGS) and adult height, which increase with country income level (Dodds et al., 2016, Perkins et al., 2016).

It is useful to take into account these broader social and environmental determinants of health, and their influence on healthy ageing, when referring to the model of individual "vulnerability" as illustrated in (*Figure 2-1*). An older individual in a low-income country (LIC) setting such as Tanzania, may start from a lower state of health and functioning, compared to an older person in a high-income country (HIC). With reference to *Figure 2-1*, the green line in Tanzania, (representing healthy independence), may run parallel, but below the HIC green line. Taking the example of a urinary tract infection, (used in the diagram to illustrate a stressor event), an older Tanzanian may face additional challenges recovering from such an insult, due to inequalities in accessing healthcare compared with HICs; the dip in health and independence may be deeper and wider, producing more frailty. Another aspect where the vulnerability model used to conceptualise frailty may diverge in rural Tanzania, is in the concept of the binary "dependent" and "independent" health state, which may be more complex in a context where older people often live in multi-generational households, continue to work late into old-age, and are frequently in care-giving roles (Aboderin and Beard, 2015).

Figure 2-1 Vulnerability of frail older people to sudden changes in health status after a minor illness



(Clegg et al., 2013)

2.5.2 The characteristics of frailty

Frailty may be characterised by its complexity, whereby multiple body systems may be involved in interacting and inter-related dysregulations (Junius-Walker et al., 2018). For example, a problem in one body system e.g. visual impairment, might worsen frailty by reducing mobility, and reducing food intake, both leading to worsening disability and frailty. This produces a dynamic state of frailty, which is generally progressive, but may change day-by-day (Gobbens et al., 2010). The instability of the frailty state is recognised in its multiple varying clinical presentations, these being worsening and fluctuating disability, delirium, falls and non-specific manifestations such as extreme fatigue, weight loss and recurrent infection (Clegg et al., 2013). There is evidence for some degree of reversibility in the trajectory of frailty. According to a recent systematic review of 16 observational studies with a mean follow-up period of 3.9 years, pooled analysis demonstrated that 13.7% improved, while 29.1% deteriorated, and 56.5% maintained their frailty status without intervention (Kojima et al., 2019). Therefore, it is agreed that frailty, at least theoretically may have some degree of reversibility or be amenable to modification (Rodriguez-Manas et al., 2013). The unpredictability of the trajectory of frailty towards the end-of-life was described by Lunney et al. whereby, frail individuals were eight-times more likely to be functionally dependent in the last months of life, yet due to chronic illness, and a predisposed vulnerability to acute ill-health, the frail did not follow a predictable terminal deterioration (Lunney et al., 2003).

Frailty is often characterised by its co-existence with chronic disease, and multimorbidity has been conceptualised as a distinct but overlapping phenomenon (Fried et al., 2004). In order to make more of this distinction, frailty has on occasion been categorised as either primary or secondary frailty, that is, frailty due to underlying chronic disease, or occurring de novo (Fried LP and Walston J, 2003). Indeed, some chronic diseases such as Parkinson's disease and depression, which could mimic aspects of the physical presentation of frailty, (for example exhaustion and slow walking speed), were excluded from Fried's original phenotype study (Fried et al., 2001). It has been suggested that the link between frailty and chronic disease lies in the fact that acute and chronic disease burden leads to a faster loss of physiological reserve (Bergman et al., 2007). Alternatively, if the underlying mechanism of physical frailty is dysregulation of physiological homeostasis, both chronic disease and frailty may occur as a result of this same dysregulation (Bergman et al., 2007).

2.5.3 The utility of frailty in biomedicine

One of the primary benefits of the concept of frailty, it has been argued, is in the fact that it requires a paradigm shift away from disease-specific models of disease and healthcare, to taking a more integrated approach to older people and their health (Junius-Walker et al., 2018, Bergman et al., 2007). The added value of identifying frailty, or pre-frailty as opposed to measuring functional disability in activities of daily living (ADLs) is that it may allow for the identification of vulnerability before disabilities in functioning have become apparent (Cesari et al., 2014a). The second key argument for its value, is as a method for classifying and responding to the heterogeneity of health and functioning in older people. This argument states that chronological age is a crude, and ultimately ageist way of approaching the health assessment of older people, whereas applying frailty measures permits a more sensitive means of identifying older adults most at-risk, based on frailty as an approximation of their physiological reserves (Mitnitski et al., 2005). The concept of frailty may be a useful guide to clinical decision-making, helping to promote appropriate therapies and interventions, while avoiding withholding these from those who are physiologically robust despite older age (Khatry et al., 2018).

Diagnosing frailty has permitted the implementation of successful interventions to modify its trajectory, for example complex interventions applied through the CGA in the hospital setting, have shown improved survival to discharge and an increased likelihood of living independently (Ellis et al., 2011). Systematic reviews have also shown a modest impact from strength-based exercise interventions, with the least frail deriving the most benefit (Theou et al., 2011, Clegg et al., 2012). Frailty then, has proved useful in order to distinguish between

the irreversible and inevitable processes of ageing, and the potentially modifiable factors associated with ageing.

To sum up so far, frailty according to biomedical literature is largely conceived of as a dynamic state of vulnerability to adverse health outcomes. It is generally agreed that chronic diseases and disability are both closely related, but distinct entities, although their relationships with frailty have yet to be clearly distinguished. Frailty's utility, it is argued, hinges on the fact that it calls for a shift in thinking away from a single disease or body-system approach to health and healthcare, toward a more holistic approach, to the benefit of those living with frailty. The concept has also proved useful in order to risk-assess older people, proving a more accurate and acceptable identifier of vulnerability than chronological age, with the aim of guiding clinical decision making and optimising health in ageing.

The main areas of controversy question whether frailty should be thought of, and operationalised as a distinct clinical picture comprising a constellation of signs and symptoms, or whether frailty is the extreme of a spectrum of ageing states, formed of the sum of an accumulation of age-related adverse changes. Another area lacking consensus is which are the critical domains of frailty. It is unclear whether frailty should be thought of as a wholly biological process, or should include biological, psychological and social age-related changes. The following sections will discuss each perspective and outline the key literature in this debate.

2.6 The phenotype model

Fried proposed the simple five-item phenotype model of frailty and demonstrated that it was distinct from the similar and overlapping ageing-associated entities of disability and multimorbidity (Fried et al., 2001). The focus of the FP is on both subjective and objective physical changes, which are derived from the theoretical "cycle of frailty" (*Figure 2-2*) (Fried et al., 2001). Fried acknowledges that frailty comprises multiple systems of dysregulation, however highlights five core components forming the syndrome. Most of which can be objectively assessed: Weakness, measured by HGS, slowness, captured by walking speed, unintentional weight loss (defined as ≥5% by serial weight measurement), exhaustion and low physical activity (Fried et al., 2001). This method, produces a graded categorisation of non-frail (0/5 frailty components), pre-frail (1-2/5) and frail (3-5/5) and predicts adverse outcomes such as disability, falls, hospitalisation and death in a graded manner (Fried et al., 2001). The construct validity of the FP was assessed using independent data from the Women's Health and Ageing Studies (Bandeen-Roche et al., 2006). Analysis by Bandeen-Roche et al.

confirmed that the FP components aggregate in the manner of a syndrome as opposed to being composite of distinct symptoms and signs.

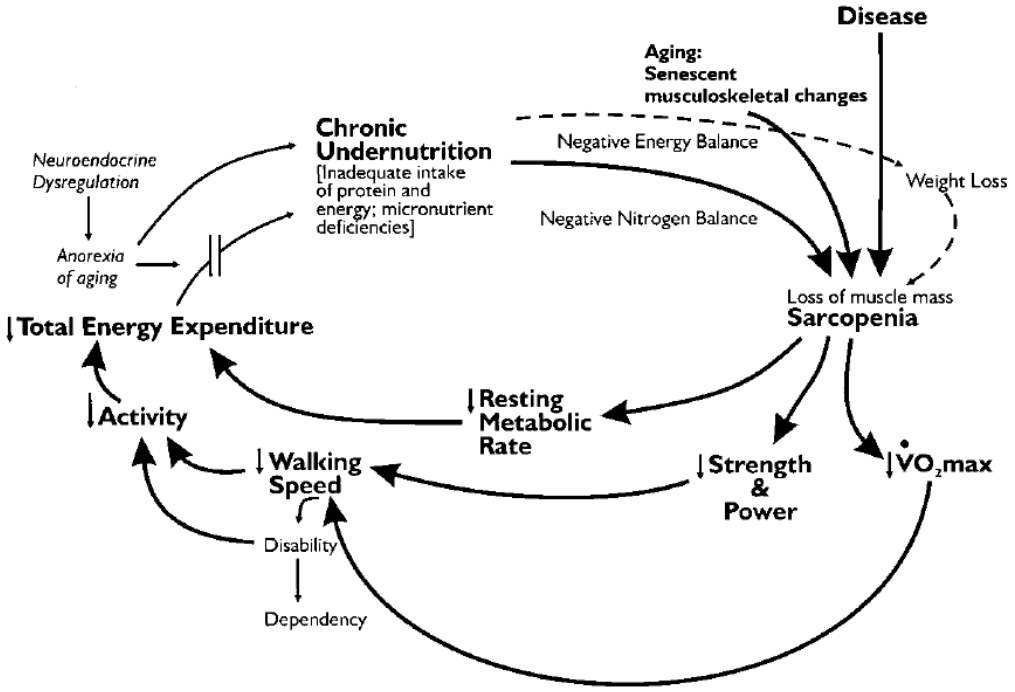
The FP has however been criticised for being too focused on the process of physical ageing, giving little weight to potential psychological and social aspects which may contribute to an older person's frailty (Gobbens et al., 2010). In one example of the limitations of the FP, the "cycle of frailty" recognises chronic undernutrition due to "the anorexia of ageing" as part of the cyclical deterioration seen in frailty (*Figure 2-2*). According to this model, the process is largely driven by a biological age-associated process of inflammation and neuroendocrine dysregulation, leading to reduced appetite (Heuberger, 2011). However the factors leading to reduced food intake in older age, are multifactorial and complex, with social factors (such as affordability of foods, difficulty preparing meals), psychological factors (low mood, loneliness) and potentially modifiable disease processes (such as thyroid disorders or tooth loss) which may contribute (Malafarina et al., 2013). There are some signs of a developing consensus among experts that a frailty assessment should include assessments of mental health, cognition, and nutritional status in addition to the "physical" aspects of syndromic frailty, suggesting that the FP offers too narrow a view of the multisystem complexity of frailty (Rodriguez-Manas et al., 2013).

The lack of consensus definition has influenced the terminology and language of frailty, causing significant heterogeneity, for example Fried's FP has also been termed the "Fried frailty index" (Collard et al., 2012), "physical frailty" (Verlaan et al., 2017), the "biologic syndrome model" (Cigolle et al., 2009), or the "frailty syndrome" (Heuberger, 2011). Such variation in terminology is also reflected in the application of these criteria. A systematic review found that only 24 from 264 studies had satisfied the criteria of the original Fried FP, with modifications most often applied to the measures of weight loss and physical activity (Theou et al., 2015). This operational variation suggests that, despite its apparent simplicity, it may be difficult to apply in practice. This is an important weakness, as modifications to the FP, and treatment of missing data caused wide variations in prevalence estimates ranging from 12.7% to 28.2%, with hazard ratios for survival also ranging from 2.47 to 3.48 (Theou et al., 2015).

Another limitation of the FP is that it may lead to an under-estimation of sarcopenic obesity, or frailty in obese individuals (Bergman et al., 2007). This may occur particularly when the "unintentional weight loss" component of the FP is categorised as those with a low body mass index (BMI) (Theou et al., 2015). Sarcopenia, its obese variant, and its relationship with

frailty will be discussed further in a forthcoming section. The FP may also under-estimate frailty in populations where disability precludes objective testing (for example of HGS and walking speed) depending on how these missing data are handled. Cesari et al. have argued as a result, that the FP is best applied in pre-disability states, and may be usefully applied as a form of screening in order to identify the pre-disabled frail and pre-frail (Cesari et al., 2014a).

Figure 2-2 The cycle of frailty



(Fried et al., 2001)

2.7 The deficit accumulation model

According to Rockwood's deficit accumulation model, an individual's frailty in all its complexity can be distilled elegantly into an single number (Rockwood and Mitnitski, 2007). The underlying concept is that, as a person ages, their multiple body systems start to fail - through mechanisms such as cell senescence, and dysregulated inflammatory and neuroendocrine pathways- leading to an increased "allostatic load", or "wear and tear" at a sub-cellular level (Mitnitski et al., 2005). This process leads to a measurable build-up of "deficits" affecting tissues, organs, and body systems with time (Rockwood and Mitnitski, 2012). The FI simply represents the proportion of deficits from all those counted. The characteristics of the FI include a stable rate of deficit accumulation of 3% per year at a population level (Mitnitski et al., 2005). Additionally, there is a reproducible upper limit (0.65+/-0.05) after which, even in HIC settings it is not possible to survive further deficit accumulation (Rockwood and Mitnitski, 2006).

These characteristics of the FI, in contrast with the FP, show considerable stability as long as its key tenets are adhered to. “Deficits” are defined loosely as any age-associated symptom, sign, disability or diagnosis, which are health-related (Searle et al., 2008). Additionally, deficits should not reach saturation too early, for example presbyopia, an age-associated difficulty with near vision, which is almost universal by age 55 years, would not be a suitable deficit to include in a FI (Searle et al., 2008). The question of which deficits to count is also flexibly defined, as long as a range of different body systems are included, and these reach around 30-40 deficits (Searle et al., 2008). Thus, included parameters are usually a combination of measurements and survey responses, defined by medical/research professionals. Whether to include deficits on an ordinal or binary categorical scale (deficit vs no deficit) does not affect the performance of the FI (Pena et al., 2014). There is some contention as to whether social and psychological components should feature, however in general, the deficit accumulation model provides a broader multi-component approach to frailty than the FP (Collard et al., 2012).

One of the many strengths of the FI is that it produces a continuum of values, avoiding the influence of any arbitrary cut-off points. Indeed the FI, it could be argued, is primarily an epidemiological tool which can illustrate frailty trajectories in a population (Cesari et al., 2014a). It enables comparisons of frailty between countries and populations, and predicts population level outcomes accurately. However this is a potential weakness, when applied to individuals in a clinical setting, as it is not *how many* deficits which is likely to matter to the individual, but *which* deficits. While a population’s rate of deficit accumulation may occur at a stable and predictable rate, deficits occur at varying and unpredictable rates within individuals. Therefore, the FI provides an indication of risk but does not help to predict individual level variation in the rate or characteristic of decline (Rockwood and Mitnitski, 2006).

The FI requires large numbers of variables (>30) to produce stable estimates (Searle et al., 2008). This has traditionally limited its practical application in clinical settings. However, this was challenged recently following the development of the electronic FI which uses routinely collected data from UK primary care electronic health records to calculate FI scores for individuals (Clegg et al., 2016). The electronic FI has predictive validity for hospitalisation, institutionalisation and death, and authors claim it has potential for enabling the delivery of evidence-based interventions to modify frailty trajectories. Yet, at which stage, and how to best influence the trajectory of frailty is unclear, as is the question of how an individual’s FI score should be interpreted to guide person-centred healthcare.

2.8 The comprehensive geriatric assessment

The CGA comprises several key components; multidisciplinary assessment, geriatric medicine expertise, identification of problems across multiple domains including social and psychological, and the formulation of a personalised care plan (Ellis et al., 2011). In essence the conceptual framework underlying the CGA privileges the expertise and skill of a multidisciplinary team of healthcare professionals. It has been called the "gold standard" for the detection of frailty (Clegg et al., 2013) and correlates highly with the FI in its predictive validity for hospitalisation and death (Rockwood et al., 2005, Jones et al., 2004). In contrast to the FI and FP, the CGA is designed to be individualised, drawing on the priorities and values of the older person and their family or care-givers. The CGA takes into account the complexity of caring for older people, acknowledging that a single problem may impact on and be affected by, many other domains. The application of a personalised care plan allows for adaptation between individuals and over time, thus remaining responsive to the dynamic nature of frailty. Importantly, the CGA improves clinical outcomes for inpatients (Stuck et al., 1993, Ellis et al., 2011).

While the main perceived strength of the CGA may be its capacity for delivering "person-centred care", a recent study has highlighted that the CGA may in-fact be more health-professional-centred in practice: Trained nurses conducting CGA assessments in community-dwelling older people in the Netherlands identified a median of eight geriatric conditions per participant, the most prevalent being functional dependency, risk of alcohol dependency and polypharmacy (van Rijn et al., 2016). However, the older people identified a median of 1 geriatric condition as a problem, the most recognised being pain and depression (van Rijn et al., 2016). This lack of concurrence between CGA-assessors and older people's perceptions of what constitutes a "problem" highlights that the CGA may not always align with older people's priorities, despite its potential for doing so.

2.9 Comparing frailty models

Studies have shown that while there is much overlap between these three dominant conceptualisations and measures of frailty, in practice each identifies different individuals as frail within a population (Cigolle et al., 2009). Cigolle et al. found some overlap between three models termed the "biologic syndrome model" (FP), "burden model" (FI), and "functional domains model" (which is most closely aligned with the CGA). Almost one-third (30.2%) of respondents were frail according to at least one model, however only 3.1% were frail according to all three (Cigolle et al., 2009). Data from the Canadian Study of Health and Aging were used to produce a FI and FP and their degree of correlation were compared

(Rockwood et al., 2007). Overall correlation between the two models was good (R=0.65) however the correlation for cognitive impairment was low. They concluded that both measures of frailty have utility, while the FI may provide more precise estimates given its continuous rather than categorical frailty classification.

The potentially complementary and differing nature of these frailty models has important implications for this study of frailty in a low-income rural SSA setting, where older adults have poor access to healthcare (Frumence et al., 2017). One factor to bear in mind is the fact that the FI relies heavily on diagnosed medical conditions and "describes a risk profile closer to the one measured by a clinician" (Cesari et al., 2014a). In contrast, an individual may be classified as frail according to the FP in the absence of ever having received a clinical diagnosis. Yet, in its conceptualisation of frailty as a precursor and contributor to disability, the FP may under-estimate the true burden of frailty in a context where frailty may progress more rapidly to disability due to a lack of access to affordable healthcare.

Across all measures, frailty is highly predictive of death, but the prevalence of frailty has consistently been found to be higher among women, and in older ages (Collard et al., 2012, Shamliyan et al., 2013). These systematic reviews also reveal a pattern of higher prevalence rates when frailty is measured according to broader definitions, such as the FI, compared with the FP (Collard et al., 2012, Shamliyan et al., 2013). For example, where the overall weighted prevalence of frailty was 10.7% (21 studies, N= 61,500 participants), the weighted prevalence was 9.9% for "physical frailty" (15 studies, N= 44,894 participants) and 13.6% for the "broad phenotype of frailty" (8 studies; 24,072 participants) (Collard et al., 2012). In a study of mobile community dwelling adults in China, the sensitivity and specificity of the FI and FP for mortality were compared by sex (Woo et al., 2012). Frailty by both measures had a similar sensitivity and specificity for death, however the positive predictive value for both measures was higher for men compared with women. A meta-analysis of the FI has described the phenomenon of higher FI scores in women at all ages compared with men, but a higher risk of death for men (Gordon et al., 2017).

While the reasons for this consistent, reproducible finding, termed the "male-female health-survival paradox" are unclear, it is likely to be due to multifactorial biological, social and psychological factors (Gordon et al., 2017, Gordon and Hubbard, 2019). There are likely to be some biological sex differences which explain some of this finding, for example chronic inflammation may mediate the relationship between cognitive impairment and sarcopenia to a greater degree in women (Canon and Crimmins, 2011). Gordon et al. have also hypothesised

that women may have a higher physiological reserve compared with men, allowing them to tolerate higher levels of frailty (Gordon et al., 2017). Yet this is a poorly understood phenomenon, with particularly little known about the impact of social and psychological factors cross-culturally.

2.10 Related concepts: Sarcopenia, Cognitive frailty and Social frailty

2.10.1 Sarcopenia

Sarcopenia is described as skeletal muscle failure occurring in old age, due to adverse muscle changes that accrue over time (Cruz-Jentoft et al., 2019). It could be described as a single system frailty, and consequently has many areas of overlap with frailty: According to the FP, sarcopenia is integral to the "cycle of frailty", measured by HGS (*Figure 2-2*). Slow walking speed may also be perceived as a functional measurement of sarcopenia, and weight loss, a further component of Fried's syndromic model, forms part of the aetiology of sarcopenia (Cruz-Jentoft et al., 2019). Cesari et al. hold a pragmatic view, arguing that there is little clinical value in seeking to untangle the causal relationship between frailty and sarcopenia (Cesari et al., 2014b). Rather, the authors assert that what the two conditions share in common is their ability to detect measurable physical impairment in advance of the development of functional and mobility-disability. Given this shared characteristic, frailty and sarcopenia may both help to identify targets for prevention of disability in old age (Cesari et al., 2014b). Indeed, the therapeutic approaches between frailty and sarcopenia both overlap, particularly with regards to exercise for building strength (Cruz-Jentoft et al., 2019).

In conjunction with a loss of skeletal muscle mass with age, adipose tissue can increase. A high ratio of body fat to skeletal muscle mass is termed sarcopenic obesity (Zaslavsky et al., 2013). Adipose tissue has been shown to release pro-inflammatory cytokines which may contribute to the pathogenesis of both sarcopenia and frailty (Cooper et al., 2012). Importantly sarcopenic obesity has been shown to be more significantly associated with ADL and instrumental activity of daily living (IADL) -disability in a longitudinal study of men, compared with sarcopenia alone (Hirani et al., 2017). Both phenotypes were significantly associated with developing frailty over the five year follow-up (sarcopenia adjusted OR 2.12 and sarcopenic obesity adjusted OR 2.00) (Hirani et al., 2017).

2.10.2 Cognitive frailty

Cognitive frailty has evolved as a concept over recent years, initially used to describe the co-occurrence of mild cognitive impairment and physical frailty, without the presence of dementia (Facal et al., 2019). The characteristics of cognitive frailty have since been

developed, so that it is now viewed as including the potentially reversible state of subjective cognitive decline and pre-physical frailty (at which stage it is thought preventative interventions could be targeted). Conceptually, it is thought of as a state of reduced cognitive reserve differentiated from "normal" brain ageing by a theoretical potential reversibility (Ruan et al., 2015). Despite this, no empirical trials of interventions for these potentially reversible states have been published (Facal et al., 2019). Facal et al. conclude by explaining that neither physical nor cognitive areas of functioning are subordinated to each other, and recommend that the operational definitions of physical and cognitive frailty also incorporate social and psychological variables, (for example reading habits and social environment) given that these factors are likely to influence an individual's cognitive reserves as they age. Interestingly, these authors seem to be arguing for a broader more multi-component approach to (cognitive) frailty (Facal et al., 2019). This emerging convergence between concepts can be evidenced by the fact that operational frailty instruments increasingly include a component screening for cognitive impairment: In a systematic review of 94 frailty tools, 46% included a cognitive measure, a significant majority of these papers being published after 2010 (Vella Azzopardi et al., 2018).

2.10.3 Social frailty

Social frailty has been defined as *"a continuum of being at risk of losing, or having lost, resources that are important for fulfilling one or more basic social needs during the life span"* (Bunt et al., 2017). This was concluded following a scoping review of 42 studies relating to the concept. Most of the studies analysed included assessments of general and social resources, for example education level and marital status, however these variables may also act as proxy measurements for other social need fulfilment, such as for affection or status (Bunt et al., 2017). Bunt et al. acknowledge that social needs are culturally determined, and that there is a lack of research investigating cross-cultural differences, a significant knowledge gap, given that all prior research on this topic has been from HIC settings.

It has been shown that frailty is distributed along socio-economic gradients, both between and within high and LMICs when employing both FP and FI methods (Hoogendijk et al., 2018, Szanton et al., 2010, Etman et al., 2012). Individual wealth and neighbourhood deprivation were both independently associated with frailty (by FI) in a nationally representative population-based English study (Lang et al., 2009), suggesting the importance of environmental factors and broader social determinants of health in shaping health in old age. In a longitudinal study of frailty status changes in European countries, older community-dwelling adults were at an increased risk of developing frailty earlier in southern European

countries, which was attributed to differences in healthcare access and patterns of institutionalisation; both factors which differ significantly in rural SSA compared with HICs (Etman et al., 2012). Analysis of data from the Women's Health and Aging Studies found that odds of frailty were increased for those of low socio-economic status measured by income and education status, independent of age, race, health insurance, smoking and co-morbidities (Szanton et al., 2010). African-Americans were more likely to be frail than Caucasians ($p<0.01$), however, the effect of race was confounded by socio-economic status, an important finding to consider when investigating frailty in a low-income rural African setting. That is, any differences found between HICs and LMICs should not be attributed to genetic or racial differences, without first controlling for the disparity in wealth.

Education status has often been used as a measure of socio-economic status, and older adults with low educational attainment have substantially higher odds of being frail (Hoogendijk et al., 2014). The effects of education level over a 12-year cohort study in the Netherlands showed that, while frailty increased over the follow-up period, frailty rates did not differ according to education level (Hoogendijk et al., 2014). The authors concede that the impact of education on frailty may have been underestimated due to deaths in those with lower education levels over the follow-up period, however the effect of education on frailty was largely explained by income, self-efficacy, cognitive function, obesity and chronic diseases in longitudinal regression analysis. That is, education status was a proxy for a host of interacting factors, and may mediate an increased frailty prevalence through poorer health behaviours and knowledge.

Overall, it can be concluded that the concept of "social frailty" may be an approximation of an individual's lifetime of disadvantages or resilience to withstand stressor events through their ability to access social support and general resources. Despite the lack of clarity around its assessment, the "social aspects" of frailty are increasingly included in research and clinical tools. In a systematic review of frailty instruments with social components, 27 assessment tools were identified which included at least one social measurement (Bessa et al., 2018). The extent to which these assessments focused on frailty's social aspects ranged from a 5% to 43% weighting, while three assessments focused solely on social frailty. The domains of social frailty most often included in assessments were social activities (participation and frequency), social support (instrumental and emotional), social network (its composition, size and strength), the experience of loneliness and living alone.

Summarising this section on the three related concepts, it could be argued that sarcopenia, cognitive frailty, and social frailty, are all the products of a single specialism or system-based perspective on frailty. Taking a more focused approach could be beneficial by resulting in more focused solutions or therapies. However, these related models could all be criticised for lacking an appreciation of the complexity of frailty in ageing, and for prioritising one form of functioning (physical strength, cognitive processing, or social participation), over others.

2.11 Frailty tools including the B-FIT and Clinical Frailty Scale

There is some degree of agreement on the need for the detecting frailty in the clinical setting through the use of validated screening tools (Morley et al., 2013). These authors recommend that every adult aged ≥ 70 years and those with ≥ 5% unintentional weight loss be assessed for frailty, in order to detect frailty and pre-frailty early and offer optimal clinical management. Clinical frailty assessment instruments are increasingly common; a systematic review of frailty screening tools for use in primary care found ten different instruments (Pialoux et al., 2012), while Sternberg et al. identified 22 different clinical measures of frailty, most of which have been validated against the outcomes of death 76%, disability 41%, and institutionalisation 35% (Sternberg et al., 2011). It is beyond the remit of this literature review to discuss all of these tools, however the two that have been applied in this study will be introduced and rationalised below.

Task-shifting is the concept of moving clinical tasks away from doctors and other specialist professionals, to be performed by trained non-specialists in order to make effective use of limited human resources for health, particularly in LMIC settings (Joshi et al., 2014). There is some evidence that task-shifting may lead to efficiencies and cost-savings for LMICs health systems (Seidman and Atun, 2017), in addition to improving the prevention and management of non-communicable diseases (NCDs) in LMICs (Joshi et al., 2014). The thesis supervisory team have previously developed and validated a three-question screening tool for task-shifting of IADL assessments in this population (Stone et al., 2018), as well as a culturally appropriate, short screening tool to aid in the detection of frailty; the Brief Frailty Instrument for Tanzania (B-FIT) (Gray et al., 2017).

2.11.1 The Brief Frailty Instrument for Tanzania

In a systematic review of frailty instruments it was found that 73% included a measure of physical function, while gait speed/mobility and cognitive function were included in 50% (Sternberg et al., 2011). Therefore, in keeping with popular methods, the B-FIT was developed to include a modified questionnaire on independence of ADLs, the Barthel Index (BI) (Wade and Collin, 1988, Dewhurst et al., 2012), and a shortened assessment of cognitive

function. This cognitive screening tool was developed and validated in Hai District, specifically for the detection of cognitive impairment in older Tanzanians with low literacy (Gray et al., 2014, Paddick et al., 2015). These two questionnaires in combination were predictive of ADL disability or death at three years (Gray et al., 2017). It remains controversial as to whether ADL disability should be included both as a component of frailty, and among its adverse outcomes. This stance, it has been argued, is justified given that disability itself has been shown to predict hospitalization and death, and by combining it with other markers of vulnerability, such as cognitive impairment, the level of risk for an already vulnerable group may be quantified (Sternberg et al., 2011). Section 3.8.2 describes exactly how the B-FIT screening tool was employed in this study.

2.11.2 The Clinical Frailty Scale

The second short screening instrument used as part of this study was Rockwood's Clinical Frailty Scale (CFS) (Rockwood et al., 2005). The CFS was developed as a short screening tool based on clinical judgement which correlates highly with the FI and was predictive of death or institutional admission over a follow-up period of five years (Rockwood et al., 2005). In multivariable models that adjusted for age, sex and education, each categorical increment in the CFS led to significant increases in risk of death and requiring institutional care. This tool was chosen for application in the present study for its visual nature, which was thought to improve the potential for cross-cultural understanding (Appendix A). The CFS has not been validated for use in this context, but particularly in settings of low human resources for health, brevity and simplicity are qualities which should be prioritised in a screening tool.

2.12 Frailty in low and middle income countries

The focus of this section is in providing a synthesis of the studies to date which have investigated frailty in community settings in LMICs (as classified by the World Bank). One review (Nguyen et al., 2015), and two systematic reviews have been published detailing the epidemiology of frailty in LMICs (Gray WK, 2016, Siriwardhana et al., 2018). Given that research coming from SSA will be examined separately, those papers have been excluded from discussion here.

One systematic review aimed to produce pooled prevalence estimates for frailty in LMICs (Siriwardhana et al., 2018), however only a single study, derived from the current study's research setting in Hai District was included representing a LIC (Gray et al., 2017), while the majority (of N=56 studies), were from upper-middle income countries. The pooled prevalence of frailty was 17.4% and pre-frailty was 49.3% (Siriwardhana et al., 2018). Prevalence estimates followed patterns found in HICs, whereby frailty rates increased with age, and were

higher in females (Siriwardhana et al., 2018). Siriwardhana et al. estimated a higher pooled prevalence of frailty in upper-middle income countries as compared with HICs, which is in contrast with the World Health Organization Study on global AGEing and adult health (WHO SAGE) findings of lower prevalence rates in LMICs when frailty was measured according to FI (Biritwum et al., 2016) (Appendix B).

The systematic review by Gray et al. (2016) included 70 studies compared with Nguyen's 14 (Nguyen et al., 2015). This can be accounted for by its broader search strategy and inclusion criteria. Yet, from the studies of community-dwelling participants, two additional studies were included and discussed by Nguyen et al. which were not included in the Gray et al. systematic review (Nguyen et al., 2015). One was a Mexican study, which found an association between FP frailty and worsening cognitive function over 12 months of follow-up (Alencar et al., 2013). The second, a study from Russia (variously classified as a high-income and upper-middle income country by the World Bank) reported a FP community prevalence of 21.1% from a random sample of older adults in St Petersburg (Gurina et al., 2011). Authors posed the suggestion that this high prevalence as compared with the original Fried study may be due to the latter's stringent eligibility criteria, which excluded those with Parkinson's disease, stroke and cognitive impairment and depression (Fried et al., 2001).

In general, studies from LMICs report slightly higher prevalence estimates of community frailty. However there are exceptions, for example in a study of Chinese older adults a prevalence of 5.4% according to Fried's criteria was reported (Lee et al., 2011). This low estimation is likely to be due to selection bias introduced at participant recruitment, as participants were invited by self-selection, were required to be mobile enough to attend a health check-up, and were excluded by medical assessors if they were deemed unlikely to survive to follow-up at four years (Lee et al., 2011).

2.13 Frailty in sub-Saharan Africa

There are limited data from SSA on the topic of frailty, however two major publications have derived data from the World Health Organization (WHO) Study on Global Ageing and Adult Health (SAGE), which included representative populations in Ghana and South Africa (Harttgen et al., 2013, Biritwum et al., 2016). Adults aged ≥ 50 years were included in these surveys and a FI produced from 40 variables (Biritwum et al., 2016). The age-standardised prevalence of frailty was 37.9% in Ghana and 38% in South Africa. Women had a statistically higher FI compared with men across all countries, a consistent finding when the FI sex-differences in seven large population-based studies from both developed and developing countries were analysed (Gordon et al., 2017). Higher educational attainment (above

secondary school), reduced the adjusted odds of frailty in Ghana and South Africa, but no association was found across income quintiles (Biritwum et al., 2016). A very similar pattern was shown in the distribution and prevalence of disability according to World Health Organization Disability Assessment Schedule (WHODAS 2.0), which may be due to the fact that seven variables overlapped between the two constructs (Biritwum et al., 2016). The same FI data were compared with a 39 item FI produced from the SHARE survey of European countries, and despite adjusting the FI weighting by WHO standard population structure, European HICs had the highest mean FI scores (Harttgen et al., 2013). The authors suggested this finding could be due to a form of survival effect, whereby older people in wealthier countries survive to higher FI scores due to better social support and healthcare provision. Within both HICs and LMICs, frailty was distributed according to socio-economic and education gradients (Harttgen et al., 2013), so that those the lowest wealth and educational attainment in each country had the highest likelihood of frailty.

Further work from the WHO SAGE study highlights that frailty is associated with socio-economic disadvantage (Hoogendijk et al., 2018). Data from over 31,000 respondents across LMICs (including Ghana and South Africa) were used to produce a modified FP from the same WHO SAGE data (Appendix B) The prevalence of frailty by FP was 11.2% in Ghana and 14.5% in South Africa, and overall it was shown that lower socio-economic status (measured through either educational attainment, or measures of household wealth) was inversely associated with frailty. That is, lower wealth quintiles had higher odds of frailty, but this effect was not mediated by a higher prevalence of chronic disease or multimorbidity in lower educated or lower socio-economic groups (Hoogendijk et al., 2018). It was postulated that due to a reliance on self-reported diagnoses, low rates of reported chronic diseases may be due to inadequate access to affordable healthcare, or earlier mortality due to lack of treatment. This finding, in relation to the potential narrowing or reversing of socio-economic gradients in health status has been noted and discussed previously (Vellakkal et al., 2015), however for such large-scale survey-based studies alternatives to self-report are unlikely to be practical. In an example from Hai District, where this thesis is based only 14.6% of neurological disorders had been previously diagnosed, of whom only 9.9% were receiving treatment, and there was a gender bias, with males more likely to have received a diagnosis and appropriate treatment (Dewhurst, 2012), therefore it is likely that this will be a factor affecting the present study.

Other than these publications, (excluding the publications derived from this thesis (Lewis et al., 2018b, Lewis et al., 2018a)), there is one other published study of frailty in rural SSA.

This community-based cohort study of 5,059 adults reported frailty prevalence and mortality according to the FP (Payne et al., 2017). Authors operationalised the FP to estimate frailty prevalence in a rural South African setting, producing nine variations, each leading to a different frailty prevalence estimate and mortality hazard ratio (Payne et al., 2017). Frailty prevalence ranged between 5.4% and 13.2%, depending on the measures used to produce the phenotype, and frailty was significantly associated with death at a mean of 17 months follow-up. There are important limitations in this study's generalizability to a setting such as rural Tanzania given that this was a much younger population (aged ≥ 40 years, mean age 61.7 years), and with a 21% prevalence of HIV-infection (Payne et al., 2017). There were few reports of challenges in the operationalisation of the FP in this context, except for in the translation of the Centre for Epidemiological Studies-Depression scale (CES-D) "exhaustion" questions, the translation of one of which was too ambiguous in the local language to be usefully included. The authors instead preferred to use a question which evaluated overall change in health status over the previous 12 months (Payne et al., 2017). While this has not hampered the overall construct of the FP, the authors argue, it does highlight the potential difficulty in translating concepts such as "exhaustion" cross-culturally.

2.14 Disability in older community-dwelling adults in sub-Saharan Africa

As previously discussed, the relationship between frailty and disability in old age is difficult to disentangle (Fried et al., 2004). Disability is undoubtedly closely associated with frailty, either as an adverse outcome of worsening frailty, or as an age-associated deficit accumulating to produce frailty. The following literature defined disability according to either a difficulty performing ADLs or culturally-appropriate IADLs, or according to the WHODAS 2.0. The WHODAS 2.0, in its long and short-form has been validated for the assessment of functioning across six life domains (cognition, mobility, self-care, getting along with others, life activities and participation) (Ustun et al., 2010). In order to better describe the current picture of disability and its associated factors in community-dwelling older adults across the African sub-continent the published literature to date will be presented and discussed by country, with reflections on the implication of these findings on the investigation of frailty in rural Tanzania. SSA includes many of the world's poorest countries, however many are now classified by the world bank as upper-middle income countries, (for example, Botswana, Equatorial Guinea, Gabon, Mauritius, Namibia and South Africa) (World Bank, 2019). Thus, findings from one African country should not be assumed to be broadly applicable across the sub-continent.

2.14.1 South Africa (Upper-middle income country)

Disability follows similar patterns of distribution as frailty. In age and sex-stratified data from the WHO SAGE study, the prevalence of disability (defined as difficulty performing ADLs) was higher in women compared with men across all age-groups (Santosa et al., 2016). The prevalence of ADL disability overall was high, with 46% of older Ghanaians and 42.3% of older South Africans reporting disability. Women in these countries also had a lower disability-free life expectancy, despite longer life expectancies overall. The authors call for a gender-equity focus to address the biological and social determinants of disability (Santosa et al., 2016). Reflecting on the fact that a similar gender disparity also exists in frailty, this finding has not usually not been framed as a gender-equity issue, perhaps due to its being understood as having a largely biological underpinning (Gordon et al., 2017). It has been suggested for example, that women may have a higher physiological reserve to withstand stressors, while men succumb to conditions which have a higher fatality, although there is a lack of conclusive evidence (Gordon and Hubbard, 2019).

A study of the needs of "frail elderly" living in three informal settlements in South Africa defined frailty as adults aged ≥ 60 years with at least one ADL disability (Rand and Engelbrecht, 2001). This paper provides valuable descriptions of the living environments of older people in urban informal settlements. Despite the unconventional definition of frailty used, the finding of a high prevalence of arthritis and hypertension among these older adults with at least one ADL disability points to the observed overlapping but distinct conditions of disability, comorbidity and frailty (Fried et al., 2001). Small living spaces and uneven floors were common and deemed inappropriate for wheelchair use, that is, the environment of the informal settlements was not disability-enabling. In a small study of older nursing home residents in Bloemfontein, multimorbidity with at least two chronic conditions was common, and resulted in pain and impaired mobility (Gerber et al., 2016). Another study, using WHO SAGE South African data to investigate the relationship between severe disability (measured by 90^{th} percentile WHODAS 2.0 scores), multimorbidity (≥ 2 diagnosed diseases) and hypertension (either by diagnosis or measurement) found that multimorbidity increased the odds of severe disability, while almost half of the sample had high blood pressure detected by measurement, but were undiagnosed as hypertensive (Waterhouse et al., 2017). This reflects the methodological challenge of investigating disease prevalence in settings without good NCDs screening. The probability of people in the poorest wealth quartile having disability increased with the number of diseases reported, while the overall prevalence of severe disability was 11% (Waterhouse et al., 2017).

2.14.2 Nigeria (Lower-middle income country)

Much of the research characterising the health of older people in Nigeria comes from the Ibadan Study of Ageing, a cluster-sampled survey of the health and functioning of 2,152 Yoruba-speaking adults aged ≥ 65 years (Gureje et al., 2006). Functional disability, defined by an inability to perform one or more IADL, was prevalent at 9.2%, while ADL disability was less common at 3%. Functional disability was associated with chronic painful conditions, malnutrition and living in urban settings, (Gureje et al., 2014) while 19.8% of those with a functional disability lacked an informal care-giver. In a longitudinal follow-up of the same sample, chronic painful musculoskeletal symptoms were the most disabling conditions, and were significantly associated with incident disability over five years (Ojagbemi et al., 2017). In both studies IADL functional disability was measured according to largely physical tasks such as sweeping with a broom or carrying a 4.5Kg load, which while culturally appropriate, may have limited the scope of disability to the domains of mobility and daily work activities. In a small cross-sectional urban study, prevalence estimates of functional disability in ADLs and IADLs were much higher than the previous studies, at 30% and 40% respectively, however a different instrument was used, and authors highlight that disability rates tend to be higher in urban settings (Akosile et al., 2018). A possible explanation for this might be that rural-to-urban migration in older people might be driven by a need to seek care or healthcare where it is more accessible.

The prevalence of interviewer-rated dependence was 24.3% for older adults in a further cross-sectional survey in rural Nigeria (Uwakwe et al., 2009). Dependence in this study was defined as requiring care “some, or much of the time” and was determined by the interviewer. Depression, cognitive impairment, physical impairments and stroke were each associated with dependency, as was higher out-of-pocket health expenditure (Uwakwe et al., 2009). The prevalence of requiring assistance with at least one from ten ADLs in a cross-sectional survey of 1,824 rural-dwelling older adults was 28.3%, and was greatly increased in older age groups and in women in another study conducted in rural Nigeria (Abdulraheem, 2011). The overlap between disability and chronic disease was re-emphasised given that arthritis, diabetes, stroke, depression and visual impairment were strongly associated with ADL disability.

2.14.3 Tanzania (Low-income country)

A series of publications prior to the this thesis have investigated the prevalence and characteristics of disability in rural Tanzania, in the same area; Hai District (Dewhurst et al., 2012, Dotchin et al., 2015, Gray et al., 2016). The age-adjusted prevalence of disability, according to the modified BI was 9.9% in adults aged ≥ 70 years, with higher prevalence

estimates in women and older age groups (Dewhurst et al., 2012). Furthermore, in a study of dementia prevalence in the same setting it was found that mild cognitive impairment, dementia, self-reported hearing impairment, lack of formal education, and use of a walking aid were associated with increased adjusted odds of disability (measured by WHODAS 2.0 scores above the mean) (Dotchin et al., 2015). The same cohort of n=2,232 adults aged ≥ 70 years was followed-up at three years (Gray et al., 2016). Mortality rates were highest in older age groups, those who were underweight, those with self-reported cognitive impairment, and disability (Gray et al., 2016). Notably, these findings closely parallel the epidemiological features of multidimensional frailty: That is to say, key features which may coexist in frailty (cognitive impairment, underweight and disability), particularly affected the oldest age groups and women, and were associated with increased mortality. Remarkably, when death rates were compared with expected death rates in the UK, age-adjusted mortality rates were lower than expected (Gray et al., 2016). The authors postulate that in the absence of adequate healthcare, "frailer" individuals may tend to die at younger ages, leaving a more robust older population. Thus, without formally assessing frailty this study of factors associated with vulnerability to death has obliquely done so.

A study that investigated the nutritional status (BMI) and function (ADLs) of older adults in Morogoro Tanzania, compared a small sample of 50 institutionalised and 50 non-institutionalised adults aged ≥ 60 years (Nyaruhucha et al., 2004). Participants were recruited from two institutions, managed by the government and Catholic Church respectively. Descriptive statistics illustrated that the institutionalised older adults had more urinary incontinence and had higher numbers of overweight individuals, which was attributed to a more sedentary lifestyle and being sure of receiving at least one meal daily. In contrast, the majority of non-institutionalised individuals relied on begging for their income, and more were underweight. Despite being a small cross-sectional study, it provides a fascinating description of the difficulties facing older people in Tanzania, concluding with the assertion, expressed by the Tanzanian academics that *"the elderly who are living together with their families, do not get the necessary care, particularly sufficient food"* (Nyaruhucha et al., 2004). Of particular relevance to the concept of frailty, chronic undernutrition has been postulated to be a key aspect of the theoretical "cycle of frailty" (*Figure 2-2*).

2.14.4 Other Sub-Saharan African countries

Botswana (upper-middle income), Ghana (lower-middle income), Zimbabwe, Malawi and Uganda (low-income countries)

While not overtly mentioning the term "frailty", a further study inadvertently took a multi-component approach to the assessment of older people living in rural Botswana by investigating the cognitive, physical and social predictors of death at 6 months (Clausen et al., 2007). An unexpectedly high mortality rate was found, which was associated with cognitive impairment, reduced lower-extremity strength, eating alone and/or living alone. The authors suggested an explanation for this may be a lack of physiological, functional and social reserves so that *"when older Africans cross the dividing line between independence and dependency they are left with little or no public or informal support; and thus they literally die. There may be no specific disease causing this high mortality; rather the sum of mortality from any cause resulting from lack of care and support when functional abilities are below a critical level."* (Clausen et al., 2007, p6). Having discussed the fact that cultural norms are likely to impact on social aspects of frailty in different settings, these authors measured the prevalence of "eating alone" as a proxy marker for nutritional deficiency and social isolation and found it to be significantly associated with an increased odds of death (OR 6.7 adjusting for age). While this was a relatively small study, which did not adjust for confounders other than age in its logistic regression analysis, and only assessed for death as an outcome after a short duration of follow-up, it is one among very few longitudinal studies in rural SSA, with findings which are applicable to this thesis.

Two publications were derived from analysis of cross-sectional survey data from the WHO SAGE study conducted in rural Ghana (for a nationally representative sample of adults aged ≥ 50 years). The first found higher rates of disability as measured by the WHODAS 2.0, in older age groups, women, and those with poor self-rated health (Debpuur et al., 2010). It was noted that in spite of rapid urbanisation the majority of older people live with functional disabilities and poor health status in rural areas where there is *"inadequate healthcare and weak social support systems"*. The second publication demonstrated a significant association between chronic disease and functional disability; stroke, hypertension and arthritis were all significantly associated with difficulties with ADLs (Amegbor et al., 2018). Also, this study found a high proportion, (79.62%) of older Ghanaians reported difficulty with performing "intermediate self-care functions" such as walking a long distance or performing household responsibilities. These functional limitations, likely to impact on an individual's ability to work and subsist were significantly associated with being female, living rurally and having no formal education. And while arthritis and hypertension were the most prevalent self-reported chronic NCDs (13.08% and 12.78%, respectively) these are likely to have been under-estimated due to reliance on self-report (Amegbor et al., 2018). In evidence of this, according

to the WHO SAGE study, self-reported hypertension was estimated at 14.2% while prevalence derived from blood pressure measurements reached 51.1% in Ghana (Minicuci et al., 2014).

A cross-sectional survey of 278 adults >60 years, living in both rural and urban areas of Zimbabwe found a 4% prevalence of ADL disability and a 30% prevalence of difficulty with IADLs appropriate for this setting (these primarily included household physical activities such as making a fire, planting, and collecting water) (Allain et al., 1997). The causes of disability in older Zimbabweans were mostly due to visual impairment and mobility problems; cataracts were present in 55% but only 10% had received surgical treatment, while 97% complained of painful joints. The sampling methods used limit the study's broader applicability, but based on their observations the authors claim that simple measures such as analgesic medications, dentures, and mobility aids could substantially improve this older population's morbidity and disability levels (Allain et al., 1997).

A longitudinal study of rural-dwelling adults aged ≥ 45 years (the Malawi Longitudinal Survey of Families and Health) sought to estimate relevant functional limitations causing moderate or severe limitations for older people, and uniquely sought to estimate the changes in disability states over time (Payne, 2013). It was found that functional limitation, by self-report for a range of culturally relevant IADL tasks, was higher than estimated by the global burden of diseases study (Stuck et al., 2013). In two striking ways functional limitation and frailty epidemiology were shown to be similar; firstly functional limitations were higher in females at any age, with severe disability more predictive of death in males compared with women, and secondly there was some degree of reversibility in functional limitation with time (Payne, 2013). Frailty has been demonstrated to be a dynamic state, with reversibility particularly for pre-frail moving to non-frail states (Kojima et al., 2019). Similarly, in Malawi as many as 41% of participants with mild functional limitation recovered to a healthy state without functional limitation over a 5 year period (Payne, 2013). The impact of functional limitation was discussed as having important implications for the economic development of LICs in SSA, given that functional limitations affect individuals' abilities to work and could lead to a requirement for informal care, further limiting others' economic productivity. Additionally, the vast majority of those with moderate and severe functional limitations reported that pain had interfered with their ability to work and impacted negatively on their wellbeing. Several important limitations should be noted, particularly that this study was not nationally representative, and had a relatively low (3%) prevalence of HIV/AIDS (Payne,

2013). Yet it is a similar context to the present Tanzanian study (a rural subsistence farming population with low HIV/AIDS prevalence among older adults) (Walker et al., 2013).

According to the Uganda National Household Survey, ADL or IADL disability in adults aged ≥ 50 years was prevalent at 33%, and was associated with living alone, living rurally, and requiring remittances, suggesting an important social component to the characteristics of disability in old age in rural SSA settings (Wandera, 2014). The same author also found that mobility disability (measured by a self-reported difficulty in walking) was inversely associated with accessing healthcare, suggesting that in rural Uganda, where walking may be the main form of transport, this form of disability may be a particularly important barrier to accessing healthcare (Wandera et al., 2015).

2.15 Summary of disability in older community-dwelling adults in SSA

- Disability and frailty are closely related concepts. Disability of ADLs has variously been conceptualised as distinct but overlapping with frailty, a deficit contributing to frailty, and an adverse outcome of frailty.
- Much of the research to date investigating disability in older community-dwelling adults in SSA derives from cross-sectional surveys conducted as part of the WHO SAGE study.
- Disability has been defined most often by the WHODAS 2.0 and ADL disability.
- Chronic pain and disabling conditions such as osteoarthritis were consistently reported as prevalent among older Africans.
- Functional disability was consistently distributed along socio-economic gradients (using proxy measures of income or educational attainment).
- Authors of these papers frequently highlight the need for improved social and healthcare services for the increasing SSA older population, the needs of whom have thus far largely been neglected.

2.16 Falls in sub-Saharan Africa

Falls are frequently categorised as an adverse outcome associated with frailty (Ensrud et al., 2008, Fried et al., 2001), however the research to date in SSA has not overtly made this association. However, multimorbidity and disability in older people have been associated with falls and falls-associated injury in SSA. The prevalence of injurious falls in adults aged ≥50 years was 1% in South Africa and 2.6% in Ghana according to WHO SAGE data (Stewart Williams et al., 2015). In the multivariable model living rurally increased the odds of an injurious fall by 36% and those with symptoms of depression had a 43% higher odds of a fall-

related injury. Those with multimorbidity (≥2 conditions) were more than twice as likely to report a falls-associated injury in the previous year compared with those without chronic conditions OR 2.15 (Stewart Williams et al., 2015).

Kalula et al. contributed to this literature with multiple publications from a South African survey-based study of falls in older adults with a mean age of 74. The authors found rates of 26.4% and 21.9% for falling, and 11.0% and 6.3% for ≥ 2 falls, at baseline and 12-month follow-up respectively (Kalula et al., 2015). Risk factors for reporting falls at follow-up were a history of previous falls and ethnicity (Kalula et al., 2016). Those categorised as white were at highest risk of falls compared with those of mixed ancestry and black Africans, however the authors acknowledge that ethnicity was likely to be a proxy for multiple interacting factors which may collectively contribute to falling; the majority of white older adults lived in the neighbourhood where it was more common to live alone, and to drink alcohol for example. Methodological challenges faced in conducting this study included gaining access and permission to conduct the study in the majority black African neighbourhood and designing the study accounting for low literacy and non-universal phone ownership, which made the gold-standard prospective follow-up and recording of falls impractical (Kalula et al., 2017).

The prevalence of falls was reported from a survey of N= 2,096 adults ≥ 65 years in the Ibadan Study of ageing in Nigeria (Bekibele and Gureje, 2010). Those who reported falling in the previous year were 23% of the total sample, and falls and fall-associated fractures were more common in women compared with men. Notably those reporting chronic pain and arthritis were at an almost two-fold increased risk of falling, when adjusting for sex. A further cross-sectional study with a smaller sample of older adults in rural Nigeria sought to assess some of the social risk-factors for falls (Maruf et al., 2016). Making fewer than two social visits per week to friends or relatives was significantly associated with falls (OR 3.8) and recurrent falls (OR 4.8) on multivariable analysis. Whether this was a sensitive measurement for social participation, or due to confounding by mobility it is difficult to assess.

Falls and other geriatric syndromes associated with frailty were investigated in a cross-sectional study of 98 adults aged ≥ 60 years in Blantyre, Malawi (Allain et al., 2014). Forty people (41%) reported a fall in the 12 months prior to the study, and 13 of this group (33%) had fallen more than once. Urinary incontinence, self-reported memory problems and a low abbreviated mental test were all significantly associated with falls by Chi-squared testing. This study has many limitations, including the potential for bias introduced by its sampling technique, and the high proportion of women in the sample (70%), however it is one of the

first studies of falls in a LIC in SSA and the discussion reflects helpfully on social and cultural factors which may influence the incidence of falls in community-dwelling older people, suggesting that *"economic pressures require that old people keep working throughout their lifespan, even when illness and chronic morbidity intervene"* (Allain et al., 2014, p106). Other factors listed include ill-fitting or inappropriate footwear, demands of care-giving for children and grandchildren and reliance on walking as a means of transport.

2.17 Frailty and HIV/AIDS in sub-Saharan Africa

The HIV/AIDS epidemic has disproportionately affected the countries of SSA, and due to the successful treatment of working-aged adults, and new infections in older adults the prevalence of HIV in older age-groups is increasing (Vollmer et al., 2017). It is debated whether HIV infection causes accelerated ageing, or whether the adverse effects of ARVs are primarily to blame for the accelerated cardiovascular risk factors which develop in this population (Brothers et al., 2014). Consequently there is concern regarding the longer-term non-AIDS-defining sequelae affecting adults as they age with HIV-infection (Bernard et al., 2017). The scarcity of research investigating the impact of HIV-infection on frailty in older adults living in SSA is an important research gap (Bernard et al., 2017).

There are two small-scale case-control studies which investigate frailty according to the Fried FP. The first included 248 HIV-infected adults (mean age 41.1 years), the majority of whom were receiving antiretroviral therapy, and sex- and age-frequency matched HIV-seronegative individuals in South Africa (Pathai et al., 2013). There was an increased prevalence of frailty in HIV-infected compared with HIV-seronegative adults (19.4% vs 13.3% respectively), and HIV-infection was found to increase the adjusted odds of frailty (Pathai et al., 2013). Frailty was also associated with older age and a lower CD4+ count (an indication of more advanced disease). However, the second study that included 202 age and sex-matched cases and controls (mean age 46.8) in Dakar, Senegal, found a non-significant difference in frailty prevalence rates between HIV-infected (3.5%) and HIV-seronegative (6.9%) adults (Cournil et al., 2014). While the present study aims to estimate the prevalence and characteristics of frailty in older adults living in rural SSA, an investigation of the particular phenotype of frailty in older HIV-infected adults is not within this study's scope.

2.18 Summary of the biomedical literature review

- The concept of frailty as described by biomedical models is characterised as a dynamic state of vulnerability to adverse outcomes.

- The lack of consensus definition of frailty has led to a plurality of concepts, multiple assessment instruments and a wide variation in findings, making cross-study comparisons more challenging.
- Frailty is generally accepted to be a distinct precursor to disability in old age, therein lies its potential clinical benefit.
- There are many important knowledge gaps remaining, including knowledge of the prevalence, characteristics and outcomes of frailty in rural SSA, subsequently the aim of the quantitative component of this thesis.

2.19 Interpretive social sciences literature review

This section will describe and discuss the interpretive social sciences literature relevant to the current thesis. Much of the work presented provides a critical perspective of the dominant biomedical models of frailty discussed thus far. By introducing a critique of frailty in modern medicine and in high-income industrialised countries, where the majority of the interpretive social sciences literature on frailty has originated, this aspect of the literature review places the concept of frailty in a social sphere. This literature raises pertinent questions as to the potential utility and harms of a concept such as frailty, and suggests that the construct of frailty has not been used to serve those living with frailty, rather it has more often served to strengthen power differentials between patients and professionals within biomedical structures, as well as reinforce ageist and distancing attitudes towards older people with frailty within broader society.

Following on from this discussion, the social sciences literature relating to the study setting will be introduced. Discourses on ageing and frailty from the perspectives of international public health literature will be critiqued as a discourse which usually frames global ageing as a crisis for which SSA is particularly underprepared. Very little interpretive social science literature has explicitly focused on frailty in SSA, whereas the social meanings of care in old age has been studied in more depth. While previously in this chapter the concept of disability in old age was included as a concept which is closely related to frailty, similarly, literature on care and dependency in old age in SSA have been included here.

Thus, this part of the literature review seeks to answer the following three questions as precursors to this thesis's research questions. First, how has frailty been conceptualised in the social sciences literature. Secondly, what has research revealed about the lived-experience of frailty. Both of these areas of research have largely been focused on frailty in the context of "western" cultural, and high-income settings in North America and Europe. However, lastly the literature characterising frailty, ageing and care for older people in SSA will be explored.

2.20 Critique of frailty in biomedicine

There are several inter-related criticisms of the concept and use of frailty in biomedical practice. First, frailty problematises and medicalises what is within the spectrum of normal ageing (Kaufman, 1994). It is argued that the distressing aspects of ageing (even the personal and social) have been made the domain of the medical professional, with the hope that this may help avoid or at least manage the distress of decline towards the end of life (Pickard, 2014).

Second, frailty is used to reinforce power dynamics through its use as a third person label by medical professionals (Grenier, 2007). Rarely is it used in the first person by older individuals who have self-identified as “frail”. The power differential in this relationship permits the medical profession to act to benevolently to manage risk, and restrict autonomy (Becker, 1994). In Becker’s investigation, older adults who subscribed to American cultural ideals of independence and autonomy and never self-labelled as “frail”, had their individual autonomy restricted, due to their frailty states (Becker, 1994). For example, this included being forced to live in an institution.

Another criticism of the use of frailty in modern health and social care systems is that that it is used to justify rationing; denying services to some in favour of those deemed more vulnerable (Grenier, 2006). This approach fails to promote preventive care or encourage health for all in old age. Nicholson et al. discuss the fact that despite public and patient antipathy towards the term “frailty” it has largely been welcomed by the medical profession, and particularly Geriatric Medicine, which has developed a host of frailty services, screening tools and assessments in order to help manage patients’ risks and assess vulnerability (Nicholson et al., 2017). It was asserted that the speciality of Geriatric Medicine has become defined by the concept of frailty, and its clinical tool the CGA, which has become skewed towards a measuring and grading of a person’s deficits and impairments (Nicholson et al., 2017). The authors argue not for a complete rejection of the term, but for a more balanced approach including an assessment of an older person’s assets as well as deficits.

Lastly it is claimed, the term “frailty” leads to the “othering” of frail people (Higgs and Gilleard, 2014). “Othering” in this instance was defined as the process of marking out and naming those thought to be different (Higgs and Gilleard, 2014). This process inevitably produces a distance between the labeller (usually a professional) and the labelled (older person). The application of frailty in clinical practice can also lead to objectifying older people, reducing the individual to a “body at risk” (Grenier, 2007). The problem associated with this use of frailty as an objectifying, “othering” construct, is that an individual’s identity may become usurped by their frailty identity (Kaufman, 1994). Indeed, its argued that the term may homogenise older people, reducing their individuality (Becker, 1994). There is potential harm imbued in the label “frail”, of which, the authors claim, the biomedical world is often unaware (Richardson et al., 2011). It is suggested that the “frail” label perpetuates negative stereotypes which may feed into ageist attitudes, and even become internalised by older people themselves. This can in turn impact on older people’s outlook and physical function (Hausdorff et al., 1999). While seeking to help older people, those in biomedical

spheres, may in fact be serving themselves, and the healthcare system first, using frailty as a tool for control and distancing, leaving older people depersonalised. The same can be said for many labels used in medicine, for example being considered "disabled", however while other labels have tended to be re-claimed by the individuals in question, for example through disease support groups or the disability rights movement, frailty has not undergone such a positive re-framing (Gilleard and Higgs, 2011). It has remained a feared and resisted notion, even by older people deemed to be frail.

Having conducted a review of the term "frailty" in key geriatric literature, Susan Pickard has described the importance of the concept of frailty to the development of modern-day Geriatric Medicine (Pickard, 2014). Pickard described how the term "frail" was initially used to refer to older people who required social, rather than medical care, suggesting that this state was an infirmity 'natural' to old age, and was therefore not the domain of medicine. In keeping with this, Rockwood et al. originally proposed the "dynamic balance" model of frailty (Rockwood et al., 1994), whereby an older person's frailty was seen as dependant on the changing balance of assets and deficits which may promote or threaten independence and function in late-life. However, over time this analogy has been lost in favour of the syndromic and deficit accumulation models of frailty. The development of these two dominant models, has legitimised the geriatrician's task of attributing vulnerability and risk to certain older adults, and given weight to the unique clinical skills of the geriatrician through the CGA (Pickard, 2014). The author describes how the central tenets of traditional Geriatric Medicine asserted that out-with the pathology of diseases and disability, certain age-related changes were "normal" and irreversible (Pickard, 2014). Whereas the concept of frailty led to the production of a problematised, and pathologised age-related change, which is separate from disease and disability, but nevertheless requires "diagnosis" and "management" by Geriatric Medicine. One of the reasons given for this problematising of frailty is that although the frail are not "diseased", they are identifiable by certain characteristics; poor endurance, weakness and slowness, all of which *"are antithetical to productivity"* (Pickard, 2014, p558) an integral value in current "western" cultures.

In summary;

- The concept of frailty has been criticised for medicalising and pathologising the normal processes of ageing.
- Frailty, according to much interpretive social sciences literature, is used as a label which is "othering", stereotyping, and objectifying of older people.

- The concept of frailty has proven useful to the medical profession, and the specialism of Geriatric Medicine in the work of risk-assessing and managing the vulnerable and "risky" old. But frailty, may to some extent serve as a form of benevolent structural ageism.

2.21 Frailty in "western" or "modern" societies

It is relevant to describe frailty in "western" society in a thesis about SSA given that it is the author's and likely the academic audience's frame of reference, and the context of much of the social sciences research to date. "Western" cultural norms as referred to in this thesis may be best encapsulated through the descriptions of Gilleard and Higgs who describe the cultural context in which their work is situated (Gilleard and Higgs, 2000b). When referring to "western" society in this thesis therefore, it is the societies of high-income, industrialised countries dominated by secular capitalism which are generally referred to, often in juxtaposition with the Tanzanian or SSA context. "Western" society and culture has often been used interchangeably in the literature with the term "modern society". Thus both terms are useful, particularly when considering modernisation theory in relation to ageing, a much discussed and disputed gerontological theory used to explain the decline in status and condition of older people in society (Cowgill, 1974).

Cowgill and Holmes's theory of "Ageing and Modernisation" was developed from a list of correlations relating to aspects of the status of older people, and variations observed from comparison across fifteen different societies (Cowgill, 1986b, Cowgill, 1974). Thus this theory was developed by taking a cross-cultural perspective and may be useful to apply in the present cross-cultural study of frailty. The theory suggests that as societies "modernise", an accompanying demographic transition takes place, leading to increasing proportions of older people with a lowered status. Three particular aspects of the "modernisation" process lead to a reduced status for older people; first, the use of modern technology in health and economics, secondly, urbanisation and thirdly increased levels of education (Cowgill, 1986b). It was suggested that as societies adopt modern technologies, older occupations and knowledge become obsolete, with the urban migration and education of the younger generation leaving older people isolated and irrelevant, thus devalued in status within society. Gilleard and Higgs describe a fragmented post-modern "western" world, where the conflict between "modern" and "traditional" is irrelevant, and "tradition" is presented as one of many commodified choices, rather than a foundational underpinning for life (Gilleard, 2000).

Another important gerontological theory describes how industrialised "modern" society has tried to create *"a stable life course with recognizable stages"* (Gilleard and Higgs, 2000b, p25). Peter Laslett originally proposed a theory of the life-stages in response to the development of the welfare state and retirement from physically demanding employment in industrialised nations (Laslett, 1996). The "Third Age" according to Laslett, was the period after retirement where one could enjoy the rewards of a productive working life and work toward a new goal which was the attainment of self-actualisation (Laslett, 1996). This was an aspirational period of life which he described as the "crown of life". After which followed the "Fourth Age", the inevitable time of decline and decrepitude, occurring chronologically after the "Third Age" and prior to death (Laslett, 1996).

These concepts have evolved, so that the "Third Age" has since been described as both a generational, and cultural phenomenon (Gilleard, 2000, Gilleard and Higgs, 2002). The "Third Age" as Higgs and Gilleard developed the concept, has occurred within the generation of "baby boomers" born after the Second World War, and who live in relative prosperity in "western" European or North American countries. This generation share the common values of freedom of opportunity and choice, and combined with a welfare state and period of economic growth, are retiring in a culture of consumption and consumerism (Gilleard and Higgs, 2002). Culturally, this "Third Age" is a rejection of "agedness" (Higgs and Gilleard, 2014).

If the "Third Age" in "western" cultural settings is hallmarked by consumerism, the primacy of an individual's autonomous capabilities to choose, consume, experience and enjoy (Higgs and Gilleard, 2006, Gilleard and Higgs, 2010), then the "fourth age" exists as the antithesis of these values (Higgs and Gilleard, 2014). In this view of frailty and the fourth age, those deemed frail are alienated and cast away from society, due to our collective horror at life beyond the social "threshold". According to this theory, the fourth age exists in "western" societies as a harmful "social imaginary", (where the concept of "social imaginary" places the life course as a universally understood shared set of beliefs which are reinforced symbolically, institutionally and through popular discourses) (Gilleard and Higgs, 2013). Frailty in the "fourth age" social imaginary is a form of abjected "social death", and "ageing without agency" (Gilleard and Higgs, 2011, Higgs and Gilleard, 2014). Even older people participate in this social imaginary through resisting frailty and the "social imaginary" of the fourth age, emphasising the ways in which they are autonomous, thus not "ageing without agency", even in the face of increasing physical frailty (Becker, 1994). Gilleard and Higgs suggest that only

through the maintenance of personal relationships might this depersonalising influence of our "social imaginary" be avoided (2014).

The last key gerontological theory which has an implication for the way that frailty in old age is regarded in "western" society is the "successful ageing" theory of Rowe and Kahn. The theory provides a framework for what the authors regard as an aspirational goal which challenges negative stereotypes and myths about ageing. The authors define "successful ageing" as having the ability to maintain three characteristics; avoidance of disease and disease-related disability, maintenance of high mental and physical function, and an active engagement with life (Rowe and Kahn, 1999). The emphasis is on individual choice and agency to resist what they term "usual ageing"; its opposite (rather than the inferred "unsuccessful ageing") (Rowe and Kahn, 1999). The authors firmly place the burden of ageing successfully on the individual, stating *"In short, successful aging is dependent upon individual choices and behaviours"* (Rowe and Kahn, 1999, p37).

This "successful ageing" framework was developed from the "American dream" of the self-made man, based on "western" cultural values of individualism and competitiveness (Richardson et al., 2011). Richardson et al. argue that while the notion of "successful ageing" may help to challenge the often negative representations of old-age, there is a potentially harmful aspect to this framework. The implication, being that the "usual agers", including those ageing with frailty, have failed, and should take personal responsibility for their frailty (Richardson et al., 2011). The authors state that while this construct is culturally situated in the "west", there are likely to be other culturally-situated models of different "successful ageing", and indeed, even within "western" societies not all older people subscribe to Rowe and Khan's definition of successful ageing.

An example of this is a study that analysed viewers' comments responding to a video entitled "Make Health Last" produced by the Heart & Stroke Foundation of Canada (Harris et al., 2016). The video depicted an apparent choice to live healthily and remain "actively engaged in life", contrasted with spending the last 10 years of life with disease, disability and frailty in a laudable attempt to promote healthy life choices. However the authors highlight the fallacy of the underlying message, which is that healthy ageing is an individual decision. This message diminishes the effects of broader social and environmental factors which may influence one's ability to age healthily, and makes frailty the fault of the individual. The harmful outcome of this being that people who do not, or cannot, "choose health" become marginalized and the old and sick are blamed for their failure to *decide* to stay healthy. Katz

emphasises that this discourse of encouraging people to remain active and age healthily and "successfully" has occurred in the context of a diminishing welfare state (Katz, 2000). Katz states that policies which seek to "empower" and "activate" older people are consistent with, and encouraged by neo-liberal[3] political and economic systems, which primarily value citizens for their productivity and independence (Katz, 2000). Thus, frail older people are burdensome and problematic to the state and society as they are failing to participate productively as "good citizens" should. The successful ageing paradigm in "western" contexts may troublingly lead to the devaluing of frail individuals within society, framing them as irresponsible and disengaged citizens. Indeed, frail older people with means, who can afford to pay for their care privately may be valued for their contribution as consumers, and to some degree may be classed as third agers, in contrast with the abject fourth age (Higgs and Gilleard, 2014).

These problems have led to the questioning of who should define "success" in ageing. A systematic review of the quantitative and qualitative literature addressing this question highlights the importance of taking into account lay older people's perceptions of successful aging (Cosco et al., 2014). There was a divergence between quantitative publications, which focused on physical and cognitive functioning, while qualitative research in a largely North American population, focused on personal resources and engagement. Thus an "active engagement with life" could actually be an important component in the conceptualisation of ageing successfully for older people in "western" cultural settings, while other aspects of maintaining health and function may not be prioritised as highly. Importantly, these findings suggest that successful ageing and frailty are not necessarily incompatible (Pickard, 2014). That is to say, despite the presence of physical and cognitive decline, one might feel able to age successfully if one feels able to engage meaningfully with life.

Another alternative paradigm to "successful ageing" is productive ageing, expressed as the recognition and enabling of older people to work in paid and unpaid roles in older age (Butler, 2010). In some senses it is similarly problematic to the previously discussed definition, asserting that it is the individual's responsibility to remain economically productive or at least actively contributing to society in order to maintain their societal value. On the other hand, the concept seeks to recognise the ways in which older people contribute, often through unpaid volunteering and caring work. Productive ageing also highlights that older adults remaining

[3] The authors define neo-liberalism as an ideology that favours privatization, self-regulating markets, and smaller government to deal with social problems, such as rising health care costs.

productive is the norm globally. Working into older ages is a *necessity* in many LMICs (Butler, 2010), and is certainly the case in the present study's setting.

There are many proposed alternatives for Rowe and Khan's "successful ageing" which take into account subjective evaluations of psychosocial and spiritual domains (Martin et al., 2015). Two examples of theories will now be described with reflection on their implications for frailty. One is "Selective Optimisation with Decompensation" (Baltes, 1997, Baltes and Smith, 2003). This theory argues for an explicit recognition of individual and cultural differences, and for the role of culture in helping older people to select (prioritise capabilities), optimise (enhance those selected capabilities) and compensate (through individual and societal adaptation) during the ageing process. A simple example of this may be of a farmer who chooses to, and is enabled to focus their energies on gardening, instead of labouring, after developing worsening mobility (Baltes and Smith, 2003). Yet, the authors acknowledge that there are limits to successful ageing according to this theory given that frailty diminishes even one's abilities to make decisions through an erosion of personal identity and agency (Baltes and Smith, 2003, Gilleard and Higgs, 2010).

Another theoretical example is the "Preventive-Corrective Proactivity" model, which has been applied to older adults living with stigma, disability and ill-health due to HIV/AIDS (Kahana and Kahana, 2001). These authors theorise that an individual's ability to age successfully relies on their social and psychological resources. The theoretical model takes into account potential limitations which older individuals may face in ageing successfully, due to factors such as gender, race, education, and socio-economic status. The authors reason that a person ageing successfully, is one who proactively engages in the adaptations required in response to the challenges of ageing, even where these efforts are ultimately unsuccessful and limit a person's quality and meaning of life (Kahana and Kahana, 2001). In this respect, this model does not preclude ageing successfully with frailty because taking a proactive approach to managing one's experiences of ageing is what constitutes "success".

In summary;

- Key gerontology theory as applied to "western" cultural settings have been reviewed.
- Frailty has been conceptualised in four key ways: as a chronological fourth age which is inevitable toward the end of life, as a feared "social imaginary", as "usual ageing" in contrast with Rowe and Khan's "successful ageing", and as a form of irresponsible citizenship.

- Researchers have highlighted the culturally-situated and socially-produced nature of frailty as a concept, however these theories have all been generated and applied in relation to "western" cultures.
- It has been suggested that definitions of "successful ageing" should be informed by older people's experiences of ageing, as well as acknowledging that frailty and "successful ageing" need not be mutually exclusive.

2.22 The lived-experience of frailty

So far, this review has focused on conceptualisations of frailty from biomedicine and social science, and the voice of the older person has been absent. This section will present the qualitative literature that examines the lived-experiences of frailty. Two key points can be synthesised from these data. Firstly, older people generally resist calling themselves frail, even when they would be deemed frail by others or by objective measurements (Becker, 1994, Warmoth et al., 2015, Puts et al., 2009, Kaufman, 1994). This reinforces the criticism that frailty is a label given by others, and used in the third person (Grenier, 2007). For example, in a study of older adults in the South West of England, identifying with the term "frail" meant a disengagement with and "giving up" on life (Warmoth et al., 2015). One nuanced but important aspect of this finding is that older people have tended to make a distinction between "being" frail and "feeling" frail (Grenier, 2006). This emotional and psychological quality of frailty is usually ignored in favour of objective physical and functional measurements. In an example from Grenier's study of older Canadian women, a participant, who was objectively deemed "frail" by professionals sometimes felt frail, for example when she felt afraid of falling, but protected her sense of "self" from the label (Grenier, 2006). Acknowledging the emotional impact, and this common lay interpretation of the concept is likely to have important implications for delivering high quality person-centred care in old age (Nicholson et al., 2012).

The second key finding of studies exploring the lived-experience of frailty, is that it involves multiple and cumulative losses, and strategies in order to manage or adapt to these losses (Warmoth et al., 2015, Becker, 1994, Grenier, 2006, Lloyd et al., 2012). Loss was a dominant theme in many of the qualitative studies, however it is older adults' responses to these losses which are most relevant. Loss of mobility was seen in one study as symbolic of loss of independence, however it did not alter the participants' sense of autonomy and agency, in fact *"deficits became testaments to their autonomy in the face of adversity"* (Becker, 1994, p65). Older people redefined what autonomy meant to them as a means of adapting and coping with their loss. For example, one 90 year old participant who was homebound re-conceptualised

his immobility and isolation as independence *'Well, I'm independent because I stay right here.'* (Becker, 1994, p68).

In Lloyd's investigation of life in the fourth age for older community-dwelling adults living in England, participants maintained their sense of dignity and autonomy through perseverance and adaptation (Lloyd et al., 2012). Despite losing cherished hobbies and activities, bodily energy and relationships, older people maintained their autonomy and dignity through adapting and persevering (Lloyd et al., 2012). This study challenges Higgs and Gilleard's assertion that the fourth age leads to an inevitable loss of agency, as older people become subjugated to the will of professionals, and become institutionalised (Gilleard and Higgs, 2010). However, this was sample of older community-dwelling adults who had capacity to consent to take part in the study, so these findings may not represent the lived-experiences of those with more severe frailty or cognitive impairment.

Nicholson investigated the lived-experiences of frailty through an analysis of repeated in-depth interviews over 17 months with frail older people living at home in the UK (Nicholson et al., 2012, Nicholson et al., 2013). Loss associated with physical decline was a key factor which shaped older people's experiences, however older people responded creatively to their losses (Nicholson et al., 2013). Frailty-associated losses were managed by maintaining and creating new connections with others (Nicholson et al., 2013). Other strategies employed by participants living with feelings of uncertainty and loss, included producing stabilising routines and forging and maintaining connections within the home (Nicholson et al., 2012, Nicholson et al., 2013). An illustrative example given was of a participant 'Evelyn' who refused to de-clutter her home of ornaments accrued over her life, as they kept her connected with her past. The experience of living with frailty was found to require high levels of resilience and the ability to adapt and respond to a *dynamic* state of loss and uncertainty, for which, the authors claim the current health and social care system is poorly equipped to support.

Another study from Scotland also described the lived-experiences of older people as one of responding to and managing *dynamic* changes in losses and adaptations (Lloyd et al., 2016). The author interviewed community-dwelling frail individuals serially over 18 months, with the aim of better understanding the trajectory of frailty towards the end of life. These participants attempted to adapt to their uncertain and changing state in similar ways, through maintaining their sense of self, gaining support from care-givers and community structures as well as focusing on their day-to-day lives rather than contemplating the future. Similarly, the

authors concluded by stating that frailty poses a challenge to health and social care services given its unpredictable and dynamic nature (Lloyd et al., 2016). Interestingly, both of these longitudinal studies find a parallel between the lived-experience and the biomedical conceptualisation of frailty as a changing, dynamic entity. And where the majority of these studies describe the lived-experience of frailty as a struggle to balance "losses" with "adaptations", there is a notable similarity with Rockwood's original "dynamic balance" model of frailty, which measured "deficits" alongside "assets" (Rockwood et al., 1994).

2.23 Frailty in the context of international public health discourse

2.23.1 Frailty and "capabilities"

According to Sen's "capabilities approach", the aim of human development efforts should be to increase the freedom that people have to enjoy *'valuable beings and doings'* (Sen, 1985). That is, the aim of human development should be to provide resources and choices aligned with beneficiaries' values. While not specific to ageing, this "capabilities approach" has been suggested as a more inclusive approach to addressing health in older age, as it theoretically does not make assumptions about what older adults value "being" and "doing", and subsequently which freedoms and functions are desired (Stephens, 2016). It aims to align public health policy discourse with the values of the individual older person (Alkire, 2006, Alkire, 2005).

This framework underpins, and can be seen throughout the language of international public health discourse on ageing, which promotes "healthy ageing throughout the life course" (WHO, 2016, Bowling, 2007). The WHO defines "healthy ageing" as *"the process of developing and maintaining the functional ability that enables well-being in older age"* (WHO, 2015). Thus leaving the individual to define which "functional abilities" they value, and what "well-being" means to them. However, these dominant public health policy messages have been criticised for excluding poor and marginalised groups, such as that of the current study; a population of often uneducated, multidimensionally poor, older subsistence farmers living in rural villages in Northern Tanzania. The criticism being that when older people facing such disadvantages become frail and lose their valued functional capabilities, it becomes the problem of the individual, regardless of their individual ability to make healthy lifestyle choices, manage chronic medical conditions, or live in environments conducive to ageing in a state of well-being. This objection is similar to the common critique of the "successful ageing" ideology, highlighting that "healthy" and "successful" ageing are often mistakenly taken as equivalent (Stephens, 2016, Pickard, 2014).

Another important criticism of Sen's capabilities approach, is that when used, it often fails to take into account cultural differences, in particular differences between individualist and collectivist cultures (Westerhof et al., 2000). Specifically, the *individual's* valued capabilities are given primacy over *family or community* capabilities, in line with dominant "western" cultural norms, but in contrast with African cultural norms (Dean, 2009). The concept of promoting "intrinsic capabilities" was included in the recently published WHO guidelines, which seek to improve the integrated healthcare of older people in low-resource settings (WHO, 2017a). However older people's "intrinsic capabilities" are assumed to be equivalent to the ability to maintain functional independence for daily activities. Thus moving away from Sen's notion of the individual's valued capabilities, to applying "western" cultural values which assume functional independence and autonomy are universally desired.

2.23.2 The "cost" and "burden" of frailty globally

The second dominant discourse within international public health policy is of frailty as a growing "burden" on LMICs. In these narratives older people are discussed in terms of growing numbers of dependent people in need of health and social care. The demands of an ageing society, it is claimed, will put a strain on ill-equipped social and healthcare systems, and are likely to produce high costs for LMICs (Prince et al., 2015). Within a recent report on ageing in commonwealth countries the term "frail" was used, only as a descriptor of an increasing and homogenous number of older dependents (CommonAge, 2018). Frailty has also been framed as a public health issue, the scope and scale of which is described as a severe threat to the long-term sustainability of healthcare systems globally (Buckinx et al., 2015, Cesari et al., 2016). This literature is also frequently associated with a call to action, asking for measures to promote "healthy ageing" throughout the life course, with the aim of preventing frailty. One common concern is that ageing might impede economic growth in SSA; *"Issues of Africa's older populations are now increasingly recognized as a "development" concern for the continent"* (Aboderin, 2017a, p644). One of the main limitations of this narrative is the simplistic equation of older people with dependency, whereas the majority of older adults across SSA continue to work in the informal sector (Aboderin, 2017b). Makoni is also critical of this discourse, which they term "the lament trope", stating that *"an increased number of older people in an unprepared continent"* is an assumed problem (Makoni, 2008, p201). Whether this assumption aligns with the experiences of older people, and their perceptions of the problems and challenges associated with ageing has rarely been interrogated. The author reasons that there is too little empirical research representing the diverse experiences of older people in SSA (Makoni, 2008).

2.24 Introduction to ageing in sub-Saharan Africa

Much of the interpretive social sciences literature discussed thus far comes from and relates to ageing in "western" settings. While much of this provides useful background and these concepts will be used to discuss and reflect on the findings of this thesis, these studies are unlikely to be directly relevant for understanding the conceptualisation and lived-experience of frailty in rural Tanzania.

While the term "western" or "modern" has been used thus far to refer to the cultures and societies of high-income, industrial Europe and North America, one limitation inherent in doing so is that it erases local or national variation. It must also be acknowledged that SSA is a diverse sub-continent, which includes countries with different and divergent histories, and cultures, all undergoing rapid changes associated with the processes of economic development, urbanisation and globalisation. Thus, the sub-continent should not be approached as an homogenous entity, and as Aboderin has cautioned, the older people of SSA should also not be assumed to be an homogenous group of vulnerable older people (Aboderin, 2017a).

Thus, while acknowledging the diversity of older adults' experiences and contexts across SSA, there are several aspects of commonality, four of which will be discussed here. The first shared aspect can be expressed through the concept of *"Ubuntu"*. This is an African philosophy or African humanism which is found across all bantu-speaking areas of Southern Africa (Kamwangamalu, 1999). The meaning of *"Ubuntu"* can be understood thus; being human *"is to affirm one's humanity by recognizing the humanity of others and, on that basis, establish humane relations with them"* (Ramose, 2003, p272). This underpinning philosphy is likely to influence people's expectations for their old age and attitudes toward the care of older people within families and communities.

The second shared factor has been the huge impact of the HIV/AIDS epidemic in SSA, which has undeniably influenced the meaning of old age, and family-based care across the sub-continent (Small et al., 2017). Much of the gerontology literature on care in old-age in SSA has focused on the impact of the HIV-epidemic on the experiences of older people in caregiving roles (Chazan, 2008, Hoffman, 2018, Schatz and Seeley, 2015), however, due to the fact that the prevalence of HIV-infection in the present study was relatively low, and this literature review was iterative and data-driven, this topic will not be discussed in detail here.

Thirdly, attitudes toward ageing and old age may also have broad cross-country similarities. In general attitudes to ageing are more positive than in high-income "western" cultures, with

old age often being described as worthy of respect and virtuous in and of itself. This may be due to the relatively exceptional nature of reaching old age in SSA, where life expectancy at birth is 63.6 for women, and 60.0 for men (Kassebaum et al., 2016). Reaching old age has never been taken for granted, and is often referred to as a "blessing" (Teka and Adamek, 2014, Van der Geest, 2002a), implying that becoming aged is a form of reward. Positive old-age stereotypes may also be more prevalent in African cultures, for example through the notions of wise, peace-keeping elders (Okemwa, 2002, Macia et al., 2015). Additionally, widespread ancestor beliefs in many traditional SSA cultures may have contributed to the high status of older people, as older people are seen to be in closer communication with the spiritual realm, and viewed as protectors of family lineage and tradition (Stroeken, 2002).

Cowgill and Holmes observed this finding as they made cross-cultural comparisons and devised their theory of "ageing in relation to modernisation", noting that: *"The status of the aged is high in societies in which there is a high reverence for or worship of ancestors"* (Cowgill, 1986b, p189). According to modernisation theory, the accord given to older people inevitably diminishes as societies move in a linear development from "traditional" to "modern". This theory suggests that many of the attitudes towards older people shared by countries across SSA could be attributed to the sub-continent's general low levels of "modernisation" (measured by literacy levels and per capita gross national product) (Cowgill, 1986b). Some of the factors which were observed to correlate negatively with the status of older people included increasing proportions of older people, fast rates of social change, rapid urbanisation and mobility of residence (Cowgill, 1974). Therefore, the theory suggests, in rural agricultural settings with low levels of out-migration and fewer numbers of older people, the older generation inevitably benefit from a higher status. This description might describe the majority of traditional rural SSA communities, and may also be applicable to the context of this thesis. Indeed, modernisation theory has been the dominant framework used to explain some of the observed changes and reduction in status and fortune of older people in the sub-continent (Apt, 2011, Sangree, 1992, Aboderin, 2004a). While criticising the theory, Aboderin has called for more cross-cultural examination of differing attitudes, which may exist despite urbanisation and education (Aboderin, 2004b). In a study comparing the perspectives of older people towards ageing in the US and the Congo, a literate group of older Congolese people, recruited in urban Kinshasa, completed sentence stems to reveal their hopes, fears and expectations for old age (Westerhof, 2001). Older adults in the US, valued health and autonomy, and attributed maintenance of health to a personal responsibility (in accordance with Rowe and Khan "successful ageing" paradigm). In contrast, old age was not

lamented for loss of autonomy, rather older Congolese respondents hoped to receive care (Westerhof et al., 2000). It can be concluded then that cross-cultural differences are likely to persist, even in the presence of factors associated with modernisation.

2.25 Ageing and long-term care in the sub-Saharan African context

Given the paucity of previous research investigating frailty in older people in SSA, this section will examine the existing research which has investigated the concepts of ageing and care for older people in the sub-continent. The section has been separated into sub-sections which focus first on the sociocultural implications of caring for older people, the practice of care (who cares and how), and lastly research which has investigated institutional care for older people in the sub-continent, as compared to the social norm of family-based care.

2.25.1 The meaning of care

Being cared for in old age is a demonstration of respect and an acknowledgement of reciprocity, as concluded succinctly by the anthropologist Van der Geest in their work on care for older people in rural Ghana: *"Those who are respected are assured of care. That respect depends very much on what they have achieved during their active life. Those who have worked very hard and have taken good care of others, their children, their partners and other relatives, will receive care, attention and financial help. It is only money that begets money. The guarantee of care at old age is foremost a matter of reciprocity"* (Van der Geest, 2002a, p28). Automatic respect towards older people may be changing according to Van der Geest, who found grandchildren often behaved respectfully, but lacked true reverence for their grandparents (Van der Geest, 2011). The concepts of respect and reciprocity were investigated in a study of attitudes towards older people in Senegal (Macia et al., 2015). Respect was inherent in old age, and was seen as honouring a "life debt" and "education debt" to one's parents. As with Tanzanian culture, older people in Senegal are addressed using family pronouns, of mother/grandmother, father/grandfather, even when they are non-relatives, suggesting this debt of respect and reciprocal care is applied to the older generation generally (Macia et al., 2015). Conversely, withholding respect or actively disrespecting older people has been described as a form of elder abuse (Ferreira and Lindgren, 2008); experienced as a negation of "dignity and personhood" by older people in South Africa (Sagner, 2002). A qualitative investigation of the meaning of care for older people in Namibia found that care for an older family member was perceived as a form of "nurturing the wellbeing of the family" (Leuning et al., 2000). This illustrates the role of familism, or the prioritisation of the family over the individual as a motive for providing care to older people. According to modernisation theory, these motivations have been eroded with the increasingly

individualistic value systems and neo-liberal politics[3] of "modern" or "western" societies (Aboderin, 2004b).

If the meaning of care is reciprocation of care and a demonstration of respect, it has been discussed as an inter-generational phenomenon. Care, as an expression of inter-generational reciprocity has often been described as being under pressure from rapid social and cultural changes, and discussed in terms of a conflict between the "idealised" notions of care, and its "realities" or "pragmatics" (Hoffman, 2018, Cattell, 1990, McIntosh, 2017). The meaning of idealised care in old age, was to "sit and eat" and be taken care of by one's children, according to Cattell's anthropological study of the Samia in Western Kenya. Idealised care was seen as being rewarded in old age for having met one's adult responsibilities to one's children (Cattell, 1990). However, this inter-generational reciprocity came under pressure when surviving children were few, estranged, or neglecting their duty to provide care. Particularly, Cattell described one case of an older widow who was neglected by her step-sons, and was forced to beg from co-wives and neighbours.

Exemplifying this, Hoffman describes younger generations in South Africa viewing their obligations to provide reciprocal care as "flexible", while older care-givers provided care to the younger generation, motivated by their belief that they should *"always enjoy precedence over the oldest generation"* (Hoffman, 2018, p168). While it was still held that the sacrifices of parents should be rewarded with meaningful care in old age, the challenges of resource constraints due to unemployment and HIV/AIDS, tested the meaning of care "provision" for older people. Particularly, in South Africa this was due to the fact that substantial financial income was brought into the household by the older person's pension (Hoffman, 2018). Thus care was inter-generational and reciprocal, but did not fit the traditional temporal life course ideals; care was not rewarded, but pragmatically negotiated, in a context of financial strain and future uncertainty.

2.25.2 The practice of care

According to a qualitative study of older spouses providing care for one another in Tanzania, care activities conducted for and by older people included carrying out the "daily domestic work" (e.g. handwashing laundry, preparing food, collecting firewood) and providing "emotional counselling" such as consoling, advising and praying with the older person (van Eeuwijk, 2018). Van der Geest found that, in addition to providing necessities of food, clothes, and remittances as activities of care provision, one of the most important ways of showing care was providing a fitting burial, seen as the "last act of care" for an older person

(Van der Geest, 2002a, Whyte, 2005); a funeral being a means of publicly honouring the deceased and the family itself (Van der Geest, 2002a). The underlying meaning of these caring actions was demonstrating the value and primacy of the family.

Literature describing the practices of how older people are cared for in SSA, have described the interdependency and reciprocal transfer of care across generations, and has also debated the supposed reduction in these forms of material and emotional care. Interdependency and the generational contract are both concepts of relevance here (Fine and Glendinning, 2005, Johnson, 2008). Both concepts describe a transfer of care across generations based on a sense of family solidarity or obligation, often so strongly held that it constitutes a form of unspoken contract (Johnson, 2008). This form of care, transferred between generations, was described in an investigation of the practices of care-giving for frail older adults in Kenya (Six et al., 2019). Care-giver and care-receiver relationship was not as clearly delineated as might have been anticipated, with older adults continuing to be involved in caring for grandchildren and consulted in household decisions (Six et al., 2019). Janet McIntosh's research on elderhood in a rural coastal area of Kenya balances these ideas of close generational reciprocal care with the "modernisation" discourse of social, economic and cultural changes leading to an erosion of older people's traditional authority (McIntosh, 2017). McIntosh describes what she terms "desired interdependence" as the idealised notion of care this setting; whereby older people, while requiring practical care, also wished to be *"needed for the community's functioning"* (McIntosh, 2017, p189). The author found that older people's status, while somewhat diminished, largely remains intact. *"The older ways of life have not altogether dissolved; they are transfigured, existing in an uneasy tension with newer ideologies of individualism, independence, and the valorisation of youth."* (McIntosh, 2017, p197). For example, older adults were still consulted in matters of witchcraft or traditional healing, and practical care was still provided through methods such as sending remittances by mobile phone banking.

The displacement of older people as sources of knowledge, by an increasingly educated youth is concurrent with modernisation theory (Cowgill, 1974), and has been used to explain a reduction in the provision of material care for older people (Aboderin, 2004a). Aboderin has critically examined the assumption that the influences of modernisation (urbanisation, technology, and formal education) lead linearly and causatively to a decline in the care of resources for older people (Aboderin, 2004b, Aboderin, 2004a). The "material constraints" discourse, explains that in the context of widespread economic difficulty, older people are not receiving the desired standard of family care, not out of unwillingness to provide it, but due to broader political and economic factors, such as under or unemployment (Aboderin, 2004b).

This was evidenced in a study of older adults in rural Botswana investigating the care given by, and provided for older Tswana women (Ingstad et al., 1992). Financial difficulties in the household and extended family led to some older adults facing neglect and hunger when they were no longer able to labour, as they were not receiving adequate financial or practical support from children (Ingstad et al., 1992). The authors describe the care of frail older people falling to "the losers of modern life", namely daughters or granddaughters who were forced to drop out of school due to pregnancy, or sons who were unemployed due to job shortages, lack of skills or alcoholism (Ingstad et al., 1992). Thus they conclude with a nuanced perspective that both the rapid changes of modernisation, and resource constraints are causing some degree of uncertainty and suffering, and putting pressure on the practice of care, for both older and younger generations in Botswana.

2.25.3 The place of care

The discourse around place of long-term care for older people in SSA has tended towards a binary rejection of "northern hemisphere" institutional care in favour of "African" family and home-based care (Baart, 2018, Aboderin and Hoffman, 2015). For example Nyirenda et al. in their paper examining the health implications of care-giving and receiving in rural South Africa described institutional care of older adults as *"non-existent and not normative"* and urged religious organisations, neighbours and communities to provide community-based care for older adults without family support in the spirit of reinforcing "traditional" values (Nyirenda et al., 2015, p195). This discussion has often been framed in the context of modernisation theory, whereby institutional care has been seen as a direct consequence of the "breakdown" of familism and the duty of care, the mechanism through which modernisation may lead to a reduction in family provision of care (Aboderin, 2004b). However there has been very little research investigating what culturally appropriate, long-term care would look like in a "modernising" Africa.

It is difficult to quantify the current or projected needs for long-term care provision for older people with frailty in SSA as this has been a neglected policy issue (Lloyd-Sherlock, 2014). However, a few qualitative studies have investigated the experiences of older adults in long-term institutional care in SSA. One such study interviewed 24 older adults living in a government-run institution for older adults in Ethiopia. The five themes derived from these data included "gratitude for shelter despite inadequate provisions", of which inadequate nutrition was a major complaint. According to one care-giver, there was a particular challenge in providing a balanced and appropriate diet for frail older residents due to budget shortages (Teka and Adamek, 2014). Older residents also desired meaningful social interactions, as

illustrated by the quotation; *"We prefer greeting rather than eating"* (Teka and Adamek, 2014, p396). The fact that social interactions and being fed were given equal importance highlights the need for fostering of a meaningful sense of community in institutional care in this context. Meanwhile, negative views were directed towards older retirement home residents in Kinshasa (Pype, 2018). These institutions were commonly thought of as "houses for witches", derived from the common belief that older people possess supernatural powers which may be used for good or evil (Pype, 2018). Instead of being given respect and care, and thus accorded value within the family, they were seen as people with less value as they were reliant on the state, the church, or donors to provide their care (Pype, 2018). Thus, although these residents received care in the form of having their essential needs met, they were also people who had lost their identities through the usual relational means within the family. Both studies share in common the finding that the care provided in institutional settings lacked the culturally meaningful psychological and social aspects of care, such as respect and social status, in addition to meeting essential needs for food and shelter.

2.25.4 Theory of care for older people in SSA

In response to a lack of encompassing theory to underpin discussions around care for older people in SSA, Andries Baart developed the following four discourses of care (Baart, 2018). These four discourses of care will be introduced here, and returned to in later chapters when answering the research question of how frail older people are cared for in Tanzania.

The first discourse of care, is the "cultural-conformable discourse", which is underpinned by tradition and convention (Baart, 2018). This discourse is conservative, upholding the positions of older people and following expected traditions. According to the second, "structural-adaptive discourse", care is provided on the basis of rights and needs, delivered through the formal avenues of organisations or bureaucracy, or through trained community solidarity. This may be the dominant discourse in Tanzania, where the age-cohort studied may expect government provision of services, as was seen in nostalgic complaints of older people in coastal Tanzania who yearned for a return to a single party socialist government (Kamat, 2008). The third discourse is the "calculating-innovative discourse", which breaks away from the communitarian and traditional orientations of care provision, described in the first and second discourse. Here, care is commodified and organised based on financial capital and skilled expertise (Baart, 2018). Modernisation theory, introduced previously, might imply that factors such as urbanisation and increasing reliance on a cash economy would lead to an increased market for commodified care (Cowgill, 1986b). Lastly, the "functional-subsistence

discourse", describes the active or passive non-participation of older people in care-receiving (Baart, 2018).

2.26 Long-term care policy

The current levels of formal and informal care provided for older people with disability and frailty in SSA are unknown, and are difficult to estimate other than through broader demographic trends (Lloyd-Sherlock, 2015). Part of the difficulty in estimating current long-term care provision comes from the fact that outside of family-based care, formal opportunities for long-term care provision are patchy, and provided through multiple avenues such as the state, religious organisations, and NGOs (Lloyd-Sherlock, 2015). The WHO, echoing the assumptions of modernisation theory, refers to widespread social and economic changes which mean that "traditional" forms of family-based care are unlikely to be relied upon to the same extent in future (WHO, 2017c). The WHO recommends that countries consider culturally-acceptable alternatives to family-based long-term care for older people, arguing that it is an unsustainable and inequitable form of care provision (WHO, 2017c). The economic costs placed on households (through direct costs of care and healthcare expenditure) (Nortey et al., 2017), and opportunity costs, usually affecting women (through the provision of unpaid care work at the cost of loss of potential earnings), mean that family-based long-term care is both inequitable for the care-giver as well as for the older person receiving care (Aboderin, 2017b). Yet, there appears to be some resistance to considering more formal means of care provision for older people, with the most recent policy document on ageing from the Tanzanian government stating:

"The ability of the oldest old to manage themselves is either minimal or not existing. Due to this fact the society has the responsibility of providing them with care and support. However the family will remain the basic institution of care and support for older people. Institutional care of older people will be the last resort." (Ministry of Labour Youth Development and Sports, 2003).

While this policy document rather simplistically observes there to be only two options; either informal family-based care or formalised institutionalisation, the question of whether and how the government might support the family as the "basic institution of care" remains unaddressed. As Lloyd-Sherlock has emphasised, research in this area has been scarce, and has not translated adequately into influencing social policies (Lloyd-Sherlock, 2014, Lloyd-Sherlock, 2015). This lack of evidence and effective engagement with policy makers has permitted the issue to remain a low priority for many governments, including that of Tanzania.

2.27 Frailty in old age in Tanzania; "Sina nguvu" (I don't have strength)

There are very few studies that have investigated frailty in old age qualitatively in SSA, yet the few studies which have mentioned "frailty" as a concept, derive from research carried out in coastal Tanzania. Obrist and colleagues conducted their research in rural Rufiji District, urban neighbourhoods of Dar es Salaam, and Zanzibar, and sought to investigate social resilience in ageing (Obrist, 2016), practices of care for frail older people (van Eeuwijk, 2018, van Eeuwijk, 2014), as well as an exploration of the place of care for older people self-defined as *"sina nguvu"* (I don't have strength) (Obrist, 2018). Another study from rural Kagera, Northwest Tanzania, investigated the experiences of ageing longitudinally for 11 families and found neglect of frail older people to be an important theme (de Klerk, 2018). Each of these studies will be described in detail, with reflection on the gaps in the present understanding.

Obrist's study of the place of care for frail older people, found that a loss of strength to conduct the activities of household maintenance and livelihood signified frailty. This was defined by the individual categorising themselves as *"sina nguvu"* (I don't have strength) (Obrist, 2018). The researcher graded those who could no longer work and self-identified as *"sina nguvu"* into three groups of increasing severity, each occupying increasingly diminishing spaces: There were those who were able to leave the house occasionally to engage in some activities other than work, those who were housebound, and those who were bedridden. In the care arrangements which formed around the *"sina nguvu"* person, boundaries between homes were fluid and intersecting. That is, close relatives need not live in geographical proximity in order to contribute to the care of their older relative (for example by sending remittances or employing a paid helper). In contrast, neighbours who were close geographically, but who were not related, provided solace, friendship and practical support, but not intimate care, unless they were being paid. The author highlights the need for further research to investigate what constitutes "good" home care in the context of recent gerontological research on "ageing in place" (Vasunilashorn et al., 2012), which has emphasised the promotion of policies and programs designed to enable older people to remain living in their homes and communities.

Frailty was discussed in van Eeuwijk's study of the phenomenon of older people providing care for older people, particularly through the description of care activities performed by older people (van Eeuwijk, 2018). Care activities that "related to frailty and illness" included watching over an ill older person, accompanying them to the toilet, buying medicine and accompanying them to the healer or hospital. The author found that in a third of households

older people were providing care for another older person, which was inconsistent with traditional expectations for children to provide care for their older family members. Older people, van Eeuwijk reasons, have been forced to adapt to rapidly changing social circumstances, for example the rapid out-migration of adult children to Dar es Salaam. Adult children were mobilised mostly in situations of acute illness (van Eeuwijk, 2014). In these "critical health situations" older adults frequently drew on their children's support (for provision of hospital fees, transport, or additional care), and this support is still maintained according to the values of family solidarity and inter-generational reciprocity (Whyte, 2017). This is a precarious situation however, which puts the older care-giver under a considerable degree of vulnerability too. However the author describes institutional forms of care provision occurring as a last resort for *"socially excluded and economically neglected elderly people"* (van Eeuwijk, 2018, p89).

In another study situated in rural Kagera, Tanzania, De Klerk introduces the topic of care for older people. In both advanced old age and sickness, the frail dependent person belongs to their family (de Klerk, 2018), a finding which was also echoed in a study of attitudes toward palliative care in northern Tanzania (Lewis et al., 2017). According to the social norm of belonging to one's family in times of illness and dependency, and in the absence of institutional or other formal avenues of care, family are the main providers of care. Factors putting pressure on this social norm according to de Klerk, were rural-to-urban migration, death of working-age adults and economic hardship (de Klerk, 2018). In discussing frailty in the local language *"Kihaya"*, the old were distinguished into older people with strength, and those without. The author tells the story of an 86 year old "frail" and bed-bound widow, who was neglected by her grandson. This neglect, was judged as deserved by neighbours who understood her maltreatment to be an outcome of her poor decisions in earlier life, when as a wealthy widow she had sold the family plot (*"shamba"*) and distributed the inheritance unevenly between her grandchildren. Thus, according to de Klerk, reciprocal family care is not unconditional, but rather depends on the older person's "good" moral judgement. Interestingly, de Klerk's investigation suggested that the frail body may symbolise the state of family relations; a neglected, underweight, unkempt older body suggesting poor inter-generational relationships (de Klerk, 2018). In conclusion, care for older people in rural Tanzania was hoped-for, but not guaranteed, and preparing for and receiving care in old age involved valuing the family's best interests and maintaining close family relationships.

While these studies provide vivid contextual detail and challenge some of the idealised notions of family-based care and respect for older people in rural and urban Tanzania, these

researches have not focused on the conceptualisation of frailty itself. Beyond the description of frailty as a self-reported binary category, *"sina nguvu"* (I don't have strength), there has been little exploration of the meaning of frailty in old age in this context. This thesis aims to address this gap in understanding, while drawing on these data which elaborate on the uncertain care situations which characterise ageing in Tanzania.

2.28 Discussion

Having presented a narrative review of the relevant biomedical and interpretive social sciences literature to date, it is evident that this thesis will add considerably to this field of research. There are very few studies that have explicitly focused on frailty in an older SSA population, and none which have investigated the biomedical construct of frailty through mixed methods in a rural low-income SSA setting.

There is need for research in this area, which can be argued on the basis of a lack of prior research and knowledge of frailty in this setting. As discussed above, there is current disagreement about whether frailty prevalence rates are higher in LMICs as compared with HICs, with the few large studies of frailty in LMICs producing conflicting findings (Siriwardhana et al., 2018, Harttgen et al., 2013). There is theoretical evidence for a likely increased prevalence, as frailty has been shown to be higher in lower socio-economic groups (Hoogendijk et al., 2018), and with key components of frailty such as HGS and walking speed, showing LMIC disadvantages in ageing when compared with HICs (Capistrant et al., 2014, Dodds et al., 2016). Conversely, it is normal for older adults in rural African settings work in manual subsistence farming into old age (Aboderin, 2017b), and this increased physical activity may confer a benefit compared with HIC sedentary working life. This thesis will add valuable additional data to this discussion, uniquely providing an opportunity for comparing the main biomedical models of frailty with each other, and with a clinical diagnosis according to the CGA. By taking multiple approaches to measuring and defining frailty it will be possible to provide a more refined view of the prevalence and characteristics of frailty in this population, as well as provide additional opportunity for comparisons across studies. Practically speaking, adapting and applying the dominant biomedical models of frailty in a rural low-income SSA context has rarely been attempted (Payne et al., 2017). This study will provide valuable reflections on dealing with some of these methodological challenges, for example in the cross-cultural and cross-language interpretation of "exhaustion", one of the components of the FP.

The interpretive social sciences literature reveals that despite the consensus that frailty is culturally-situated and socially-constructed, there has been very little work exploring the

construct and experience of frailty in cultures other than that of “western” HICs. The anthropological work conducted examining ageing and health in Tanzania has thus far discussed frailty only in superficial terms (Obrist, 2018), with a focus on the care arrangements of older adults. This thesis takes a unique approach, by illuminating the voices of older people and their lived-experience and understanding of frailty, these findings will be presented with reference to gerontology theory with the aim of contributing to a more mature and nuanced understanding.

To the author’s knowledge this is the first study taking a mixed methods approach to investigating frailty in the African sub-continent. A dialectical mixed methods approach will provide a deeper understanding of the construct of frailty, with complimentary and conflicting findings producing fruitful debate: While the quantitative investigation may give a broad estimation of frailty prevalence in the study setting, it cannot provide an understanding of the *meaning* of frailty to older people, their families and communities living with frailty in this setting. This is a key strength of this thesis.

As discussed, the interpretive social sciences literature suggests that the concept of frailty can be potentially harmful, particularly in the ways the concept has been used in “western” biomedical settings, where it is employed to categorise older people according to their vulnerability to risk, and to rationalise and ration their care. It is important to consider whether applying the concept of frailty in this study’s context could reproduce the same, or other unintended potential harms. The qualitative aspect will allow for reflections on whether the concept of frailty *should* be transposed from “western” medical settings. The concept of frailty could provide a useful means of prioritising older people with the highest vulnerability, particularly useful where resources are scarce. Additionally, frailty may be helpful to promote an improved quality of care for older people. Many have called for a move away from healthcare services that are designed around single diseases or body systems in LMICs, (Cesari et al., 2016) and the concept of frailty, especially of multidimensional frailty is congruent with this approach.

In summary, this study is novel and unique in that very little is known about the prevalence or characteristics of frailty in rural SSA. The lived-experiences of frailty and its sociocultural understanding have also only been superficially investigated. Through the application of mixed-methods this thesis has the potential to produce valuable and important insights. The following methods and methodology chapter will describe the detail of the methods employed and theoretical stance taken.

Chapter 3 Research methodology and methods

3.1 Introduction

This chapter conceptualises the study and choice of mixed methods employed. The theoretical and paradigmatic stance taken to addressing the research questions will also be discussed.

3.2 The study conceptualisation

This study's starting point was the broad research question: What is frailty in rural Tanzania? From this broad research question came multiple more specific sub-questions. These study questions previously presented in the introduction chapter require different research approaches. In other words, the sub-questions would be best answered by single methods, yet taken together, the sub-questions would address the broader research question through a mixed methods approach (Teddlie and Tashakkori, 2013). The specific sub-questions were each informed by the biomedical and interpretive social sciences literature outlined in the previous chapter.

The first question asks, to what extent can the biomedical models of frailty be applied to measure and characterise frailty and its outcomes in this setting? This question required a positivist stance, approaching the study of frailty as an investigation of a naturally occurring phenomenon to be tested and measured by empirical means (Teddlie and Tashakkori, 2003). Thus survey questionnaires and anthropometrics were utilised to measure frailty as a quantifiable entity defined according to biomedical frameworks. The challenge would be in ensuring appropriate adaptation and operationalisation in the study's setting. The other sub-questions set out to understand frailty from a contextual, experiential perspective. These questions acknowledged the need to accommodate culture in science, and recognise the "cultural distance" between the researcher and study participants (Moghaddam et al., 2003). Despite the fact that cross-cultural positivist research has attempted to bridge cultural differences through use of methods such as back-translation procedures, or developing culturally equivalent questions, these procedures and questions are still created from the interpretation of "culturally distant" researchers. Investigating frailty qualitatively, taking a constructivist stance, would foster a "different way of knowing" (Greene and Hall, 2010). This stance challenges the idea that frailty is an objective and measurable entity, unchanged across contexts, and seeks to construct the meaning of frailty from the perspective of this study's cultural context. This leads to the acknowledgement that the UK biomedical cultural context is not (and should not be) the standard from which other cultures diverge, and to which other cultures must accommodate (Moghaddam et al., 2003). While sometimes these two paradigms (positivist and constructivist) might corroborate one another it was also

recognised that these data may counter and challenge each other. Overall it was believed that taking this mixed methods approach would lead to a deeper, more whole understanding (Greene and Hall, 2010).

3.3 The mixed methods approach

The qualitative and quantitative methods have been given "equal status" in this mixed methods research, with neither forming a core or supplementary aspect of the study (Johnson et al., 2007). According to the pluralism which is characteristic of mixed methods research, a "methodological eclecticism" was developed, alongside multiple epistemological stances, in order to best answer these research sub-questions (Teddlie and Tashakkori, 2013). The rationale for mixing methods can be expressed as a means of juxtaposing the structured researcher-defined biomedical model of "knowing" frailty with the emergent contextually-defined phenomenon (Greene and Caracelli, 2003). Therefore, a dialectic stance to mixed methods has been taken. The dialectic stance claims that all paradigms are valuable, with something to contribute to understanding (Greene and Caracelli, 2003). The approach enjoys the tensions and contradictions created by opposing perspectives, believing that in the conversation produced is the potential for more meaningful understandings to be generated (Greene and Caracelli, 2003).

The study of frailty may lend itself particularly well to this approach of mixing paradigms as well as mixing methods, because as was discussed in the literature review, the definition of frailty within the biomedical sphere is contentious, and the concept of frailty as it is understood in "western" cultural contexts has been widely critiqued. As previously mentioned there is a "cultural distance" between the researcher and study participants; that is the research team being largely white, middle-class, highly educated, medical professionals living in British urban centres, researching a population of older Africans who are income-poor subsistence farmers, with low educational attainment, living rurally, and who remember gaining independence from British colonial rule within their lifetimes. The qualitative aspect of this investigation assumes that this difference cannot be bridged by adapting a questionnaire developed for use in the former setting. Rather, being a cross-cultural and cross-language study, a dialectical approach seems appropriate in that it intentionally encourages an examination of, and engagement with, multiple *"sets of assumptions, models, or ways of knowing toward better understanding"* (Greene and Caracelli, 2003, p97). Particularly relevant when researching such an ill-defined phenomenon such as frailty in a foreign context, the dialectic stance allows the researcher to more meaningfully engage with difference

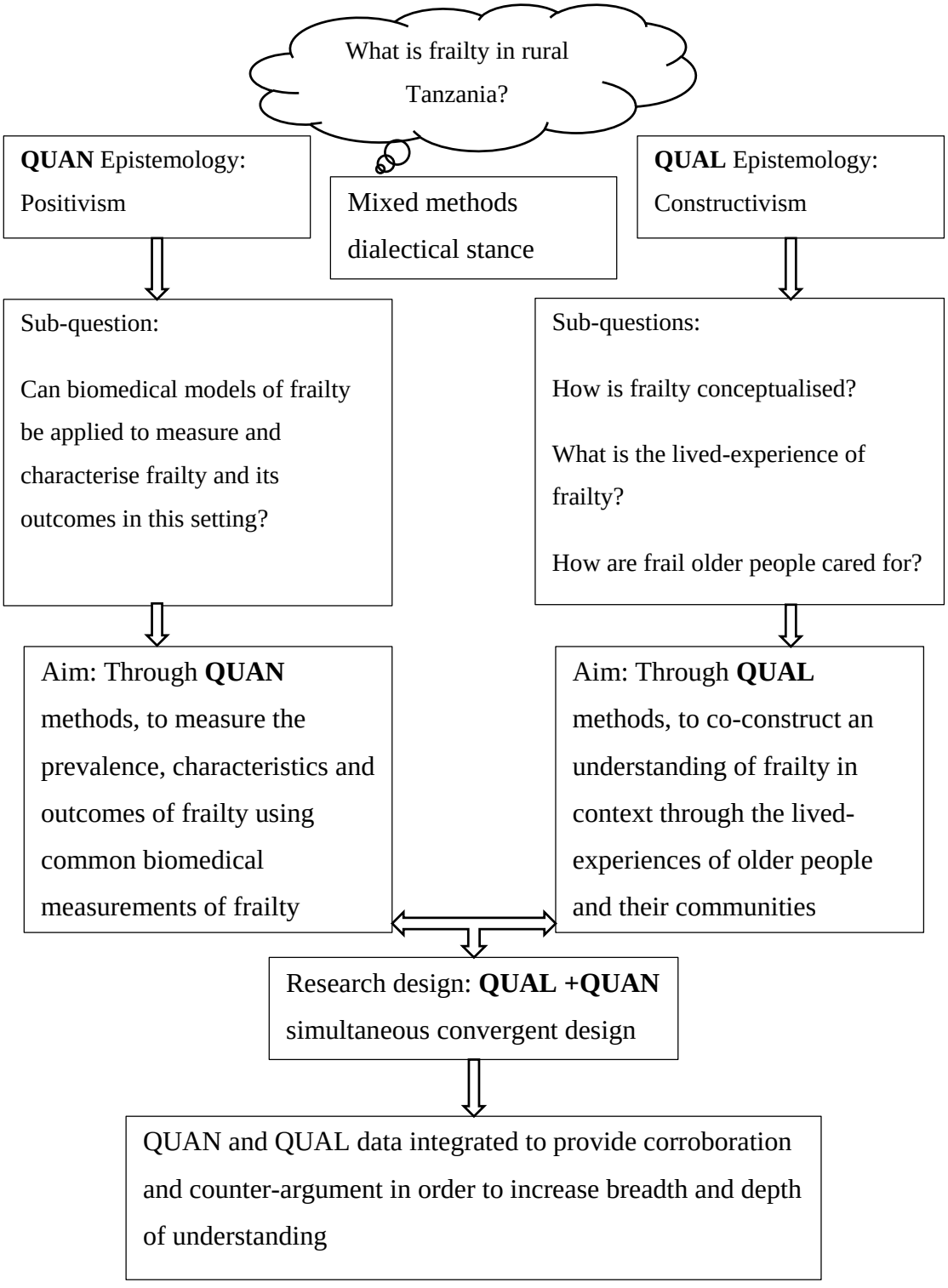
encountered in the research context, and promotes a means of respectfully engaging those differences throughout the study process (Greene and Hall, 2010).

This was preferred to the popular pragmatic stance to mixing methods, given that pragmatism is a problem-solving action-based process (Teddlie and Tashakkori, 2013). In view of the fact that the broad research question was not clearly defined as a problem (what is frailty in this context?), taking a pragmatic stance in order to provide a workable single solution was not philosophically aligned with this particular study (Greene and Hall, 2010).

3.4 Outline of the study design

Figure 3-1 illustrates the simultaneous convergent design with reference to the study's aims and questions. The quantitative sub-question is addressed across both quantitative results chapters, and qualitative sub-questions are answered by the two qualitative results chapters. These data converge at the point of the discussion chapter where both datasets will be used to investigate areas of tension and corroboration between the findings. It is hoped that the qualitative dataset will provide more than a triangulation or corroboration of the quantitative dataset, but rather will lead to a critique of the concept of frailty. In this use of mixed methods, multiple methods and epistemologies have been used to approach the broad question "What is frailty in rural Tanzania?", allowing for fuller exploration of this question, and an investigation which draws together multiple perspectives and conceptualisations of frailty in order to get closer to its meaning in the context of the study.

Figure 3-1 Illustrating the study's mixed methods design



QUAN= quantitative methods, QUAL=qualitative methods

3.5 Quantitative methods

The quantitative methods, which aimed to measure the prevalence, characteristics and outcomes of frailty according to the major biomedical models, will be outlined here. Throughout these methods a positivist stance was taken, with the biomedical models of frailty applied in as neutral a way as possible (Greene and Hall, 2010). For example questions for surveys were translated by a professional linguist and back translated for coherence and equivalence of meaning. Tanzanian research colleagues were also seen as passive conveyors or documenters of information, adding as little of their own personal intervention and interpretation as possible.

3.6 The research setting: Hai District, Northern Tanzania

While the qualitative investigation was conducted in the same location, the following section describes particular factors at the village and district level which were important in the quantitative data collection process.

Eight villages within Hai District were randomly selected from the total of 80, and stratified by size and altitude zones to participate in the study. As previously explained in the introduction (1.4.2) each village can be separated administratively into hamlets, which in turn are broken into groups of ten-cells, or ten households. Each ten-cell has an appointed leader that represents the inhabitants of those ten households at village meetings. In the absence of road names, house numbers or post-codes, a participant's ten-cell leader formed a means of locating an individual within the village, as well as a point of contact.

From each village health committee (VHC), one person with good literacy, was chosen as an enumerator. The village enumerator had often been in this position for many years, having been recruited and trained originally as part of the Adult Morbidity and Mortality Project, a district-wide census conducted as a Health and Demographic Surveillance System site (Tanzanian Ministry of Health, 1997).

For this thesis, the enumerator's role was crucial for the enrolment of adults aged ≥60 years to the quantitative survey, and for assisting in the purposive sampling of older adults, and their family members who were interviewed for the qualitative component. From the eight villages selected, quantitative work was conducted in five villages (due to limitations of time and resources), but these remained stratified by size and zone location. This stratification was in order to provide a representative sample across the district, as climate, farming practices, and socio-economic status vary across these locations.

3.7 Research colleagues recruitment and training for baseline data collection

Tanzanian research colleagues were employed to assist with data collection in the selected five villages. Aloyce Kisoli (AK), Dr John Kissima (JK), and Jane Rogathi (JR), have long-established working relationships with researchers affiliated with Northumbria Healthcare NHS Foundation Trust (NHFT) and Newcastle University. Other research colleagues were recruited through recommendation, primarily by JK (for example, Antusa John Kissima and Paulina Elias Tukay). At the time of data collection in February 2017 there was a national shortage of junior doctor jobs for new graduates, therefore Dr Ali Mohammed Ali, Dr Ally Mohamed Imani, Dr Deborah Mdegella, Dr Joyce Mkodo, and Dr Francis Zerd, all junior doctors, were employed on a short-term basis after being recommended by senior doctors based at Kilimanjaro Christian Medical Centre (KCMC). Newcastle University MRes students, Selina Coles, Harry Collin, Louise Whitton, and Greta Wood were involved in data collection, and assisting in the daily running of the project. Additionally, the author (EGL) two UK-trained volunteer doctors, Dr Louise Mulligan (LM) and Dr Bhavini Shah (BS), and a Clinical Teaching Fellow, Dr Kate Howorth (KH) (also employed by NHFT) all with geriatrics experience, assisted with the general project co-ordination, and in conducting Comprehensive Geriatric Assessments (CGAs). Reflections will be made on the use of the term "research colleague" and on the research team as a whole later when discussing reflexivity and research ethics.

One week of intensive training was conducted with all members of this large, multi-skilled, multi-cultural research team. The training included an oral checking of the Swahili translations, for comprehension and equivalence of meaning. Training was provided in gaining participant consent and assent, with a review of the consent and information leaflets. Additionally, guidelines were reviewed for conducting standardised questionnaires, such as the World Health Organization Disability Assessment Schedule (WHODAS 2.0) (WHO, 2010a), and the whole survey was practiced for fluency and familiarity. Time was also spent practising standardised methods for undertaking anthropometric measurements and functional assessments such as hand grip strength (HGS). The team also used the training period to familiarise themselves with the tablet computer and Open Data Kit (ODK 2.0) software which would be used for data collection (Brunette et al., 2013).

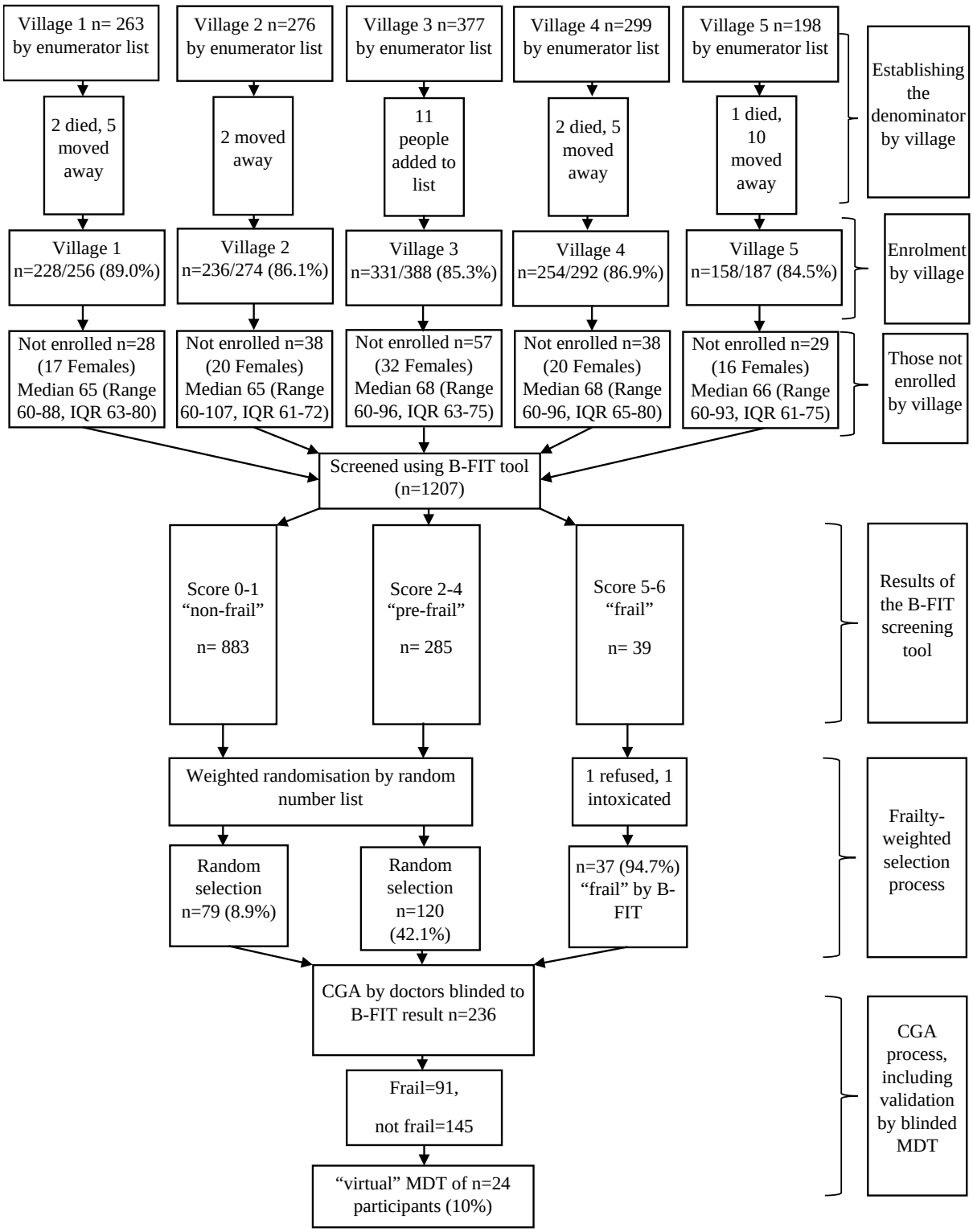
3.8 Participant enrolment

The enumerator for each village was charged with conducting a focused census of all adults aged ≥60 years, currently resident in their village. The enumerators, (Willy Chuwa, Clemence Kulaya, Anankira Mwanga, Alendwa Tarimo and Kanankira Urasa) were given this task to

complete in one week and were recommended to visit households door-to-door as well as interviewing ten-cell leaders for the details of older adults living in their respective areas. They each compiled a paper list, documenting every older person's name, their estimated age, their ten-cell leader's name and if possible, a contact telephone number. This list was cross-checked prior to data collection, by holding a meeting to which all elected ten-cell leaders were invited and where the listed names were individually verified. In this way we established an accurate denominator; removing the names of any older person who had died or moved away from the village, and adding any which had been missed. A validated method using recall of historical events (e.g. Tanzanian independence or the end of the Second World War), was used to assist in age-estimation where this was uncertain (Paraiso et al., 2010). *Figure 3-2* describes the steps of this process.

All named older adults were invited to attend screening days, held at village centres, (usually the village office or dispensary) within walking distance of participants' homes. Information about the study was given verbally and in writing, with opportunities for questioning, before the participant was asked to sign or give a thumbprint indicating consent. Thumbprints were used primarily where participants had not received formal education so had never learnt to read and/or write, or where they were no longer able to do so, due to visual impairment or problems with manual dexterity. In cases where an older individual was unable to give informed consent due to lack of capacity, written assent was obtained from a close relative. This meant that participants with cognitive impairment or communication difficulties were not excluded from participating. The ethics of the consent process will be returned to later in section 3.25.1. Individuals who were unable to attend the centre were identified by the enumerators, who arranged a home visit. The start of data collection coincided with planting in the rainy season and ended at harvesting, so patterns of work, market days and ceremonies such as funerals were taken into account when enrolling participants.

Figure 3-2 Flow chart demonstrating the process of selecting the stratified frailty-weighted sample



3.8.1 Data collection

Baseline data collection took place between the 24th of February 2017, and the 9th of August 2017 inclusively. Data were collected using ODK 2.0 collect open access software using

hand-held tablet computers (Android Samsung Galaxy Tab A6) and collated using a secure password-protected ODK 2.0 aggregate hosted on an encrypted server. Follow-up data collection was conducted between the 20th of August and 10th of October 2018 inclusively.

3.8.2 B-FIT screening

A frailty screening tool termed the Brief Frailty Instrument for Tanzania (B-FIT) was developed from previous Hai District longitudinal cohort data (Gray et al., 2017). The B-FIT contains an abbreviated version of the IDEA (Identification and Intervention for Dementia in Elderly Africans) cognitive screening tool (Gray et al., 2014), and a culturally adapted version of the Barthel Index (BI) (which provides a rating of functional independence for the activities of daily living (ADLs) (Wade and Collin, 1988). The BI has previously been used successfully to identify older adults with disability living in the same district (Dewhurst et al., 2012). The following scoring system was used for the B-FIT; from a maximum score of 6, 5-6 was categorised as "frail", 2-4 was "pre-frail" and 0-1 "non-frail" (Gray et al., 2017). The B-FIT was administered to a total of 1,207 participants across five villages. According to the enumerators' focused census lists, between 84.5% and 89.0% of eligible participants were screened in each village (*Figure 3-2*).

3.9 Stratified frailty-weighted sampling

A process of randomisation (using a random number list) was carried out based on the B-FIT result, and individuals' randomly allocated study numbers, so that 236 participants were selected to receive a CGA, and also for a survey questionnaire and anthropometrics and functional measurements. The participants selected for CGA were weighted so that 94.7% of those who were "frail" according to the B-FIT were assessed by CGA. Of the "pre-frail", 42.1% were randomly selected, and a further 8.9% of the "non-frail" were also randomly selected for CGA (Lewis et al., 2018b). This epidemiological method of weighted-randomisation has often been used in low and middle income country settings (LMICs), (Prince, 2000) and was successfully employed in this district for the study of dementia prevalence (Longdon et al., 2013). The primary reason for conducting this weighted-randomisation procedure was due to funding and time limitations, however this method would allow for inferences to be made about the screened population, and Hai District generally. This process of selecting the stratified frailty-weighted sample is illustrated in *Figure 3-2*.

3.9.1 Methods for construction of the Frailty Phenotype and Frailty Index

Assessments were administered by the Tanzanian medical doctors and senior clinical officers or nurses named previously. They were supported by the UK-based medical students, who helped to carry-out functional and anthropometric measurements and facilitate the smooth-

running of the data collection process, while also ensuring that participants were comfortable. All research colleagues involved in the FP and FI data collection were blind to the CGA findings.

Assessments included functional and anthropometric measurements and questionnaires which encompassed the key domains in the concept of frailty. Despite the lack of overall agreement on these areas, several domains have been identified by expert consensus according to the Delphi method (Rodriguez-Manas et al., 2013), these were: physical performance, including gait speed and mobility, nutritional status, mental health, and cognition (Rodriguez-Manas et al., 2013). These were incorporated with additional domains of assessment recommended by the British Geriatrics Society (BGS), which were physical symptoms, including pain and underlying illnesses, and social support (British Geriatrics Society et al., 2014). All of these domains were included in order to produce an assessment from which a frailty index (FI) and frailty phenotype (FP) could be produced. In order to make valid comparisons between these two frailty models, no overlap was permitted between them in terms of the exact method of measurement, while both may have included similar domains. To illustrate this, the FP included an estimate of self-reported unintentional weight loss, while the FI included other nutritional parameters; calf circumference (CC) and mid-upper arm circumference (MUAC). The FP methods have been published in a paper describing the prevalence and characteristics of the FP in this setting (Lewis et al., 2018a). The measurements used for the FP and FI were as follows:

3.9.2 The Frailty Phenotype methods

Our construction of the Hai District FP, is compared with Fried's FP in Appendix C. The aim of which was to apply Fried's FP as faithfully as possible, so the five measured components of frailty were operationalised thus:

Weakness: Hand Grip Strength (HGS) was measured with participants sitting upright with the arm in flexion at 90 degrees. Three measurements were averaged from the participant's dominant hand using a JAMAR Hydraulic Hand Dynamometer (Model J000105, Lafayette Instruments, Lafayette, IN, USA). Frail criterion were met if the average HGS in the dominant hand was <21Kg in men, or <10Kg in women, based on the median HGS in African adults aged 61-70 years (Leong et al., 2016).

Slow walking speed: Participants were asked to walk in a straight line, a distance of 4.5 metres (15 feet). The distance was measured out on a flat floor surface using a rigid tape measure. The type of floor surface varied, for example participants who were assessed at their

homes were often assessed walking outside due to limited space indoors. However, if the surface was slippery due to recent rain, or uneven, a surface indoors was found. At the local assessment centres (church buildings, dispensaries and local schools) smooth concrete floors were available. Walking speed was not adjusted for height or sex. Participants walked in their usual footwear and were permitted to use any walking aids.

Exhaustion: A positive response was counted, to either of the two Centre for Epidemiological Studies Depression scale (CES-D) statements (Orme et al., 1986): "I felt that everything I did was an effort" or "I could not get going". These questions were translated verbatim into Swahili, and back-translated by a separate translator. Participants were asked to grade how often in the past week they had felt this way.

Weight loss: Given that no serial weight measurements were possible, self-reported weight loss was preferred as a measure of unintentional weight loss. Participants were asked "Have you lost weight during the last 3 months?" with the option of answering "Weight loss greater than 3kg", "weight loss between 1 and 3kg", "no weight loss" or "does not know". This variable was turned from a categorical to a binary variable for analysis as described in Appendix C.

Low physical activity: The International Physical Activity Questionnaire (IPAQ), (Craig et al., 2003) was used to record participants' estimations of their physical activity over the preceding 7 days. The IPAQ has been used widely, and in similar studies of older adults, for example the Ibadan study of ageing in Nigeria (Gureje et al., 2014). Those who reported not being able to carry out tasks of moderate physical activity on any day of the previous week scored positively on this parameter.

Other recorded parameters: A questionnaire was conducted asking participants or responding close relatives about socio-demographic characteristics as well as self-reported diagnoses. Multiple chronic diseases were included in the list of diagnoses about which participants were routinely questioned, including HIV-infection. A culturally specific Instrumental Activities of Daily Living (IADL) tool was used (Collingwood C, 2014), where difficulty with any one of eleven instrumental activities, (e.g. carrying out small works in the home, giving advice and presiding over ceremonies) was classified as IADL disability. Being unable to independently complete any one of the ADLs mentioned in the BI was categorised as ADL disability.

3.9.3 The Frailty Index methods

Guidance outlined by Searle et al. were followed in the development of the FI (Searle et al., 2008). As recommended, each variable met the following criteria for inclusion: the variables were health deficits associated with age, not saturating too early, and covering a variety of domains (Searle et al., 2008). The following five domains were included; Function, Cognition and mood, Comorbidity, Health attitudes and Physical performance. Thirty seven items were included in constructing this FI. In general, the more deficits included in a FI, the more accurate the estimates produced, however 30-40 variables have been recommended for producing stable estimates (Searle et al., 2008). Each item, whether ordinal or categorical data, was given a value between 0= "no deficit" and 1= "deficit", where a deficit was defined as any age-associated health impairment, sign or symptom, (Rockwood and Mitnitski, 2007) as outlined in Appendix C.

Function: The WHODAS 2.0 12-item questionnaire was used as a measure of self-assessed function (Ustun et al., 2010). Questions ranged from self-care ADLs, to more complex IADLs, such as joining in community activities. Where the response "not applicable" was documented, these were checked and if necessary corrected in the analysis, with reference to CGA data. For example, where a participant couldn't stand for long periods due to having an amputation, the correct response according to the WHODAS 2.0 manual would be "extreme/cannot do" rather than "not applicable" given that the participant was clearly limited by their disability or health state (WHO, 2010a). Questions were translated verbatim into Swahili and little cross-cultural adaptation was needed, however culturally appropriate examples were given. For example when asked "How much difficulty did you have in dealing with people you do not know?" relevant examples were offered such as interacting with people at the market when shopping or trading.

Cognition and mood: The shortened IDEA cognitive screening tool was used with the same scoring as the B-FIT tool (Gray et al., 2017): From a possible 12 points, scores of 8-12 indicated good cognitive function, scores between 5-7 indicated moderate cognitive function and scores 0-4, poor cognitive function. The 3-item brief IDEA-IADL questionnaire was included to provide a culturally-appropriate assessment of instrumental activities of daily living (Stone et al., 2018). The EURO-D screening questionnaire was used to assess for depression symptoms, with a cut-off score of 5 or more used for depression, as recommended following the tool's cross-cultural validation across nine LMICs (Guerra et al., 2015). The domain also included two questions, adopted from the World Health Organization (WHO)

Study on Global Ageing and Adult Health (SAGE), (Kowal et al., 2010) in order to include the symptoms of tiredness and worry.

Comorbidity: Participants were asked to report any known diagnoses from a list of age-associated conditions. For the purposes of the FI, diagnoses excluded were TB, HIV, sickle-cell disease, chronic renal impairment, mental health problems (other than depression), epilepsy, and cancer, either due to very low numbers reported, or due to the prevalence of these conditions not demonstrably increasing with age. Questions on self-reported sensory impairment and chronic pain were asked, also based on the WHO SAGE study questionnaire (WHO, 2010b). The number of self-reported falls over the preceding year was recorded, where a fall was defined as *"unintentionally coming to rest on the floor, ground or other lower level"* (Kojima et al., 2015).

Health attitudes: As per the WHO SAGE questionnaire, participants were asked to give a general self-assessed health rating (WHO, 2010b). Participants were also asked whether they considered themselves to be "ill" or "living with frailty", where positive responses scored as a deficit. These questions were devised specifically for this study, and back-translation was employed to ensure equivalence of meaning, where "being ill" was translated as *"mgonjwa"* (noun for a patient or sick person), and "frailty" was translated as living with weakness of the elderly or *"udhaifu wa wazee"*[4].

Physical performance: Body Mass Index (BMI) was calculated from weight measured using Microlife Diagnostic WS 80 digital weighing scales and height using the Marsden Leicester Height Measure. Blood pressure (BP) was measured three times in the participant's right arm with the participant sitting, using an A&D Medical UA-704 digital blood pressure monitor. High BP was counted as a deficit where the average systolic BP and/or diastolic BP were elevated (Systolic BP ≥140 mmHg and/or diastolic BP ≥90 mmHg). Both MUAC and CC were measured with a flexible, inelastic tape measure to the nearest 0.1 mm on the right hand side, apart from when there was an abnormality with the right side, in which case the left was used. Both were categorised according to the Mini-Nutritional Assessment criteria for malnutrition (≤ 21.0 cm for MUAC, ≤ 30.0 cm for CC) (Guigoz et al., 1996). The 'Malnutrition Universal Screening Tool' (MUST) was applied as per guidelines to determine

[4] The questions asked; *"Je, unadhani wewe saivi ni mgonjwa?"* translated as "Do you think you are a patient/sick person currently?" and *"Je, unadhani wewe sasa hivi unaishi na udhaifu wa wazee?"* translated as, "Do you think that you are living with weakness of the elderly currently?"

the risk of malnutrition (BAPEN, 2011). The domains and exact variables and cut-off points used in constructing the FI are included in Appendix D.

3.9.4 Comprehensive Geriatric Assessment

A semi-structured multidimensional assessment was conducted by one of four UK-trained physicians (EGL, KH, BS, and LM). All were MRCP (UK) postgraduate diploma holders, had experience of working in LMICs and had completed a diploma in tropical medicine (DTMH/DTMPH). They worked alongside an experienced Tanzanian colleague, most often a KCMC junior doctor or JK. As previously, hand-held tablet computers were used to record the details of the multidimensional assessment.

The assessed domains followed BGS guidelines (British Geriatrics Society et al., 2014), and included the following; physical symptoms and underlying conditions (including an assessment of pain), mental health symptoms (including an assessment of cognition and mood), functional ability for ADLs (including continence) and culturally appropriate IADLs (Collingwood C, 2014). Social support, living environment and level of social participation were assessed by questioning of the participant and/or relative and through direct observation where possible. CGAs were most often conducted at the participant's home to facilitate this. A likely diagnosis of depression, dementia or other cognitive or mood disorder was given by the assessing doctor, with reference to DSM-V diagnostic criteria (American Psychiatric Association, 2013). Factors which may lead to increased risk of social isolation were listed, for example factors such as finding it difficult to use local public transport or reporting not having many visitors. In order to assess an individual's level of social participation, participants were asked whether they were regularly able to attend any of five common social events; religious services, the market, village meetings, visiting friends or neighbours, and ceremonies such as weddings or funerals. Nutritional status was assessed clinically and through questioning about diet, meal frequency, anorexia, unexplained weight loss and swallowing or chewing difficulties. The participant was given an opportunity to express any concerns and a problem list was formulated. The assessing doctor then made a diagnosis of frailty or not, based on the information obtained through CGA. In order to grade the severity of frailty, the Clinical Frailty Scale (CFS) was used (Rockwood et al., 2005) (Appendix A). Both diagnoses were reached by consensus between the UK and Tanzanian research colleagues. Crucially, both assessors were blind to the results of the B-FIT and findings of the survey and anthropometrics.

The diagnoses of frailty by CGA, were validated at a UK-based multidisciplinary team (MDT) meeting, which included two consultant geriatricians with extensive experience of research in Tanzania (Dr Catherine Dotchin, Prof Richard Walker), a senior occupational therapist, Catherine Towler, and senior physiotherapist Lynn Bridges, both of NHFT and with a special interest in frailty. All members of the MDT were blinded to the outcome of the original CGA, and came to a consensus after discussion for a random stratified sample of 10% (24 participants). Agreement was 100%, which was taken as indicating robust frailty diagnoses by CGA. These methods have been published in detail in the Journal of the American Geriatrics Society (Lewis et al., 2018b).

3.9.5 Verbal Autopsy methods

Verbal autopsy (VA) is an interview carried out with family members and/or care-givers of the deceased using a structured questionnaire to elicit signs and symptoms and other useful information which can be used to assign a probable underlying cause of death (COD) (WHO, 2017b). VA interviews were conducted at follow-up for all those who had died from the original 236 stratified frailty-weighted cohort. Deaths were often identified by the village enumerator through word-of-mouth, given that funerals are often large public events. Additionally, each participant named in the cohort was followed-up systematically, with local enquiries, phone calls or home visits. The WHO guidelines for VA interview were followed closely (WHO, 2017b). An experienced research assistant (AK) trained by a WHO-approved trainer (Richard Amaro), first contacted the participant's family by phone, confirmed the death, and gained consent to visit in order to conduct a VA questionnaire. A Tanzanian Ministry of Health-approved Swahili translation of the WHO VA 2016 tool was used, however this translation was not created by the WHO (therefore the WHO should not be held responsible for its content or accuracy) (WHO, 2017b). The questionnaire was produced as an ODK 2.0 form enabling completion on a hand-held tablet computer. Questionnaire data were uploaded to a password-protected ODK aggregate database held at a secure server.

3.9.6 Follow-up assessment

Three UK medical doctors, the author EGL, Dr Elinor Burn, and Dr Fiona Richardson all with geriatrics experience led the follow-up assessments, and worked with experienced colleagues from either medical or nursing backgrounds (Ally Mhina, Antusa John Kissima, JK, and Ester Shali). As before, participants who were mobile were invited to a local assessment centre (often the village office or dispensary) and those who were unable to attend due to mobility problems were visited at home. The assessment was conducted, followed by a brief opportunity to seek medical advice and to have their blood pressure measured.

Follow-up assessments included a repeated B-FIT screening tool, the WHODAS 2.0 full version (WHO, 2010a), and questions investigating a number of potential outcomes of frailty. Participants were asked to recall the number of falls experienced, as well as episodes of acute illness (managed in the community) or overnight hospital admissions over the preceding 12 months. Clinical judgement was used rather than using a criterion definition of an "acute illness episode". Given that long-term institutional care of older people is very rare in Tanzania, this was not included as a potential adverse outcome.

The assessors reviewed the older person's baseline CGA documentation, and baseline CFS score (Rockwood et al., 2005). After discussing the issues raised in the previous CGA, an updated problem list (1-4) was formulated. Finally, a new consensus CFS score was agreed, with assessors unblinded to the previous score.

3.10 Data analysis

All data were downloaded from the secure ODK aggregate online database. Data were cleaned in Microsoft Excel 2016, and imported for analysis to either Stata/SE 15.0 or IBM SPSS Statistics 25 software packages.

3.10.1 Analysis of the screened population

The association between demographic characteristics and frailty by B-FIT for the entire screened population was analysed using binary logistic regression. All further analyses were conducted for the frailty-weighted cohort.

3.10.2 Analysis of frailty according to CGA

All simple descriptive statistics were performed with unadjusted odds ratios for frailty (according to CGA) by each variable. The alpha value was set at 0.05. When calculating the prevalence of frailty, the weighted stratification was taken into account. A bootstrapping method (Stata command 'svyset') was used to control for clustering by village and to adjust for the stratified weighting within our sample when calculating the 95% confidence intervals (Lewis et al., 2018b). Age standardization was employed using a method recommended by the WHO (Ahmad et al., 2001). Demographic characteristics were analysed through binary logistic regression, controlling for multiple demographic variables. In order to describe the association between the sample's socio-economic characteristics and frailty by CGA, binary logistic regression was conducted adjusting for age, sex and education status.

3.10.3 Frailty Phenotype data analysis

In primary analysis, cases with missing data necessary for calculating the FP were excluded from the analysis, and thus, were assumed missing completely at random and non-

informative. In secondary analysis, values for missing data were imputed under the assumption that they were not missing completely at random and were informative. Simple descriptive statistics were calculated, with the frequencies of each of the five components of frailty presented by sex. The prevalence of frailty by FP according to both methods were calculated by demographic characteristics, with 95% confidence intervals estimated using the same bootstrapping method described above. Binary logistic regression was conducted to produce crude and adjusted ORs for frailty by FP, for different health characteristics in the study sample. Lastly, the overlap between frailty by FP, ADL disability and comorbidity (of ≥2 conditions) were investigated (using the Stata 15 command 'pvenn').

3.10.4 Frailty Index data analysis

Data were imported into SPSS, where variables were coded as described (Appendix D), and a FI calculated as a proportion of the total number of deficits included (Searle et al., 2008). Missing variables were imputed using an expectation maximisation (EM) approach. In order to report frailty by FI as a binary outcome, ROC analysis was conducted using frailty by CGA as the diagnostic standard. The co-ordinates of the curve were then used to assess the most accurate cut-off point for detecting frailty by FI. Analysis was also conducted using a common cut-off point for frailty found in the literature (FI ≥0.25 was considered to be frail). (Song et al., 2010). The FI was also categorised and displayed by quartiles, where the 99th centile value was taken as the upper limit, as per the methods of Clegg et al. (Clegg et al., 2016). The prevalence of frailty was reported according to these different cut-off points, and by demographic categories of age, sex, education, and marital status. Grouped scatter plots were employed to investigate the relationships between age, sex, education status, CFS scores and frailty by FI.

In order to compare each frailty operationalisation, proportional Venn diagrams were produced in Stata 15 by using the command 'pvenn'. Frailty according to the FI (by each cut-off point), CGA, FP, and B-FIT were plotted in proportioned and positioned 3-circle Venn diagrams. The secondary analysis of the FP (which treated missing data as informative) was included, so as to include the maximum participant data in these comparisons.

3.10.5 Follow-up frailty analyses

The mortality rate (incidence) in the broader population of community-dwelling adults aged ≥60 years in Hai District was estimated by adjusting the number of days of follow-up and number of deaths by the B-FIT weightings.

The VA questionnaire responses were downloaded from ODK 2.0 aggregate into an excel database, and blinded to the results of the baseline CGA and CFS scores, a VA COD code and title, and corresponding ICD-10 code and title were assigned by an expert panel (WHO, 2007). The author (EGL), Dr Catherine Dotchin, and Prof Richard Walker participated in this work. The use of an expert consensus panel for these purposes has been validated previously (Setel et al., 2006, Chandramohan et al., 2007). Given the small number of deaths overall, descriptive data were presented by frailty status. Where possible, an "international form of the medical certificate for cause of death" was produced following WHO guidelines (WHO, 2007). Cox Regression Survival analysis was used to calculate the risk of death for each measure of frailty employed. Crude and adjusted Hazard Ratios were calculated (controlling for the effects of age, sex, and education status) on the risk of death.

The WHODAS 2.0 full version results were coded according to the "item-response-theory" (IRT) scoring method described in the WHODAS 2.0 manual, which allows for different weighting according to items' difficulty levels (WHO, 2010a). The WHODAS 2.0 full version included 32 items, because remunerated work items were excluded due to high numbers of retired participants (Ustun et al., 2010). These domain scores were plotted against the CFS scores, and Mann-Whitney Testing used to compare the scores between CGA frail and non-frail groups across each of the disability domains. Other outcome data (e.g. number of falls) were also presented by simple descriptive statistics. Wilcoxon Signed Ranks testing was used to compare the medians where the same assessments were carried out at both baseline and follow-up assessments, these were for the B-FIT and its components, the WHODAS 2.0 short form, the CFS, and the number of falls in the preceding 12 months. Binary logistic regression analysis was also conducted in order to investigate the risk of falls, hospital admission, and acute illness as binary outcomes of frailty, controlling for age, sex, and education status.

3.11 Quantitative methods limitations

One important weakness of the quantitative methods is that the denominator was produced from a "focused" census of households known to have older occupants. Due to resource constraints no complete census of the studied villages was conducted. There is a possibility therefore that some older residents were missed or counted twice. Errors and inconsistencies in the denominator list of adults aged ≥60 years were minimised by conducting 'checking meetings' at each village, where all ten-cell leaders were invited, and individuals' names were read aloud and verified collectively. This process (illustrated in *Figure 3-2*) was successful in this setting, yet was highly reliant on local community knowledge.

The employment of a frailty-weighted cohort which underwent the more detailed assessment was a pragmatic design which has previously been used successfully to provide prevalence estimates of dementia in the same district (Longdon et al., 2013). However, these methods inherently introduce a potential sampling bias, although this was minimised through careful randomisation and blinding.

In order to produce a FI, many variables were needed across a broad range of domains. This resulted in a rather lengthy assessment, lasting a mean of 1 hour and 38 minutes. Fatigue is likely to have been a significant factor which may have impacted on survey responses and functional performance, particularly for frail individuals. This was difficult to avoid, given the lack of any pre-existing data records. The team were mindful at all times to prioritise participants wellbeing, and minimise the impact of fatigue on data collection, by providing refreshments, breaks and alternative appointments where required.

There were significant weaknesses to conducting the CGA based on a single assessment, and in the absence of multi-disciplinary team (MDT) input. This was due to a lack of expert allied health professionals in Tanzania, and was overcome by conducting a blinded MDT meeting with trained and experienced members of the NHFT MDT (Catherine Towler and Lynn Bridges).

Assignment of likely COD from VA questionnaire data was through an expert physician panel, shown to be a valid method (Chandramohan et al., 2007, Setel et al., 2006). Yet, increasingly VA questionnaire data are analysed using algorithm-based software such as the InterVA, in order to reduce the impact of physician bias on the assignment process (Bauni et al., 2011). The main benefits to using probabilistic software for analysis is its speed and accuracy where population-level estimates are required. For the purposes of this thesis, due to low numbers of VA questionnaires, a manual rather than automated approach was felt to be more appropriate. While undoubtedly, this will have introduced some bias, physician-assigned COD has good diagnostic accuracy when compared with InterVA (Bauni et al., 2011).

3.12 Quantitative methods strengths

The significant strength of these quantitative methods was the use of multiple frailty measurements. These measurements (the B-FIT, FI, FP and CGA) have permitted a comparison of the strengths and weaknesses of each, in terms of their application, and performance, adding substantially to the understanding of frailty in this context.

Additionally, while other studies of frailty in sub-Saharan Africa are few (Gray WK, 2016), those which have attempted to investigate frailty have lacked an expert “Gold Standard” assessment, such as the CGA (Lewis et al., 2018b). Uniquely, these expert diagnoses also incorporated the expertise and perspective of Tanzanian colleagues, which ensured appropriate contextual adaptation.

3.13 Qualitative methods

The following sections describe the qualitative methods which aimed to answer the specific sub-questions outlined in *Figure 3-1*. These were; how is frailty conceptualised, what is the lived-experience of frailty and how are frail older people cared for in the study's context? In summary, a constructivist approach was taken to the creation of cross-cultural and cross-language knowledge production. Focus group discussions (FGDs) and semi-structured interviews (SSIs) were conducted in Swahili with a Tanzanian colleague facilitating the interview. These were audio-recorded transcribed and translated, taking care over the meanings lost, and changed, during the translation process. Thirty seven transcripts in total were analysed (using Nvivo Pro 11 software for processing) and coded thematically. In general, there was considerable flexibility and pragmatism required in implementing the planned methods, which evolved considerably over time. FGDs and SSIs were held over a prolonged period, between the 16th of February, and 5th of August 2017 alongside the quantitative surveys and CGA assessments. This extensive period of time spent in the research field, and the experience of conducting CGA assessments in participants' homes undoubtedly influenced the qualitative investigation positively, leading to greater cultural competence and improved alignment with participants' priorities. These methods will now be discussed in detail.

3.14 Qualitative Research Epistemology

A constructivist approach guided methodology and methods for the qualitative investigation of this study. The beliefs underpinning constructivism can be asserted thus; rather than accepting a belief in a single identifiable reality which can be measured or studied, constructivism assumes that reality is constructed through our lived-experiences and through our interactions with others in society (Lincoln et al., 2018). This epistemology fits extremely well with the African philosophy of *"Ubuntu"*, a philosophy shared by the southern African nations (Kamwangamalu, 1999). As previously described, according to the ontology of *"Ubuntu"* the concept of what it is to be human is socially constructed (Ramose, 2003). Thus, it follows that the epistemology of *"Ubuntu"* or knowledge of humanity is also produced collectively. It can be concluded that research which takes a mutual, co-constructed approach to knowledge is culturally-appropriate. For example, the philosophy of *"Ubuntu"* was argued to be an appropriate underpinning for qualitative research carried out by Canadian researchers working in Mozambique (Schreiber and Tomm-Bonde, 2015). While *"Ubuntu"* philosophy was not the theoretical underpinning of this PhD study, it can be argued that the parallel found between this African philosophy and social constructivism made it a more culturally appropriate approach.

3.14.1 Selection of interviewees

Participants were selected from the rural community and semi-urban residential home setting. Participants were chosen by purposive sampling, a non-probabilistic means of selecting participants based on areas of research interest and pre-defined criteria (Guest et al., 2016). Initially, participant selection was largely based on convenience, for example approaching an older person and their family to be interviewed, based on the fact that they lived within walking distance from the village dispensary, where the quantitative data collection was taking place. However, as fieldwork progressed and areas of particular interest were identified, interviewees were selected based on their known characteristics or care arrangements, for example older people living with HIV infection or dementia. Purposive sampling was complete when data saturation was reached, whereby no new themes were being generated (Hennink, 2017). The following section details how participants were selected from each setting with reflections on how this has influenced the data produced. The sampling methods made use of existing organisational structures, and are described in the following sub-sections.

3.14.2 Hai District, Northern Tanzania

While the quantitative data collection was carried out across five randomly selected villages, a further three villages had been selected for inclusion in the study initially. While time and resource restraints limited the capacity to extend the quantitative survey to all eight villages, it was possible to include all eight in the qualitative study. Introductory meetings had been held at the start of the project with the enumerators from these villages, therefore, guided by JK's advice, it was felt to be unfair and exclusionary toward those enumerators and villages not to involve them in the study in some capacity.

3.14.3 Village ten-cell leaders

Ten-cell leaders from each village were interviewed in FGDs of between five and eight participants. In order to understand the implications of sampling these community representatives, it is useful to know some historical background. In 1962 "Village Development Committees" were officially launched as a means of grass-roots advancement of economic and social improvement in the rural areas (Finucane, 1974). These formed the organisational framework which the government used to communicate messages to rural communities, and through which they communicated upwards to district level organisations after independence. Ten-cell leaders were established in 1963, their roles have previously been described (section 3.6). Ten-cell leaders of a village were members of their Village Development Committees and participated in decision-making for the improvement of

services such as schools and clinics in their villages (Finucane, 1974). It has been suggested that ten-cell leaders were chosen, either because they were elders, and thus traditional leaders within the village, or because of their commitment to the government's development agenda, and were described as being "forward looking" (Ingle, 1972).

Towards the end of the ten-cell leader 'checking meeting' (section 3.8), around five ten-cell leaders were asked to stay behind for an hour to participate in a FGD. The ten-cell leaders decided on the five participants between themselves, from the group of usually around forty people. A senior ten-cell leader usually led the negotiation, perhaps asking for a representative from each hamlet, or asking for volunteers with an interest in the topic. By these methods, a self-selecting sample of community leaders volunteered to participate. The limitations to this sampling method (by convenience and self-selection) are that participants may have had particularly extreme or negative views, or been more motivated compared with their peers. Another factor to consider is that older or more experienced ten-cell leaders may have been selected by the group, due to a cultural deference to seniority.

3.14.4 The village health committees

Each village had an appointed health committee with usually one member appointed from each hamlet within the village. Depending on the size of the village therefore, the committee consisted of between 5 and 9 members. These individuals sometimes had a background of working in the healthcare sector, or had been elected by the village committee because of a personal interest in health issues. Some VHC members had attended public health training seminars delivered at the district level, covering topics such as the promotion of sanitation and hygiene, maternal and child health, and HIV prevention. Crucially, although this was a position of respect, these were unpaid and voluntary roles. We invited all VHC members to the focus group discussions through the village enumerator. VHCs were also "pro-development" institutions like the ten-cell leader organisational structure, with the aim of improving health services through the same village-led development promoted by the government of Nyerere (Green, 1995).

3.14.5 Older adults and their relatives or care-givers

Sampling of older adults and their care-givers was purposive and followed areas of inquiry. The enumerator, who had an excellent knowledge of the older adults in the village, helped identify potential participants for qualitative interview based on characteristics of interest, for example their living environment or marital status. Sometimes participants were identified based on information gained at the time of their B-FIT screening. For example an interview

was sought with a participant and their family because of an interest in exploring their experience of frailty due to cognitive impairment; which was identified from the participant's low IDEA cognitive screening score. The enumerator approached the participant and their family in advance in order to gain verbal consent and arrange an appointment.

3.14.6 Amani Residential Home[5]

This home is a government-run residential home in a suburb on the outskirts of Moshi, known as 'Amani'. It is the only government-run institution for the long-term care of older people in Kilimanjaro region. The structure was originally built by the British as a tuberculosis sanitorium and became a residential home for older adults "without means" in around 1986. Since then, several renovations have been carried out by donors such as the Rotary and British Airways. Amani's professional staff included a social officer and a nurse while several others provided the resident's daily personal care, food and security. The government funds were limited however, and covered enough for basic food rations, but did not extend to provision of transport, medications or rehabilitation equipment. An international Non-Governmental Organisation (NGO), supported the residential home, most recently fundraising for a perimeter wall, and providing short-term volunteer placements for foreign tourists. Volunteers with the NGO visited the Amani residents twice weekly carrying out activities with the residents such as chair-based exercises.

Fifteen older adults lived there permanently at the time of conducting qualitative FGDs and SSIs. Due to the rarity of institutionalised care in Tanzania, many of the residents were admitted from far-flung areas within Tanzania. The home consisted of eight, small buildings which are in a circular formation, facing inwards towards a central clearing where meetings and activities take place. Each room contained two bunk beds and up to two older adults shared one room. Each building had a porch area where residents could sit and receive visitors, eat their meals and greet passers-by. In addition to the accommodation buildings, there was a small office, dispensary, kitchen and store room, and two pit latrine toilets. The closest public hospital in the town centre is around 30 minutes away by motorised transport. Including the residents of Amani was of particular interest in order to investigate their unusual experiences of frailty in institutional care in this setting.

All residents and care-givers at Amani were invited to participate, and in total eleven residents and four care-givers participated. Four residents did not participate as their cognitive impairment meant that they did not have the capacity to consent to participate or contribute to

[5] The residential home name and some unique details have been changed for anonymisation purposes.

discussions. Unfortunately, this means that FGDs have not fully included the perspectives of some of the frailest residents of the home. Interestingly, as will be elaborated upon in the following section, inclusion was a culturally important value which the research team was required to respect. This led to some of these "non-participating" residents sitting with their fellow residents in the clearing where FGDs were held, in order to listen and enjoy the companionship, while not contributing actively.

3.15 Conducting culturally sensitive focus group discussions

FGDs have been advocated as a means of "accessing hard-to-reach groups" and diluting the power imbalance between the researcher and research participants (Barbour, 2005). For example FGDs have been used to investigate the views of hard-to reach communities of pastoralists and slum-dwellers in Kenya (Watson-Jones et al., 2015). It is recommended that FGDs should be with "homogenous" groups, for example in medical education research, interviewing groups of medical students together produced a relatively safe environment for students to share their views (Barbour, 2005). This was also the principle taken in this study, where groups of health committee members or ten-cell leaders from the same village were interviewed together in "homogenous" groups. Rarely, one or two participants of a higher "status" (due to their work, education or wealth) were included in FGDs. FGDs were mixed gender given that it would have been impractical to insist on single gender groups, yet this may have limited the ability of some female ten-cell leaders and health committee members to contribute freely.

Cross-cultural FGDs can be useful for the generation of a "group perspective" on the issue studied (Hennink, 2017, Barbour, 2005). These FGD methods enabled an establishment and validation of social norms, particularly in discussions around attitudes toward older people and care practices. Hennink reflects on the need for cultural sensitivity, which may require flexibility and adjustment of methods (Hennink, 2017). A common area where adjustments were required for the sake of respect for cultural differences, was working based on the principle of inclusion. For example, latecomers who would raise the number of participants above the desired number, could not be turned away. Rather, advised by Tanzanian colleagues, the discussion was paused in order to welcome them. Occasionally, this was to the detriment of the research, for example in situations where individuals did not fit with the group's "homogeny". In one particular instance, a clinical officer was included in a FGD with the VHC. This was partly in order to show appropriate respect and gratitude for allowing the FGD to take place at the dispensary. Participants at this FGD asserted that government policies on healthcare for older people were being successfully implemented at their

dispensary, in contrast with the findings at all other villages to date. However, after finishing the FGD, it was privately revealed that participants had been giving socially desirable responses and had been unable to discuss the situation at the village dispensary critically in the presence of the clinical officer, who was their superior. The next day, the research team conducted a second FGD in the same village, but at a participant's compound and found responses which were congruent with those of other villages.

Having chosen to follow the village organisational structure present from the time of Tanzanian independence, participating in FGDs in this way may have demonstrated to participants that the research was interested in their democratic voice and participation, and respected their established local governance systems. It may also have been an unwitting method of promoting a form of solidarity and self-emancipation and in keeping with the communitarian messages of *"Ujamaa"* rural development (Komba, 1995). Sampling participants in this way may also have led to an increased politicisation of discussions, with expectations of tangible outcomes in the form of a development projects or policy change. Another potential impact was that in talking to us in their capacity as ten-cell leaders (who would normally have been brought together to talk with "district officials" or "government representatives") the research team (the author, one Tanzanian colleague and the village enumerator) may have been received in a similar manner. Given that the government policy of free healthcare for older people was being improperly implemented, coming together to discuss in this way may have led to heightened expressions of disillusionment or disappointment on this topic. Either way, this sampling method was not unbiased, and has led to data which requires careful interpretation with this historical, cultural and political background in mind. Sub-themes of particular relevance include; *"Kwa sababu wazee wamefanyakazi sana Tanzania"*: Because the elders have worked so much for Tanzania and *"Maendeleo"*: Development, which both contain the language and political discourses of nationalism and economic development.

3.15.1 Consensus in focus group discussions

Consensus, agreement, and harmony among FGDs seemed to occur naturally. Initially, it was common for the recording device to be passed from person to person, with each thanking the former, and lending their support and agreement to the previous speaker. The following excerpt from a FGD with ten-cell leaders illustrates this rather formal turn-taking and reinforcement of agreement, with a rare example of discord after JR (facilitating) enthusiastically encouraged participants to express a difference of opinion.

JR: Any others who think that we should build for them (older people) houses to go and rest?

Mzee Swai: Myself, (Mzee Swai) I agree with the two contributors who spoke before. For sure there are people of different tribes and you may find that another person lives their own life on his own until they reach the elderly age whereby they cannot take care of themselves. So I think such kind of elders should have special places built for them. I support my fellows. (66 years, cattle herding, hamlet chairman)

JR: Sir, do you have a different opinion?

Mzee Kimaro: Thank you, myself (Mzee Kimaro) I have a different opinion and I don't think it is good to build a special house for the elders and leave them there like animals! (54 years, ten-cell leader, 14th July 2017)

The benefits to this include the quick establishment of group norms and collective opinions (Barbour, 2005). Also, audio recordings were easily transcribed as participants rarely spoke over each other, which has been a problem for researchers working with other ethnic groups (Colucci, 2008). However, it led to myself, and my research colleagues working to establish new social norms or "rules of engagement" for the FGDs (Colucci, 2008), emphasising that differences of opinion within the group would be welcomed. To a large extent, this was successful, yet some of the earlier FGDs were very repetitious as each participant took their turn to repeat and reinforce the previous point made. It's likely that these natural "rules of engagement" in this particular context reveal the importance of Tanzanian cultural values of inclusion, consensus and harmony. These values were also highlighted as an important underpinning for a cross-cultural grounded theory study in Mozambique (Schreiber and Tomm-Bonde, 2015).

3.16 Conducting culturally sensitive interviews

In this study, John Kissima (JK), Jane Rogathi (JR) and Prosper Regnald (PR) were colleagues who acted as "cultural brokers" during FGDs and SSIs (Hennink, 2008). JK and JR were "cultural brokers" while visiting and interviewing older people in their homes in Hai District, while PR assisted at Amani. The term "cultural broker" was described by Hennink as individuals familiar with the cultural context, who are able to advise and help the research team negotiate the fieldwork (Hennink, 2017). The term helpfully reflects *one aspect* of the roles played by these key colleagues. Yet, rather than acting as only as cultural guides, in this study it may be more appropriate to describe these colleagues as bicultural (Schrauf, 2016), or of having cross-cultural competence (Liamputtong, 2008), given that they had all had

experience of either visiting Europe or of working closely with white "western" foreigners in Tanzania. They comfortably switched between explaining local Tanzanian traditions to me, and explaining British norms to Tanzanian participants.

3.17 Qualitative research colleagues' reflexivity

Reflexivity can be described this way; *"We are shaped by our lived-experiences, and these will always come out in the knowledge we generate as researchers and in the data generated by our subjects"* (Lincoln et al., 2018). The same must be acknowledged for all the key persons involved in the data construction including the reflexive roles of interpreters and translators in cross-language research (Temple, 2002). Taking a constructivist approach toward qualitative data production involves acknowledging the roles these Tanzanian colleagues played in the co-production of data. Reflexive questionnaires were given to PR, JR and JK after completion of fieldwork, in order that their reflexivity and position toward the research topic may enrich data analysis; (questionnaires, full responses and reflection on how colleagues' reflexive stances may have influenced the data co-production are provided in Appendix E).

3.18 Development of the topic guide

Topic guides were devised before starting data collection, based on areas of interest in relation to frailty. Topic guides were devised to permit adaptation for discussions with village leaders as compared with older adults and their relatives or care-givers. Topic guides were translated into Swahili (by Lucy Mariki, a qualified linguist) as recommended by Hennink, in order to ensure use of familiar vernacular (Hennink, 2007). The translated topic guide was pilot tested and discussed in depth with JK, JR and PR prior to FGDs and interviews taking place, a necessary step for producing trustworthy results in cross-language research (Squires, 2008).

The original topic guide was iteratively developed into a second guide (Appendix F). Questions which were deemed too sensitive, and peripheral to the main aims of the research, particularly on the topics of death, dying, bereavement, and witchcraft were removed. Questions asking about the challenges experienced by older people were added. These questions had produced the most enthusiastic, impassioned responses and allowed participants to speak about their difficulties, and set the topic of discussion, which often related to barriers accessing healthcare. As a result of these changes, the topic guide became shorter, but gave participants and research colleagues more freedom to pursue areas of interest and importance to them.

This is an important area where the qualitative component of this mixed-methods study helped to redress some of the inherent power imbalance in the research relationship. While the UK-based researchers had set the overall research agenda, this was an opportunity for study participants to raise their own agenda.

3.18.1 Use of "real-life" vignettes

"Real-life" vignettes (Appendix G) were developed in order to facilitate focused discussion in the time-pressured environment of the FGD and SSI (Sampson and Johannessen, 2019). They were "real-life" in that the descriptions were anonymised descriptions of individuals which the author had encountered during experience working clinically in the UK and volunteering in Tanzania, with some identifying characteristics altered. The benefits of using "real-life" vignettes are that it can help to develop rapport quickly, focus engagement, and facilitate the development of an "insider" status for the researcher. (Sampson and Johannessen, 2019). That is, vignettes taken from prior observed situations reveal the author's background understanding of how things are in "real life". These methods were found to be useful when discussing potentially emotive topics in previous work by the author investigating the attitudes of healthcare professionals towards palliative care in the Tanzanian hospital setting (Lewis et al., 2017). "Real-life" vignettes have also been used fruitfully in Hai District to discuss concepts which may be difficult to define and investigate across cultural and language differences, including dementia (Hindley et al., 2017), and depression (Howorth et al., 2019). For a concept such as frailty which is inherently contextual, vignettes facilitated discussion of a contextualised and relevant example, ensuring conceptual equivalence between participants and researchers.

When vignettes were used they were read aloud by the FGD facilitator in order not to exclude any participant who was unable to read. An oral history or *"hadithi"* (meaning story/tale) is a traditional means of knowledge transfer between generations in sub-Saharan Africa: In a study of riddles in the Haya ethnic tribe of north-western Tanzania, the author argues that riddles, story-telling, and other oral African traditions are still important in the moral and social development of children, and a means of transmitting knowledge between generations (Ishengoma, 2005). It is possible that in the act of reading aloud the *"hadithi"* in this way, JK (as a respected older male) invoked this understanding in FGD participants. This may have led participants to interpret these vignettes as holding an intended message, or moral lesson. It is possible that this is why the responses were often very moralistic, (often participants were appalled at the story of 'Bibi Jones', who was often perceived as having been neglected) (Appendix G).

3.19 Conducting cross-language research

Cross-language research has been criticised for often rendering the interpreter and translator roles invisible (Squires, 2008). In the following sections, the cross-language methods will be described and reflected upon. One of the main aims of the qualitative enquiry was to investigate the conceptualisation of frailty. Language is an integral part of conceptualisation, incorporating beliefs and values, therefore great attention was paid to the choice of words and phrases used in the original spoken data, in its real-time interpretation, and its transcription and translation (Temple and Edwards, 2016). Swahili is the most commonly spoken language in Hai District, although less educated people may be less verbally fluent in Swahili and prefer to communicate in their local language. This was most often the case with older females who had never attended school. Where Kichagga[6] or Kimaasai were these older people's preferred spoken language, younger family members were used to interpret. This was an imperfect, pragmatic solution and a limitation of these qualitative methods, particularly given the fact that these additional barriers to communication were not neutral but a product of these older people's intersecting disadvantages of female gender and low socio-economic status.

Cross-language research, invites several layers of interpretation to data, which have been described as "filters" (MacKenzie, 2015). Part of my strategy for conducting cross-language research was to learn as much Swahili as possible, through lessons, self-study, and daily practice. By the last six months of data collection, my comprehension of spoken Swahili allowed me to follow conversations, and to conduct short conversations. During interviews and FGDs when it was revealed that I could understand Swahili I was sometimes referred to jokingly as an *"Mbongo"* (a slang term for a Tanzanian or Swahili speaker), rather than the default *"Muzungu"* (white foreigner). This honorary "insider" status may have helped to build rapport and trust in the research, and may have reduced social desirability in responses (Irvine et al., 2008). During data collection, following the substance of FGDs and SSIs helped to reduce interruptions to the flow of conversation, and allowed me to take a more active role in moderating the FGD. An appreciation of Swahili also benefited the data analysis, which sought to draw meaning from the language used at all stages in the data production.

3.19.1 Interpretation during interviews and focus groups

JK and JR and PR translated participants' answers periodically during FGDs, to improve my understanding and ability to ask appropriate follow-up and probing questions. This has added

[6] 'Kichagga' is the language of the 'Mchagga' ethnic and cultural group, dominant in Hai District

in an additional “filtering” of data given the individual positionality and reflexivity of each research colleague (MacKenzie, 2015). MacKenzie used two interpreters during each FGD held in Uganda, and as a result was able to demonstrate that there was ~10% difference in their interpretation of the spoken data at the time of the FGD, with one interpreter preferring a more literal translation, and the other employing a more explanatory form of interpretation (MacKenzie, 2015). Each of my research colleagues employed different styles of interviewing, reflecting their own positionality and background. These differences in terms of their influence on the data will be discussed below.

While JK and PR lacked any formal training in qualitative research skills, JR had considerable qualitative research expertise. However, none of my colleagues were in a “conduit role”, translating in the third person and ensuring “conceptual equivalence” in their interpretations (Chiumento et al., 2017). Usually, lay interpreters working in LMIC settings are trained in these skills (Chiumento et al., 2017). Rather, JK, JR and PR were taken to be active participants in the “three-way co-construction” of data (Brämberg and Dahlberg, 2013). Rather than simply interpreting the participants’ words verbatim, it was understood that my colleagues had a freedom to translate meaning, and express themselves in whichever way would best convey the underlying meaning (Brämberg and Dahlberg, 2013). Hence they were free to paraphrase questions, give examples of their own, probe and clarify, and in the case of JR, to set the topic of discussion. Her personal research interest in gender-based violence and inequality led to an unplanned avenue of investigation, and a question investigating participants’ views on gender differences in experiences of ageing was added to the topic guide.

Each colleague facilitated and interpreted in their own style, which has undoubtedly influenced the co-production of data in unique ways. For example, PR, the youngest and least experienced of the three is quiet-mannered, yet due to his teacher training was able to command the attention of a group. FGDs facilitated by PR were with the residents of Amani and were held almost exclusively in Swahili, in order to keep the duration of FGDs short, taking into account that the group tired easily. PR kept closely to the topic guide, although he repeated the questions several times, and used paraphrasing for clarity. PR had a close rapport with the residents who he had known for many years, and used respectful silence and expressions of gratitude between responses in order to encourage participation. The following excerpt illustrates an example of paraphrasing.

PR: My next question is what is the role of the older person in the family or community?

…

PR: Stop, let me ask this question in this way, that you elder, you are now old, isn't it, what support can you give to your family or society? What help can you give?

Interpreter-researcher gender-matching has been discussed as a factor which might influence the ability of researchers to work more comfortably with interpreters, particularly in settings where patriarchal norms predominate (Chiumento et al., 2017). My experience of working with JK and PR highlight the importance of other intersecting factors such as age, and social status, in addition to gender in the research relationship. As a well-respected, older professional male, JK took on the roles of advisor and conflict-resolver during many interviews. Where participants raised grievances, rather than interpreting, JK tended to provide a careful and considered solution. This behaviour would have been expected of him culturally, and although this prevented my full involvement in the discussion at these moments, forced into a passive observer role in my position as a foreign young female "outsider" (Irvine et al., 2008), it was necessary in order to demonstrate respect and facilitate our working relationship.

JR's interviewing style was different again. As an experienced qualitative researcher, she expertly handled FGDs, encouraging quieter participants to contribute, and probing effectively for alternative points of view. Her manner was relaxed, confident, and informal, and she was able to quickly gain participants trust. In the following example, contrasting with JK's more formal interview style, JR gently encourages 'Mama Pili' to talk about the difficulties she faces as a widow by revealing personal information about herself.

JR: Yes, it's like this, you work, you farm, life goes on, I too don't have a husband, though I have children. (Pause)

JR: You have said you have children but no husband, why is it like that maybe?

Mama Pili: My husband died in 2001, I have remained with 7 children, some have taken wives or been married, now I have two children to get educated[7].

[7] Naowasomesha = v (pl) 1. to teach 2. to educate. The meaning of this is that 'Mama Pili' has to pay for two of her children's school fees.

These examples help to illustrate how each colleague was involved in the co-production of data, in their own manner. This relaxed approach to the control of the interview is consistent with a constructivist approach. Discussions of the topic guide with my colleagues in advance of FGDs allowed me confidence in their understanding of the research questions. Moreover, transcription of the whole conversation, has permitted these interactions to supplement and inform data interpretation. That is, the interactions of my colleagues with participants, which might otherwise have been rendered "invisible", were documented, translated and used to contribute to data interpretation.

3.19.2 Translation of transcripts

As a bilingual Welsh speaker, I understood implicitly that *"concepts do not move unproblematically across cultures"* (Temple, 2002, p847). I knew for example, that there are many Welsh words, with no equivalent meaning in English, and approached the cross-language and cross-cultural study of 'frailty', which has no direct translation in Swahili, with an appreciation that the process of translation would be integral to the production of meaningful findings.

Audio recordings were transcribed in Swahili and translated by a professional linguist, Lucy Mariki (LM) or a junior doctor Leila Kavira (LK). Data were taken to be the spoken Swahili, and the whole conversational interaction, including everything spoken by the research colleague facilitating the SSI or FGD was transcribed. Both translators transcribed the audio recordings verbatim then produced a draft translation. The translation process was then a collaborative, iterative process between myself, LM, LK and JR and had overlap with data analysis as will be described in more detail below.

LM was a professional translator, Swahili and English teacher living and working in Moshi as a freelance professional under the company name "Swahili Linguistics Centre". LM, a single woman in her mid-twenties had completed a BA in Swahili linguistics at university level. She also had a good understanding of differences between "western" and Tanzanian cultures, from her work teaching foreign visitors to the town. I had previously worked closely with LM using the same transcription and translation process (Lewis et al., 2017), which although time-consuming proved invaluable for the interpretation of culturally sensitive data on death and dying.

LK, a 28 year old Tanzanian doctor completed medical school in Ukraine, graduating in 2015 then returned to complete her internship year at KCMC in Moshi. She was volunteering at the newly built cancer centre at the time of the study in 2017, and because of a shortage of jobs

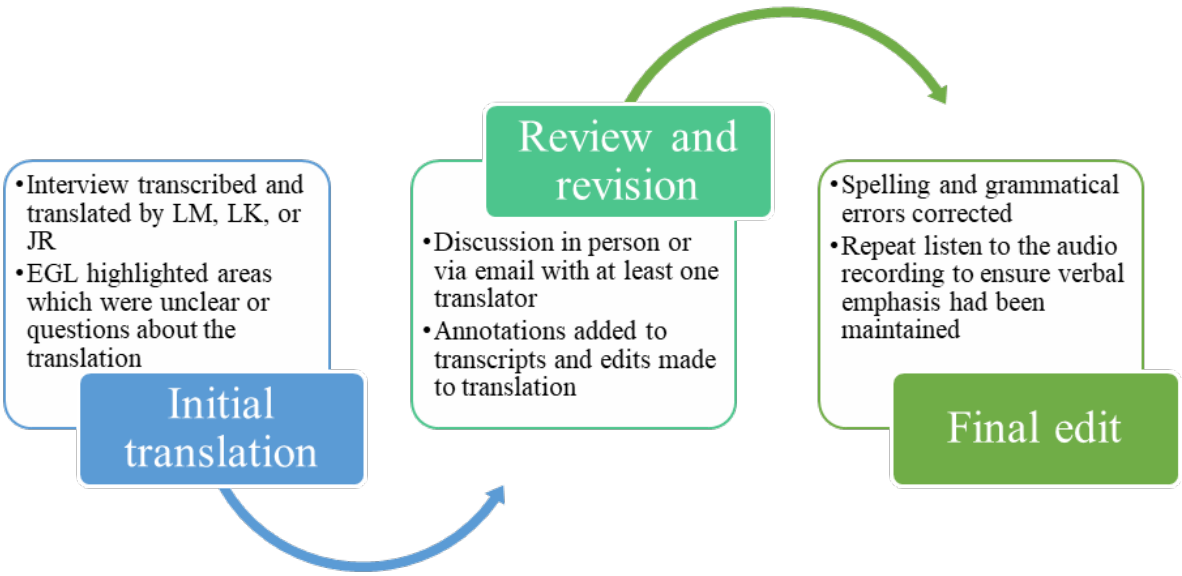
for junior doctors, was enthusiastic to work on translations of transcripts. The benefits of working with LK was that she had an understanding of frailty from a middle-income country biomedical perspective, as well as having worked in the Tanzanian medical context, which gave her a unique kind of medical biculturalism. Both were ethnically 'Mchagga' so were able to assist with the interpretation of local expressions and customs.

The translation process (*Figure 3-3*) can be described thus: I initially reviewed the draft translated transcript highlighting areas where the translation was unclear, or where there seemed to be a discrepancy between the English and Swahili, or to raise queries about the choice of word or phrase selected. Following my review of the translated transcript, I would meet with LM or LK and together we would go through the transcript addressing the areas under question. After returning to the UK communications were continued via email. Edits were made once a consensus was agreed, and throughout this process, transcripts were annotated with details of any changes made to translations or of relevant cultural details (Appendix H). This process also provided early data familiarisation and added a depth of understanding which otherwise would have been lost, even with an accurate "verbatim" translation. Temple has rightly asserted that language fluency is not equivalent to also being a cultural representative, and that this assumption may be problematic (Temple, 2002). However, LM and LK did share a lot in common culturally with participants (who largely belonged to the same ethnic and cultural *"Mchagga"* group), and through our discussions, we were able to examine cultural differences and debate intended meanings in order to co-produce a translation which was agreed to be authentically representative.

As part of this process of transcript translation, grammatical or spelling errors, which were produced in the translation process were corrected. The justification for this being that in the original spoken Swahili, participants were fluent and comprehensible, therefore without correcting errors incurred in the translation process, participants would be misrepresented, potentially causing participants to sound as though they were not speaking fluently in their native language. While verbatim transcription and translation may be understood to enhance credibility in qualitative research (Krefting, 1991), this is primarily the case where positivist attention is paid to data "accuracy" and translators are viewed as passive transmitters of "correct" translations (Temple, 2002, Temple and Edwards, 2016). It is also widely accepted that transcripts are constructed documents, "composed of both strict transcription and description" (Hammersley, 2010); details of actions, sounds, and laughter were also included in these transcripts for example. In situations where the translation had led to grammar and spelling errors, it was taken to be an issue of respectful and ethical representation of our

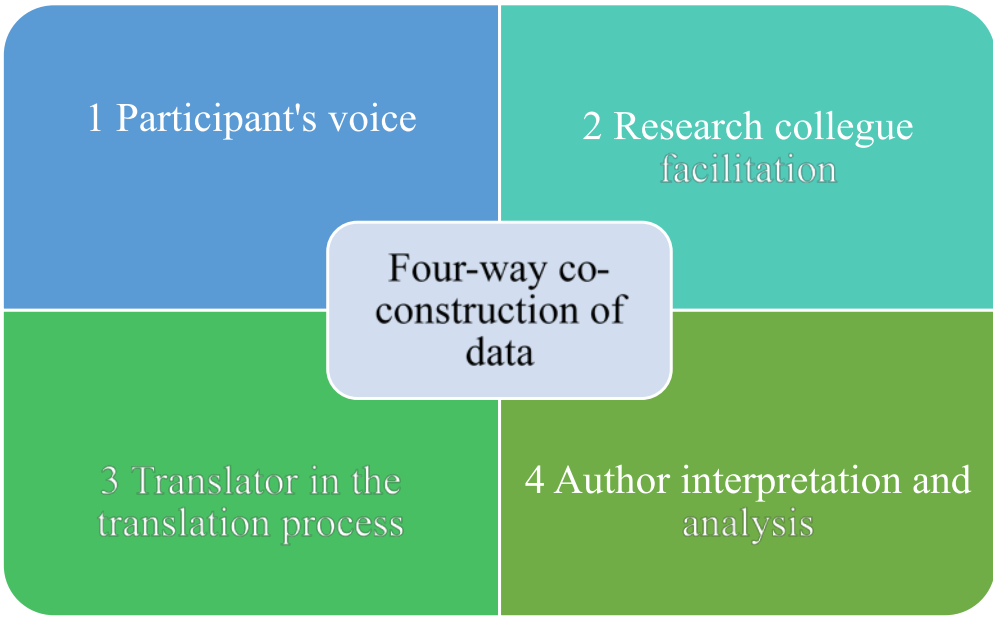
under-privileged participants, to make corrections. This was one another method employed which sought to redress the power imbalance in the research, in this instance caused by the dominance of the English language, and of written text over oral communication.

Figure 3-3 Figurative illustration of the translation process



While correcting errors introduced at the point of translation, the translators endeavoured to retain other aspects of the oral communication, such as rhythm and cadence. By listening back to the audio recordings, we were able to add punctuation, or repetition as appropriate to echo spoken emphasis (*Figure 3-3*). If the researcher, participant and facilitator have been described as being part of a "three-way co-construction" of data (Brämberg and Dahlberg, 2013), this translation process led to a fourth (*Figure 3-4*).

Figure 3-4 Illustration of the four roles and processes involved in the co-construction of data



3.20 Credibility

Credibility in qualitative research is where experiences studied, described and interpreted would be immediately recognised by people who share that experience (Krefting, 1991). It has been theorised as a core aspect of establishing "trustworthiness" in qualitative research (Lincoln, 1985). The translation process described above lends additional credibility to the data given that these discussions can be seen as a form of data triangulation, preventing the perspective of the first author (an "outsider") from dominating the interpretation. Each translated transcript was agreed upon and understood, or triangulated by at least one Tanzanian colleague and the first author.

"Member checking" is another method which has been used to enhance data credibility in qualitative research (Krefting, 1991). Due to difficulties such as participants being unable to read, (due to a lack of formal education or visual impairments), cognitive impairments and language barriers it would have been very impractical, to share data such as transcripts with participants. This would have necessitated each transcript being read aloud and discussed, and would have been a laborious, and most likely an unfruitful process for adding credibility to data.

"Member checking" was possible at the point of preliminary data analysis however. During data dissemination activities conducted in the final month of fieldwork (15th of October-17th of November 2018), fifteen health committee members who had participated in FGDs the previous year, were invited to a presentation of the preliminary qualitative themes. Verbal and written feedback confirmed that the overall findings were consistent with consensus views

and opinion. No concerns were raised about the themes suggesting that the messages inferred from the data were consistent with their intended meaning.

3.21 Data analysis

The translation process described formed the initial stages of data analysis, given that it resulted in familiarisation with data and a deeper understanding of the meaning and context. This will be evident from the example annotated transcript in Appendix H. Transcripts were imported into Nvivo Pro 11 software, which was used to help manage transcripts and for ease of developing themes. A constructivist approach was taken to the analysis of data, acknowledging that knowledge is historically and culturally specific and taking a critical stance toward taken-for-granted assumptions of concepts (Rapley, 2007). For example in this study, the meaning of concepts such as 'the body', 'adulthood' and 'independence' have been explored. Thematic analysis was conducted, based on guidance outlined by Braun and Clarke: *"Through its theoretical freedom, thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data"* (Braun and Clarke, 2006, p5). While deeper meanings were inferred from the analysis of themes with reference to the contextual, historical, and cultural background.

The initial process of data analysis by thematic coding was initiated in Tanzania, using the English translations and while continuing with interviews. Working on data production and analysis simultaneously, helped inform the direction of purposive participant selection and revisions to the topic guide. A tentative initial theory was developed which connected the themes of poverty, social vulnerability, and the lived-experience of frailty. These ideas led to seeking out participants with a variety of different living environments and social supports. Furthermore, these themes were dominant in the last few FGDs suggesting that data saturation was being reached, as existing themes were confirmed and reinforced (Guest et al., 2016).

On return to the UK, having reviewed the initial themes with the supervisory team, a new approach to thematic analysis was introduced. Given that all transcripts were documented bilingually, and much effort had been spent ensuring a credible and authentic translation, it was decided that coding should be conducted as much as possible in Swahili, thus keeping as closely as possible to the original spoken data. Coding of the Swahili data prevented a paraphrasing or summarising of participants' words into a sanitised and medicalised version. It also added richness to the analysis, by drawing attention to layers of meaning in the spoken data. For example, an initial sub-theme coded in English was "respect for elders", which became the sub-theme "*Wazee ni hazina*" (elders are treasure). Including the Swahili idiom permitted a critical analysis of this much-repeated expression and revealed it to be an

idealised notion, used to reinforce and strengthen support for traditional values. The initial themes developed and coded in English have been listed in the Appendix I. The identification and selection of quotes happened as part of the analytical process described. Key pieces of talk were highlighted as theme and sub-theme titles, and further quotes were selected as being representative of a broad range of participants, or due to being particularly illustrative or impactful expressions of the theme/sub-theme. Some quotes were selected because they illustrated a linguistic point, relating to translation and word choice, that was important to explore the message of a particular theme/sub-theme.

3.22 Author Reflexivity

Having discussed my research colleagues' reflexivity (Appendix E), here I will discuss my reflexivity as the author and lead researcher. Reflexivity has been defined as consisting of two elements, an acknowledgement of the researcher's place in the research context, and a critical self-reflection (Underwood et al., 2010). Taking a constructivist approach, reflexivity is a means of reflecting on my role in this co-production transparently. In this case, the process of reflection has enabled me to see myself as being in a position of power and newly revealed privilege in the research context.

3.23 Power imbalances

3.23.1 Between myself and Tanzanian colleagues

The power imbalances in the research relationships with Tanzanian colleagues were significant, and deserve reflection. Throughout this chapter I have referred to Tanzanian "research colleagues", in a deliberate and thoughtful attempt to reveal and redress these inherent power imbalances. Qualitative research typically attempts to reveal and address power imbalances (Karnieli-Miller et al., 2009), in contrast with positivist research epistemology where the researcher is the expert authority. Qualitative methodology posits that participants and all those involved in the process of data production are valuable contributors, sharing their cultural, language, and experiential expertise with the researcher. However, power relations inherent in research can still be seen in the terms used for various research roles. For example, "field workers", "interpreters", "assistants" "interviewer" and "cultural brokers" (Shimpuku and Norr, 2012, Hennink, 2008, Hennink, 2017, Karnieli-Miller et al., 2009, Caretta, 2014), are all terms which have been used to describe various roles in the qualitative research process and could all be applied to my Tanzanian colleagues. These terms can be contrasted with the more egalitarian "co-researcher" or "collaborator" which may be used in more collaborative or participatory research methods (Karnieli-Miller et al., 2009). In this study, I recognise that my Tanzanian colleagues contributed in all of the above roles, yet

"co-researcher" was not an appropriate term. The title "research colleague" has been chosen instead, which conveys a respect and acknowledgement of their invaluable roles and skills, yet does not give an artificial sense of an equal ownership or influence over the research.

I was uncomfortable with the hierarchy of power which was present in the researcher-research colleague relationship as it echoed colonial systems of power. My Tanzanian research colleagues were ultimately hired by me, on a short-term informal basis, in order to meet my desired ends. This produced at least in some respects, an employer-employee relationship, and should be borne in mind when considering my qualitative research colleagues' reflexivity. I negotiated their payment and provided them with cash-in-hand salaries, which may have helped provide necessary school fees or healthcare for their dependants. This work was temporary, informal and unpredictable, however over the years has produced an expectation of future employment opportunities as further research projects develop. So it is unclear to what extent JR, JK and PR could really reveal their reflexivity, where they had a financial motivation to please. Caretta has reflected on the challenges brought by the economic inequality between herself, the researcher and her "assistants" when conducting cross-cultural and cross-language research in rural East Africa (Caretta, 2014). The author claims that she and her "assistants" collaborated on feminist issues leading to empowerment in their communities, however the issue of the employer-employee power imbalance was largely forgotten. Indeed, one of Caretta's research "assistants" was balancing two jobs and childcare in order to supplement her income through the research (Caretta, 2014). In these situations it is difficult to separate a genuine interest in the research topic (in this case feminist empowerment), from a motivation to improve one's material situation, or meet necessary household demands. In another example, MacKenzie sensitively examines her "interpreters" social position, lived-experience and subjectivity in relation to the research topic, while neglecting to remember their replaceable nature as interpreters (MacKenzie, 2015). The author even describes terminating the employment of one interpreter whose language skills were inadequate, but then becomes blind to the influence that this insecure, unpredictable work might have on her "interpreters" reported positionality toward the research (MacKenzie, 2015).

Similarly to Caretta and MacKenzie, I experienced being perceived as a rich foreigner (Caretta, 2014), and of having more influence than I did (MacKenzie, 2015). Particularly study participants assumed I could influence local government and policy or mobilise NGO funds. I usually deflected these requests explaining that I was a student, and was working with a university, not a large donor. Yet, the reality of the situation is that even though the

economic divide may be greater, and more obvious, between myself and my study participants, there was still a considerable economic imbalance which separated me from my colleagues. I am fortunate not to know the financial insecurity which would lead me to take an impermanent cash-in-hand research job for a few months at a time, in the hope that it would lead to more impromptu work in the future. Even as a student, the financial security which I have has allowed me the privilege to truly reflect on my position toward the study of older people in a continent and culture foreign to my own. This is not to say that my research colleagues have provided disingenuous reflections, but rather it is likely to be "filtered" through the unequal power in the research relationship (Walsh et al., 2016).

3.23.2 Between myself and research participants

I was an "outsider" researcher, that is not sharing a language or cultural background with my participants (Irvine et al., 2008, Esposito, 2001). I want to examine some of the ways in which, as an "outsider" researcher there was a power imbalance in my favour. I will also discuss the ways I sought to redress the power imbalance in order to practice culturally sensitive, ethical research, as well as discussing the potential impact my being an "outsider" might have had on the knowledge creation process.

I had an inherent power through being a native English speaker. Most of my participants had either none, or some primary school education, and this education would have been through Swahili. Older adults particularly, were likely to associate the English language with British colonisers. English was therefore symbolically powerful, but also held very practical powers for formal communication and representation. Despite the crucial roles my colleagues played in the co-production and interpretation of data, the final decision of how to present the data was mine. Karnieli-Miller discusses a cyclical exchange of power in the researcher-participant relationship, and concedes that at the point of data analysis *"the story shared with the interviewer is 'separated' from the participant, and the researcher becomes the 'storyteller' who recasts the story into a 'new' historical, political, and cultural context."* (Karnieli-Miller et al., 2009, p283). This separation was even more prominent when the story was shared in a language with less international dominance. Ultimately, the same data in Swahili would not hold the same value as it would not be possible to disseminate internationally. As a fluent Welsh speaker, I could empathise with this dilemma. Although I appreciate the value in speaking the language of my cultural heritage, it is a minority language which is little-valued, even within the UK. I have experienced the *"linguistic imperialism central to the unquestioning use of English as a baseline language"* from a Welsh speaker's perspective

(Temple, 2002, p847). So, I appreciated that this put me in an influential position and made me a spokesperson on behalf of participants, nationally and internationally.

The second area of unequal power was in my literacy, where my research participants in general had low levels of reading and writing abilities. Temple has reflected on the academic community's focus on "written sameness" above "spoken otherness" when discussing the invisibility of translation in the research process (Temple, 2002). Thus, in this research I was instrumental in making my participants' "spoken otherness" palatable to the academic community. In Tanzania all official government documents are in English, and English is the language of their institutions, so when the topic of FGDs turned to talk of "the government should…" I felt that participants were asking me to use my English language and literacy to influence policy and bring about positive change on their behalf. This was emphasised at the end of every FGD when participants asked how we would help them: The answer we gave was that an official written report would be shared with stakeholders at the district and regional levels, with recommendations based on our research findings. There is an interesting parallel between the power imbalances at play when sign language was transcribed and translated into written English (Hole, 2007), with the production of text from older Africans' speech whose pre-colonial tradition would have been of knowledge transmitted orally (Cattell, 2008). In this study, written English was both a symbol of oppression and colonialism as well as a possible means of emancipation.

The power imbalance associated with language and literacy was acknowledged and to some degree addressed through the rigorous transcription and translation methods discussed (*Figure 3-3*). Another possible means of attempting to address this imbalance was by using my imperfect Swahili when meeting participants and during interviews. Research conducted in a researcher's non-native language, by a non-fluent researcher has been described as exposing the researcher's "linguistic vulnerability", and unexpectedly compensating for power differences in the research relationship (Muller and Gubrium, 2016). However, although I agree that this helped to improve trust in my interactions with participants, it did not change the broader fact of past and current dominance of the English language in Tanzania and internationally, and the implications of this.

Another potential power imbalance was the power differential of researching across age groups. My participants were cognitively, socially and physically aged, not only chronologically older. These so-called "age imbalances" in gerontological research become particularly stark when older research participants are frail and increasingly socially

marginalised (Sedláková and Souralová, 2017). Conducting research in the Czech republic, these authors discuss age as an often neglected factor intersecting with other areas of power imbalance, which may also be present in the researcher-participant relationship (such as gender, race and socio-economic status). They sought to address the power imbalance caused by age by adopting three researcher roles. I will briefly discuss these and how they related to my experience conducting research with older participants in Tanzania. The first role described is "researcher as message facilitator", where the researcher took on a role of assisting the older participant to communicate, helping them to compensate for any cognitive imbalances in the research relationship, (for example by allowing time, using artefacts and prompts to assist recall) (Sedláková and Souralová, 2017). Second, the researcher was described as adopting a "supporter" role, acting in a care-giving capacity to compensate and address imbalances in health and functioning. Lastly the researcher took on the role of "social world provider" helping to address the imbalance in social resources, where the researcher was seen as possessing access and opportunity for social contact and participation, while the older participant was *"prone to experiencing solitude, loneliness or feelings of abandonment"* (Sedláková and Souralová, 2017, p21). In my research in Tanzania, old age was often given elevated social status and respect, evidenced by the respectful greetings used toward older people, regardless of class or educational status. When I respectfully greeted older Tanzanians, it was received with surprised amusement, and exclamations of *"muzungu amesema shikamoo?!"* ("the white person has just greeted me respectfully?!"). Family members fulfilled the roles of "supporter" and "message facilitator", guiding older participants to a seat, and prompting or encouraging answers. As described, (Appendix E) when visiting an older participant's home, the research team (myself and JK or JR) were in the roles of welcomed visitors, or adult children returning from town (Sedláková and Souralová, 2017). Culturally, we reinforced existing age imbalances rather than diminished them, as JR put it *"we were like the sons and daughters to them"*, however this was in a culturally accepted and respectful manner.

3.23.3 Privilege imbalances

Privilege is unearned advantage based on one's group membership (Phillips and Lowery, 2018), and is often invisible to the individual benefiting from privileged group membership. Throughout my experience of living and working in Tanzania over almost two years in total, my white racial privilege was gradually revealed to me. *"Muzungu"*, meaning "white foreigner" is a ubiquitous term, which as Caretta reflected, was one of her first Swahili words learnt when researching in rural Tanzania (Caretta, 2014). It is the term used by anyone

talking *about* you, referring to you in Swahili to another Tanzanian, thus it is how you are categorised and seen first and foremost. It is undoubtedly a racial term, not applied to Asian or Indian foreigners. My whiteness was not only highlighted on a daily basis through these reminders, but also in subtle behaviours which revealed a Tanzanian subordination and attribution of a racial hierarchy. For example, as a white woman I was expected not to carry heavy objects, while Tanzanian women my age were expected to regularly carry heavy loads with ease. Meanwhile, I was expected to enjoy leisure activities and to be served.

My white racial privilege had been invisible to me prior to spending a prolonged amount of time in Tanzania, perhaps testament to the strength of the "herd invisibility" effect described by Phillips and Lowery (2018). "Herd invisibility" was described as a phenomenon which occurs where enough individuals hide their racial privilege, through techniques such as denying the existence of racial advantages, denying that advantages are unearned or denying any benefit from these advantages. A general social protection of the status quo is produced, which leads to invisible racial benefit (Phillips and Lowery, 2018). In Tanzania for the first time I was not protected by "herd invisibility" and was confronted by the legacy of a long-established system of white privilege, namely colonialism, which was more visible in Tanzania than in the UK.

My privileges are multiple however, and not limited to race. These are evident even in the fact of being a UK-based researcher who felt entitled to conduct research on a group of older people and their families living with frailty in Tanzania. The inequity between the unearned advantages which led me to this point, contrasted with the lack of advantage which my research participants and their communities have, should be made transparent. While listening to participants' stories about their struggles negotiating access to healthcare, I reflected uncomfortably on my comprehensive travel insurance provided through my university affiliation. In the event of a medical emergency I would be spared having to face these poor local services due to an un-earnt entitlement to repatriation.

It is particularly important to recognise the ways in which academia has been a part of colonial systems of privilege (through the specialism of Hygiene and Tropical Medicine) (Abimbola, 2018). In my role as a UK-based researcher in Tanzania I was benefiting from, if not perpetuating these systems. As Sonn, a South African researcher working with aboriginal communities in Australia reflected, he was part of an academic process which has been responsible for often harmful "othering" and "objectifying" of study participants (Sonn, 2004). In this research, seeking to investigate frailty in Tanzania, I have immediately implied

an “otherness” and difference in Tanzanians worth studying, and labelled participants with an objectifying medicalised term. Confronting one’s power and privilege is an unsettling and challenging process, yet I believe it has produced a valuable critical awareness of my position in the research.

3.24 Ethical permissions, ethical practice and situated ethics

Reflecting on the power and privilege imbalances inherent in this study leads on to considering the ethics of conducting such research. In this section, the bureaucracy of formal ethical approvals have been distinguished from the daily practise of conducting ethical research, and the broader ethical context. It has been highlighted that weaknesses in ethics procedures may allow *“potentially exploitative research to continue even within perfectly designed and ethically approved studies”* (Benatar, 1998, p221). This section will discuss the nuances and challenges of conducting ethical research where high-income/low-income country (LIC) disparities force a broader view of ethical research than traditional issues of consent and confidentiality.

3.25 Ethical permissions

Formal ethical approval was gained from three ethics review boards. In Tanzania, The Kilimanjaro Christian Research Ethics and Review Committee (CRERC) a local committee based at KCMC, The National Research Ethics committee (NatREC) for Tanzania, based at the National Institute for Medical Research (NIMR), Dar es Salaam, and in the UK, Newcastle University Research Ethics Committee (Appendix J). The process of gaining Tanzanian ethical approval took 6 months, the production of several large documents, and cost hundreds of US dollars. Both Tanzanian committees issue annual ethical approval certificates after receiving progress reports and renewal payments. This financial transaction as part of the ethics formalities will be discussed later (“Situated” ethics). The process was useful in the fact that it required the researcher to provide translations of all survey tools, consent and information forms, and to consider the detail of the research design. NIMR has developed guidance which clearly seeks to promote Tanzanian benefit from foreign research collaborations, for example mandating that the principle investigator or co-investigator is affiliated with a Tanzanian research institution (NIMR, 2015).

3.25.1 Ethical consent

Formal ethical approval involved outlining methods and documents to facilitate gaining ethical consent. Written or thumbprint consent was gained from each participant after giving verbal and written information about the study and reading aloud the consent form. These efforts were made in order to ensure that all those who were unable to read were still able to

give fully informed consent. There was an opportunity to ask questions and participants were never coerced or put under pressure to participate in any or all parts of the study. Qualitative interviews and FGDs were audio recorded only if participants were consenting and consent was checked again at the end of recording. It was emphasised to participants that they could choose not to answer any or all of the questions posed, and could withdraw their consent at any time without having to give a reason. The gifts which were given as thanks for participating, (1kg of sugar, or soap for handwashing clothes) were proportional yet valued commodities (worth around 1 USD) and would not have been a coercive factor toward participating. On reflection however, it is important to acknowledge that although there was no overt pressure to participate in the study, there were significant covert and unintended influences which may have increased the likelihood of consenting to participate.

Three potential factors will be discussed and reflected upon here: First, the Tanzanian culture of inclusion and consensus. If an older person's spouse and neighbour participated, this may well have swayed an undecided individual, particularly given that screening occurred at a village office or public centre where frequently 20 or more older people gathered while waiting to participate. Undoubtedly, it would be difficult to walk past, publicly going against the consensus support of the study among the village. This was particularly the case where enumerators made announcements about screening days at church, where non-participation may have risked feeling excluded from one's faith community.

Secondly, in the absence of a functioning primary healthcare system, we were offering the opportunity of time with a junior doctor from KCMC, or a UK-based doctor, and the chance of free health advice, or possibly more. This is on the background of "community outreach" programmes delivered by NGOs or other foreign research teams, which have sometimes provided one-stop clinics with investigations and treatments offered together. It would have been difficult to reject the possibility of potential healthcare in the context of services being unaffordable and difficult to access.

Thirdly, as already discussed, there was a significant power imbalance in favour of the research team, and in a culture where deference and respect for authority is the norm, non-participation might have been seen as a disrespect to the village enumerator involved in recruiting, and the senior Tanzanian colleagues involved in the study. These were largely factors outside of our control, except for reducing the need for participants to congregate. However due to limited resources and time, it would not have been possible to screen the total sample of 1,207 older people by going house-to-house. Although numbers were few, some

participants did refuse or withdraw consent, indicating that these factors did not completely invalidate the consent process.

3.26 Ethical practice

As previously raised, gaining ethical approval and practising research ethically may be two completely separate entities. Two challenging areas were encountered during the fieldwork where the aims of the study were potentially in conflict with the moral imperatives to prioritise the wellbeing of participants: There was a conflict between minimising the physical and emotional burden to participants at the expense of possible loss of data, and also, there was a problem of addressing unmet needs, at the risk of impacting on and biasing longitudinal outcomes. These issues will now be discussed with reference to ethical theory.

3.26.1 Minimising the physical and psychological burden

Some of our interviews touched on difficult topics for participants, for example the death of family members. For example, during one qualitative interview a participant became unexpectedly emotional and cried when we asked her about her life as a widow. JR used appropriate condolences and comforted her, checking that she was happy to continue with the interview before proceeding, thus we tried to tread sensitively when addressing these and other such issues. Undertaking anthropometric and functional testing could also be quite burdensome for some frailer participants. We attempted to minimise this by co-operating as research colleagues to improve efficiency and reduce the time taken for the assessment. If the participant became tired, we offered them a break to rest, or offered to return at another time or date to complete the assessments. We also provided refreshments for participants if they were waiting, particularly for longer periods or in the heat. Occasionally, taking these steps to ensure respect for our participants' physical and psychological wellbeing meant that surveys, functional assessments or anthropometrics were left incomplete or interviews were cut short. Incomplete data was not desirable; it is difficult to analyse and interpret, and shortened interviews were more likely to provide superficial data, so as a research team we strived to avoid it. However, this was not at the expense of our participants wellbeing, at least on a collective level.

According to traditional "African thought", the individual is respected, but not individualism. There is an understanding that *"people are interconnected by life, what affects one affects all – we are many yet one. For the African, it is respect for life and community that is a priority"* (Wanda, 2015, p156). Given the importance of the collective over the individual, the value of the study, according to participants was in its potential value to the community. We often found participants were determined to continue with tedious questionnaires or to complete

tiring functional measurements despite being offered a rest or to stop. Participation was seen as being for the sake of the community's good. The philosophy of *"Ubuntu"* could be described to underpin this notion (Kamwangamalu, 1999). According to this philosophy, as researchers we were validated as doing and being "good" or ethical, by an understanding and behaviour of mutual respect and reciprocity in our interactions with study participants and their communities. Participants understood that we were acting based on mutual and reciprocal co-operation, and were willing to tolerate some discomfort, in return for our showing them respect, and with the hope and expectation of our bringing the community some benefit.

3.26.2 Confrontation with unmet need

Being confronted with participants' unmet needs was perhaps one of the biggest challenges faced during data collection in the community, particularly when visiting people's homes. As a research team, we felt a moral obligation to act when we were confronted with situations of desperate need, especially when there seemed to be a practical solution which would help to alleviate suffering. One example was a mother and daughter visited as part of the initial screening. The daughter, in her sixties, was the main care-giver for her immobile and frail mother, and was herself a wheelchair user. We discovered her wheelchair was broken and too large and heavy to manoeuvre without assistance. A grandchild, who was married and living with her husband and their family, visited daily, but was unable to provide all the assistance needed. Here was a situation of urgent need, where we had the resources and knowledge necessary to intervene.

We responded by contacting an occupational therapist in Moshi, and organised and paid for a new wheelchair for the daughter. This didn't solve the overall problem of inadequate resources, care and services for them both, but helped to alleviate some of the acute suffering. As Morse has discussed when conducting qualitative health research, breaching the "passive observer" role may be necessary where there are clinical emergencies, and the imperative to act may even conflict with the goals of the research (Morse, 2007). Given that this was a longitudinal study, interventions such as this may have influenced participant outcomes, nevertheless the research team collectively felt an obligation to act where we were able, based on the underpinning values described previously. Having generously given their time and effort in participating, the research team were required to reciprocate. Unfortunately, a majority of the problems which were encountered were not possible to solve on an individual basis and required broader systemic changes. In this sense the principle of justice toward participants' communities was in question. Individual participants were benefitting on a case-

by-case basis, but it is less clear whether the study brought any tangible benefit to the community.

A review of global health research ethics guidelines found that guidelines by LMICs were likely to recommend that research participation benefit not only the study participants, but their host communities too (Lairumbi et al., 2011). In contrast, most international research ethics guidelines (e.g. The Declaration of Helsinki, UNAIDS) recommend that participants should be the key beneficiaries of research, for example receiving any trialled medication or investigation (Lairumbi et al., 2011). This reveals what may be fundamental differences between individualistic "western" norms and more collectivist cultures such as that of rural Tanzania. Likewise, it may be a recommendation based on the principle of justice, expressing the preference that where research is conducted in the absence of services, it is an issue of justice that research resources should be shared with the whole community and not the randomised few. This lack of consensus between "global opinion" and the recommendations of resource-poor countries on what is *owed* ethically-speaking to research communities, is an important area of for future debate (Lairumbi et al., 2011), particularly given the power imbalances between these actors. Much international research in Africa has been criticised for its "briefcase model", where research findings are taken away with negligible dissemination in the communities in which the research took place (Murphy et al., 2015). As part of this thesis, taking the African ethics of mutual respect and reciprocity to its conclusion, we endeavoured to produce a form of community benefit through the dissemination of data to the participating villages in the district (Appendix K).

3.27 "Situated" ethics

"Situated" ethics refers to an ethical analysis of the structural and systemic factors influencing international research projects such as this, and which are usually seen as outside the remit of traditional ethical discussion (Walsh et al., 2016). The author's personal power and privilege imbalances have already been reflexively discussed, however the author and the research team were working within a broader field of structural and systemic power imbalances. Setting the research agenda and leading the research are the two issues which will initially be discussed in relation to their "situated" ethics. Following this, the impact of the structural and systemic financial imbalance between UK and Tanzanian research partners will be discussed. Finally the section will conclude with a reflection on ethics and global health.

The power imbalance of what has been termed "institutionalised social capital" was an important factor in this study (Walsh et al., 2016). That is, where a researcher's affiliation with a prestigious high-income country (HIC) university, or international organisation,

produces a form of institutional power and privilege when collaborating in cross-country research with less powerful local research institutions (Walsh et al., 2016). Disparities exist in reputation, access to resources, training, and academic opportunities (Murphy et al., 2015). In our case, most of our Tanzanian colleagues had an affiliation with either the local medical school, Kilimanjaro Christian Medical University College (KCMUCo) or the tertiary referral hospital, KCMC. Both institutions are well respected, but this is perhaps exactly because of their long-standing relationships with high-profile HIC institutions, from whom they receive significant funding and "institutional social capital" from this endorsement. The affiliated HIC institutions- Newcastle University and NHFT- were the dominant research partners. This was particularly illustrated through the methods used to set the research agenda and in designing and leading the study. The institutional relationship with KCMC and KCMUCo was largely treated as a necessity to allow access to "the field". For example, as required by NIMR, in a policy aimed at protecting Tanzanian interests, the principle investigator was required to be affiliated with a Tanzanian research institution, therefore a largely nominal local principal investigator was chosen (NIMR, 2015).

The research topic and agenda was set by the UK-based research team without consultation or discussion with Tanzanian researchers or stakeholders, a practice which has been described as "semi-colonial" (Costello and Zumla, 2000). This is also counter to the multiple guidelines which exist for conducting ethical international or global health research, not least the Swiss Commission for Research Partnerships with Developing Countries (KPFE) guide for transboundary research partnerships, its first principle being "Set the agenda together" (KFPE, 2018). *Table 3-1* compares this study's methods with Costello and Zumla's "semi-colonial" and "partnership" models, across a number of research areas (Costello and Zumla, 2000).

Table 3-1 Comparing the semi-colonial and partnership models with this study's methods

Research area	Semi-colonial model	Partnership model	This study's methods
Setting of research agenda	Dominated by outsiders	Negotiated with insiders	Dominated by outsiders, with reference to an extensive history of epidemiological research, the agenda for which was also set by UK-based researchers.
Links with national institutions and training programmes	Peripheral	Integral	Links with national institutions e.g. KCMCUCo transactional and nominal in order to gain ethical permissions and continued access to "the field". No links to explicit training or capacity-building programmes. KCMC intern doctors employed on a temporary basis during this project, providing them with some clinical research data-collection experience.
Management	Line management by foreigner	Line management by national or insider	Management of the overall project by the foreign author and PhD supervisory team. Tanzanian colleagues had no management roles or input in budget management.
Staff costs	Predominantly foreign salaries; overinflated local salaries	More balanced investment and more sustainable in the long term	Poorly sustainable, salaries paid in cash without formal employment agreements, amounts negotiated based on previous years' salaries and advised by local research colleagues
Dissemination	Heavily orientated to international journals and conferences	International dissemination balanced by outputs in national or regional	Two international journal publications, no regional or national publications. Five further abstracts presented at UK national or International European conferences. Tanzanian authors included on papers and abstracts in a tokenistic fashion. Dissemination

Research area	Semi-colonial model	Partnership model	This study's methods
		journals, and media to reach a wider audience	also carried out locally and nationally, but without local or national media involvement (Appendix K).
Emphasis on sustainability and generalisability of research	Low	More likely	Sustainability of these methods of working maintained through good working relationships with individual Tanzanian colleagues, but no efforts made to develop sustainable methods which would be generalisable and led by Tanzanian nationals.
Influence with local policymakers	Low	High	Low; efforts taken to engage local policy makers through dissemination to the District Health Management Team and NIMR at the point of preliminary data analysis but not before, no engagement with stakeholder/NGO groups.
Effect on national institutions	Negative; attracts best and brightest away from national research institutions	Positive; builds up local academic infrastructure	The most qualified and experienced Tanzanian colleagues employed informally alongside other employment or temporarily while between jobs. No attempt to build-up or support local academic infrastructure through the study.

The decision taken by the UK-based researchers to study frailty in older people in this setting came from an extensive background of epidemiological research in this region, which was previously largely disease-specific. Research investigating the prevalence of Parkinson's disease (Dotchin et al., 2008), epilepsy (Hunter et al., 2012), disability in older people (Dewhurst et al., 2012), stroke (Walker et al., 2013) and dementia (Longdon et al., 2013) were all conducted in the same rural district. The concept of frailty, it was argued, would be a means of integrating these multiple health problems in a way that would be more needs-focused. The resultant research would then lend itself to the development of healthcare services more aligned to the needs of the most vulnerable older adults in the context of low human and other healthcare resources. However, despite this robust and well-intentioned argument, this does not detract from the fact that older adults, their communities, other stakeholders and individuals at our academic partner organisations (KCMUCo and KCMC) were not included or involved in the study conceptualisation and design. Taking another perspective, if the success of a study is judged according to its quality academic output, working according to this "semi-colonial" model is successful (Costello and Zumla, 2000), producing two high quality international publications so far. It could also be argued that these research projects would never have been conducted had a prolonged process of consultation and needs-assessment been required prior to each study. Yet, the dissemination and evaluation work conducted in the final month of fieldwork demonstrates that such processes of stakeholder consultation and involvement are possible, even though they require investments of time and resources. The hardest aspect of moving to a partnership model of working may in fact be the relinquishing of control on the part of the HIC research partner (Murphy et al., 2015).

From setting the research agenda to leading the whole research process (from the fieldwork to analysis and publication), the control was again on the side of the UK-based researchers, bolstered by what has been termed "symbolic and scientific capital" (Walsh et al., 2016). This has previously been described as the norm by researchers investigating the power dynamics in "northern-southern hemisphere"[8] health research partnerships (Walsh et al., 2016). Using Zambia as a case study it was found that southern hemisphere researchers considered that having the choice of a particular research topic, was seen "to be a northern luxury" (Walsh et al., 2016). A three-year, multi-regional consultation process conducted by the Canadian Coalition for Global Health Research found experiences of persistent inequity in research

[8] "Northern-southern hemisphere" being the term used in the quoted paper. However, I feel that this is a slightly euphemistic description for HIC working in lower-income countries in research partnerships.

partnerships, with LIC partners describing more of an “incorporation” in the research rather than “collaboration” (Murphy et al., 2015). These LMICs partners often lacked opportunities to take on leadership roles or to analyse data and author publications. This was the case in this thesis, where Tanzanian co-authors, lacking ownership of the research have been credited in a rather tokenistic fashion on publications for which their main contribution was data collection (Lewis et al., 2018b, Lewis et al., 2018a). Tanzanian co-authors were given the opportunity to comment on manuscript drafts, but rarely were these opportunities been taken-up. There are likely to be many contributing factors explaining this, for example, not having been included enough to have the necessary depth of understanding, a lack of access to essential resources (high speed internet, journal articles), a lack of confidence to comment in the academic arena or in one’s second language, or an expectation that this is simply the norm. This phenomenon reflects the findings of Walsh and colleagues who discovered a similar acceptance of the “status quo” in Zambia and a lag in response to new opportunities and shifting power relations (Walsh et al., 2016). This type of dominant-subordinate research relationship may be perpetuated in a form of co-dependency if each actor feels there are enough mutual benefits overall (Walsh et al., 2016). Perhaps this is the current situation in the Tanzanian context.

3.27.1 Ethics and Finance

Having discussed the structures of “institutional social capital” and “symbolic and scientific capital” at play in this study, this section will describe the “financial capital” in the research relationship. Financial capital was discussed as being the most dominant form of resource for power in northern-southern hemisphere research partnerships (Walsh et al., 2016). This rings true in Tanzania where the majority of health research funding comes from HIC research partners. The power imbalance due to the financial capital of foreign research partners is even seen at the point of payment for submission of research proposals to Tanzanian ethical review boards, and this problematic transactional relationship may continue throughout the research process. The impact of this imbalance of financial resources was recently tacitly acknowledged by NIMR research guidelines, which admitted that due to the current structure of health research funding, Tanzanian authorities lacked control over the “sustainability and relevance” of health research happening in the country:

“Health research funding remains the single most critical bottleneck in research performance. It is appreciated that for sustainability and relevance, the main source of health research funds shall be the Government of the United Republic of Tanzania. Recently with due recognition of the need to invest in research, the government is allocating at least 1% of the annual GDP to research programmes. However, national funding has continued to be

extremely low and health research activities have remained largely donor-driven." (NIMR, 2015)

This study was no different, where all finances for the study were from UK-based institutional sources and kept under UK-researcher control. For instance, the author's salary was funded through a NHFT Teaching and Research Fellow grant. The first period of data collection (February -August 2017) was funded by Newcastle University MRes students project fees, and the second follow-up data collection (August-Nov 2018) was funded by a British Geriatrics Society SpR Start-up grant. None of the funders had any role in the design, methods, participant enrolment, data collection, or analysis of data for this study, yet nor did any Tanzanian institutions or stakeholders. Usually, a statement asserting the researchers independence from funding bodies would be adequate to persuade of a study's ethical conduct, however given that the study's funds were controlled and managed through UK-based institutions, it is clear to see that financing has played a significant role in perpetuating and enforcing structural power and privilege imbalances throughout this project. Well-paid employment opportunities for qualified doctors and academics were particularly scarce in February 2017, which may have contributed to an "annexing" of research sites and skilled national researchers. This has been described as a frequent harmful behaviour of foreign HIC researchers because it comes at the expense of a loss of capacity for national research institutions (Costello and Zumla, 2000). Zambian researchers have similarly described having to "sell themselves" (Walsh et al., 2016); submitting to HIC-led research. While trust in LMIC institutions limits their access to independent funding, often considered untrustworthy or "risky" by international HIC donors (Walsh et al., 2016). The onus is on the HIC partner to make these research relationships true collaborations, rather than continue to preserve a self-serving norm.

3.27.2 Ethics and Global Health

Global health has been defined as;

"an area for study, research, and practice that places a priority on improving health and achieving equity in health for all people worldwide. Global health emphasises transnational health issues, determinants, and solutions; involves many disciplines within and beyond the health sciences and promotes interdisciplinary collaboration; and is a synthesis of population-based prevention with individual-level clinical care." (Koplan et al., 2009).

The concept has evolved over time, from “Tropical Medicine and Hygiene”, followed by “International Health”, and finally to “Global health”, which it is argued, represents a shift in thinking rather than a matter of semantics (Koplan et al., 2009, Abimbola, 2018). The study of frailty in old age is a transnational health issue due to global population ageing. In focusing the investigation of frailty on a vulnerable disenfranchised group of older rural Tanzanians, this study sought to improve health equity. Yet, from this review of the ethical issues involved, it is clear that these methods were not wholly equitable or truly collaborative.

The question can be raised of whether this lack of collaborative working matters, if more benefit than harm has been produced. Costello and Zumla have argued that the “partnership” model of working it is more than a matter of political correctness, because the practical outcomes of research based on a “semi-colonial” model are less likely to be translated into policy or practice (Costello and Zumla, 2000) (*Table 3-1*). Murphy et al. have argued that the fundamental aims of global health cannot be successful if its practice continues to protect entrenched inequities and privileges (2015). These authors call for global health research grounded in the “core values of equity, respect, and inclusion”, and offer a practical guide (The Partnership Assessment Toolkit) for researchers to use throughout the process of research (Murphy et al., 2015). The idealism of the aims of global health may therefore be matched with practical methods for engaging with these difficult issues.

3.28 Data dissemination and evaluation

In a survey of professionals, most based in Africa and with professional experience of working on large population-based public health projects, (Ye et al., 2012) a majority of 69% agreed that knowledge dissemination was an important potential benefit which communities should gain from participation in public health and epidemiological surveys (Anane-Sarpong et al., 2018). While the ethical imperative for this work has already been asserted, it has been acknowledged there are additional challenges for data dissemination in rural African settings due to barriers such as poor or no internet access (Anane-Sarpong et al., 2018).

Dissemination activities were undertaken between the 15th of October and 17th of November 2018. Four stakeholder groups were targeted for data dissemination activities, the medical and academic community locally, district health managers, VHC members and participants and their families. Dissemination to the local medical and academic community was in the form of a progress report which was shared with key individuals at KCMC, the District Medical Officer and with NIMR and CRERC ethics boards, as well through a 45 minute lecture given at KCMC. Eighteen district level managers (the District Health Management Team (DHMT) attended a two hour seminar on the research findings, which included a presentation and

period for discussion. Anonymous written feedback on the study and its findings were obtained on both occasions through feedback forms (Appendix K).

Volunteering VHC members were recruited in order to disseminate findings to participants and their families. First, a data dissemination seminar was held with 23 members of health committees and local village dispensaries. Posters were developed in collaboration with JK, JR, PR and the DHMT. These were printed as A0 posters and distributed for display in the district's dispensaries. Fifteen individuals volunteered to distribute purpose-designed information leaflets, going house-to-house and spending time explaining the study's preliminary findings to participants and their families. These leaflets were designed with reference to the Integrated Care for Older People (ICOPE) guidelines (WHO, 2017a), and included practical advice. Volunteers gained feedback from participants on the leaflets, and on the positive and negative impacts of the study generally. These comments were documented by volunteers in notebooks. The feasibility of these methods of data dissemination were discussed in a further meeting with the volunteer VHC members. Notes from these meetings, as well written feedback from forms or notebook documentation were collated and analysed by summative content analysis, in order to represent common comments and issues (Hsieh and Shannon, 2005). Dissemination methods and resources have been presented in more detail in the Dissemination Evaluation report (Appendix K).

3.29 Summary

The methods and methodological underpinning of this study have been discussed and will be briefly summarised here. In order to answer the broad research question "what is frailty in rural Tanzania", a mixed-methods approach has been taken. As illustrated in *Figure 3-1*, two contrasting epistemologies and methods have been employed, to produce quantitative and qualitative findings which will be drawn together in the discussion. A dialectic approach was chosen, in order to take advantage of the inherent conflict and tension produced. The "situated" ethics of this research as applied to the concept of global health research, provide reflections which will be taken up again in the discussion chapter.

Chapter 4 Quantitative Results: The prevalence of frailty in rural Tanzania

4.1 Introduction

This chapter seeks to answer the research question; "To what extent can the biomedical models of frailty be applied to measure and characterise frailty in this setting?" Five different methods of frailty measurement were used to describe and characterise the degree of frailty found in older adults living in Hai District. These have been introduced in detail in the literature review chapter. For the purposes of this thesis the "Brief Frailty Instrument for Tanzania" (B-FIT) was employed to assist with randomisation and selection of the frailty-weighted cohort (Gray et al., 2017). An evaluation of the validity and diagnostic accuracy of the B-FIT was not within the aims of this study therefore.

Some of these findings have been published elsewhere, namely the prevalence of frailty according to the Comprehensive Geriatric Assessment (CGA), (Lewis et al., 2018b) and the prevalence and characteristics of frailty according to Frailty Phenotype (FP), (Lewis et al., 2018a). Additional measures of frailty employed were the Clinical Frailty Scale (CFS), (Rockwood et al., 2005) and the Frailty Index (FI), (Rockwood and Mitnitski, 2007). The prevalence and characteristics of frailty according to the CGA, FP and FI will be described and compared, followed by discussion of how these findings relate to those found in the published literature. The CFS was used alongside the CGA allowing assessors to grade participants on a spectrum of health and functioning in old age, but given that it was used as an adjunct to the CGA the prevalence estimates can be taken as the same (Lewis et al., 2018b). The discussion chapter will take up an examination of the strengths and limitations of each model as applied in this rural sub-Saharan African (SSA) setting.

4.2 Demographics of the screened population according to B-FIT screening tool

The B-FIT was administered to a total of 1,207 participants aged ≥60 years from five villages, with ≥84.5% enrolment in each village (*Figure 3-2*). The group enrolled to the study were significantly older (median 70, inter-quartile range (IQR) 64-78, Range 60-117) compared with those not enrolled (median 66, IQR 62-75, Range 60-107); z= 3.686 P = 0.0002 by Mann-Whitney U test, however there was no significant difference in sex distribution ($X^2(1)$ = 0.278 P = 0.598) between groups. *Table 4-1* shows the demographics of the whole screened population according to their B-FIT screen result. Those scoring 0-1 (N=883) were categorised as "non-frail", those scoring 2-4 (N=285) as "pre-frail", and those scoring 5-6 (N=39) were deemed "frail". Using these categories the prevalence of frailty according to the B-FIT was 3.23% (95% CI 2.2 to 4.2) calculated from 1000 bootstrap samples. Crude odds

ratios (OR) of frailty vs non-frail/pre-frail, and their 95% confidence intervals (CI) and significance (p-values), were calculated for each demographic variable using binary logistic regression (*Table 4-1*). Categories were combined for work status and educational attainment, (not working for pay vs all other categories, and no formal education vs some education) due to very low numbers in the frail category.

Table 4-1 Demographic characteristics of the screened population by B-FIT score

Demographic characteristic	B-FIT non-frail N=883 frequency (%)	B-FIT pre-frail N=285	B-FIT frail N=39	Crude OR (95% CI)	P value
Age category:					
60-69	452 (51.2)	101 (35.4)	1 (2.6)	1	-
70-79	306 (34.7)	85 (29.8)	12 (30.8)	**16.9 (2.1-131.0)**	**0.007**
≥ 80 years	125 (14.2)	99 (34.7)	26 (66.7)	**64.1 (8.6-475.8)**	**<0.0001**
Sex:					
Men	414 (46.9)	105 (36.8)	9 (23.1)	1	-
Women	469 (53.1)	180 (63.2)	30 (76.9)	**2.6 (1.2-5.6)**	**0.011**
Marital status:					
Married	503 (57.0)	133 (46.7)	10 (25.6)	1.0	-
Widowed	299 (33.9)	125 (43.9)	27 (69.2)	**4.0 (1.9-8.4)**	**<0.0001**
Separated/ divorced	65 (7.4)	18 (6.3)	2 (5.1)	1.5 (0.3-7.1)	0.58
Single (never married)	16 (1.8)	9 (3.2)	0 (0.0)	-	-
Education:					
University	16 (1.8)	3 (1.1)	1 (2.6)		
Secondary school	43 (4.9)	8 (2.8)	0 (0.0)		
Primary school	322 (36.5)	69 (24.2)	5 (12.8)		
Some primary	359 (40.7)	120 (42.1)	10 (25.6)	1.0	-
No formal education	143 (16.2)	85 (29.8)	23 (59.0)	**5.9 (3.0-11.4)**	**<0.0001**
Literacy:					
Able to read and/or write easily	503 (57.0)	106 (37.2)	7 (17.9)	1.0	-

Demographic characteristic	B-FIT non-frail N=883 frequency (%)	B-FIT pre-frail N=285	B-FIT frail N=39	Crude OR (95% CI)	P value
Able to read and/or write with difficulty	225 (25.5)	85 (29.8)	6 (15.4)	1.6 (0.5-5.0)	0.35
Not able to read and/or write	155 (17.6)	94 (33.0)	26 (66.7)	**9.0 (3.8-21.2)**	**<0.0001**
Location:					
Low-land	261 (29.6)	120 (42.1)	13 (33.3)	1.0	
High-land	622 (70.4)	165 (57.9)	26 (66.7)	0.9 (0.4 – 1.9)	0.92
Work status:					
Government employee	4 (0.5)	1 (0.4)	0 (0.0)		
Private employee	16 (1.8)	3 (1.1)	0 (0.0)		
Self-employed	390 (44.2)	78 (27.4)	2 (5.1)	1.0	-
Employer	3 (0.3)	0 (0.0)	0 (0.0)		
Not working for pay	470 (53.2)	203 (71.2)	37 (94.9)	**13.6 (3.2-56.7)**	**<0.0001**

Work status as reported is difficult to interpret, as participants who were subsistence farmers may have classified themselves as either “self-employed” or “not working for pay”, thus these categories serve to illustrate the low numbers receiving a regular salary from either the government or private sector. Of the 710 not working for pay, the largest proportion 308 (25.5%) stated they were too “ill” to work, 159 (13.2%) reported they were “retired”, and 101 (8.4%) identified as being “homemakers”. In answer to the question “What has been your main occupation over the past 12 months?”, 935 from the total (77.5%) responded that their occupation was in agriculture, 76 (6.3%) stated they worked in professional occupations (e.g. teacher, clergy), with 51 (4.2%) working in service sector jobs such as sales. The crude odds of frailty were increased among older individuals, women, those who were widowed, those who had no formal education and who were unable to read/write, as well as those “not working for pay”.

4.3 The prevalence of frailty by the Comprehensive Geriatric Assessment

Following randomisation, 236 participants were selected to receive two separate assessments. Firstly, the CGA (which also included a global evaluation using the CFS), and secondly the survey questionnaire and physical measurements, data from which would result in the production of a FP and FI. Participants selected for CGA were weighted towards frailty, so that 37 (94.7%) of those deemed “frail” according to the B-FIT received a CGA. Of the “pre-frail”, 120 (42.1%) were randomly selected, and a further 79 (8.9%) of the “non-frail” were also randomised. The prevalence of frailty according to the CGA in community-dwelling older adults in Hai District is summarised below (*Figure 4-1*). The frequencies of frail cases by each of the B-FIT categories (used to calculate the weight-adjusted prevalence) have been included in Appendix L for reference. In keeping with the previous demographic results, the prevalence was higher in women, and in older age groups. The sample of five villages included three located in high-land locations and two in low-land locations, however the prevalence across these locations did not differ significantly. Prevalence was markedly higher in those without formal education, and in those unable to read/write however these prevalence estimates by category have not taken into account the potential confounding of age and sex.

Figure 4-1 CGA prevalence estimates by demographic characteristics

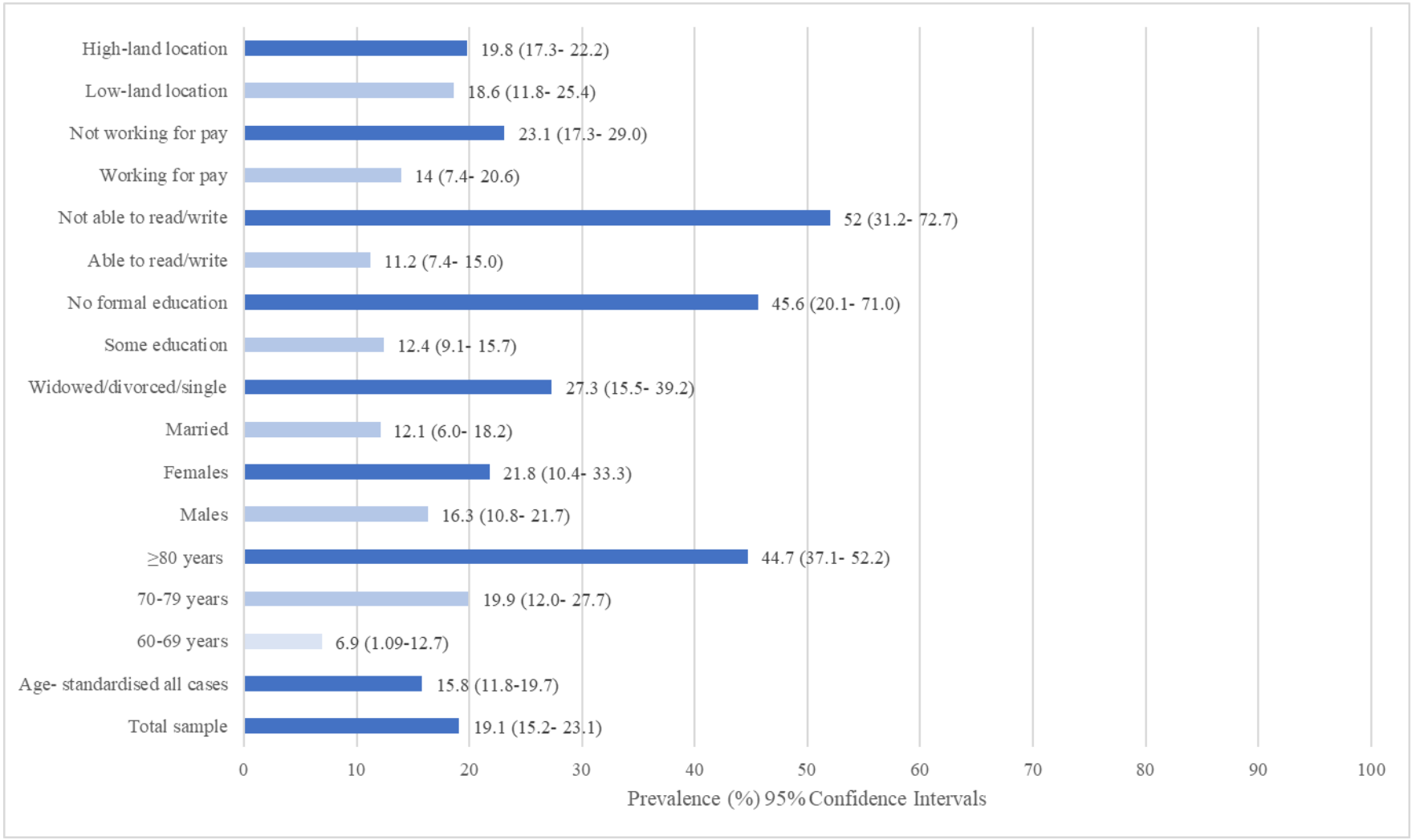


Table 4-2 presents the demographic characteristics for the frailty-weighted cohort (N=236) assessed by CGA, where 91 were deemed frail. A considerable proportion had received no schooling, and almost half were married. Despite the fact that not attending school was associated with frailty on univariable analysis, this effect was lost when all other variables were controlled for, with increasing age, being unable to read/write and not currently working for pay remaining significant, when adjusting for all other demographic variables in the table. This suggests that the increased crude odds of frailty in those without a formal education and in those not currently married, was largely confounded by increasing age. Those not currently married included those separated/divorced, single and widowed. It is possible that frailty itself has confounded the finding of a significant odds of frailty in those not working for pay, and in those unable to read/write. Not being in current employment in this context is likely to imply reduced functional capacity, and an inability to farm using manual means. Being unable to read/write irrespective of previous educational attainment is likely to be due frailty-associated impairments in vision, cognition, or manual dexterity, which may explain this finding.

Table 4-2 Demographic characteristics of the frailty-weighted cohort by CGA

	Not-frail N=145 (%)	Frail N=91 (%)	Crude OR (95% CI)	P value	Adjusted OR	P value
60-69	77 (53.1)	10 (10.9)	1.0	-	1.00	-
70-79	47 (32.4)	22 (24.1)	3.60 (1.50-8.50)	0.001	1.71 (0.59-4.96)	0.31
≥80	21 (14.4)	59 (64.8)	21.60 (7.40-62.90)	<0.0001	**7.52 (2.39-23.59)**	**<0.0001**
Men	65 (44.8)	33 (36.2)	1.0	-	1.0	-
Women	80 (55.1)	58 (63.7)	1.40 (0.83-2.45)	0.19	0.83 (0.32-2.17)	0.71
Married	84 (57.9)	28 (30.8)	1.0	-	1.0	-
Not currently married	61 (42.1)	63 (69.2)	3.09 (1.74-5.50)	<0.0001	1.57 (0.65-3.79)	0.30
Some education	118 (81.4)	47 (51.6)	1.0	-	1.0	-
No formal education	27 (18.6)	44 (48.4)	4.09 (2.20-7.60)	<0.0001	3.09 (0.39-24.36)	0.25
Able to read/write	117 (80.7)	40 (44.0)	1.0	-	1.0	-
Not able to read/write	28 (19.3)	51 (56.0)	5.32 (2.82-10.03)	<0.0001	**6.75 (1.25-36.33)**	**0.009**
Working for pay	54 (37.2)	11 (12.1)	1.0	-	1.0	-
Not working for pay	91 (62.8)	80 (87.9)	4.31 (2.04-9.08)	<0.0001	**2.90 (1.15-7.26)**	**0.017**
Low-land	63 (43.4)	27 (29.7)	1.0	-	1.0	-
High-land	82 (56.6)	64 (70.3)	1.82 (1.03-3.19)	0.035	1.77 (0.80-3.90)	0.15

4.3.1 Characteristics of frailty according to the CGA

In order to better characterise the social and economic factors of individuals living with frailty, the following table shows an investigation of key variables and their relationship with frailty according to CGA (*Table 4-3*). Data for N=234 were used (Non-frail n=144 and frail N=90), as taken from the FI database, illustrated in flow diagram (*Figure 4-2*).

Table 4-3 gives a view of frailty whereby older frail individuals were unable to attend social gatherings and church, felt restricted due to difficulties using transport, and were financially dependent on others. The financial impact of a frail older person on the household appears to be important, as there was a three-fold increased odds of a family member having given-up economically-productive work in order to care for a frail individual. Notably, older people living alone were in a minority, and there was no association with frailty. Having an interest in politics initially reduced the odds of frailty, yet this effect was lost after adjusting for age, sex and education. Feeling unsafe alone at home was also initially associated with frailty, but also confounded by the effects age, sex and education. Despite, not being associated with frailty it is important to note the low proportion of both frail and non-frail older adults who had health insurance coverage. Lower still were the number who had successfully used either their insurance or the exemption scheme in order to access healthcare within the previous year[9]. Those who were in receipt of a pension were very few, given that subsistence agriculture was the main source of income for the majority.

The adjusted odds of a Malnutrition Universal Screening Tool (MUST) score indicating “high risk of malnutrition” was raised two-fold in frail older adults. The MUST score, which is derived from low BMI, unintentional weight loss and recent acute illness, recommends dietician assessment for those at “high risk” of malnutrition (BAPEN, 2011). There is a theoretical underpinning for the role of chronic undernutrition in frailty (Fried et al., 2001), and these data suggest that in this context, malnutrition may be a contributory factor to frailty.

[9] According to government policy, adults aged ≥ 60 years should be exempt from paying user fees at government health facilities.

Table 4-3 Social and economic factors according to frailty status (CGA)

	Not-frail N=144 frequency (%)	Frail N=90 frequency (%)	Crude OR	P value	Adjusted OR (by age, sex and education)	P value
Lives alone	15 (10.49)	8 (8.99)	0.84 (0.34-2.08)	0.71		
Never attends religious services	10 (6.94)	66 (73.33)	36.85 (12.27-110.64)	<0.0001	21.98 (7.22-66.88)	**<0.0001**
Never attends social meetings	23 (15.97)	74 (82.22)	24.33 (9.61-61.56)	<0.0001	21.79 (7.17-66.19)	**<0.0001**
Interested/very interested in politics	49 (34.04)	18 (20.22)	0.49 (0.26-0.92)	0.002	0.63 (0.30-1.35)	0.23
Problems using transport	50 (34.72)	72 (80)	7.52 (3.76-15.02)	<0.0001	4.40 (2.15-9.01)	**<0.0001**
Difficulties with transport restrict life activities	42 (29.37)	67 (74.44)	7.00 (3.60-13.60)	<0.0001	4.39 (2.10-9.18)	**<0.0001**
Feels unsafe when alone at home	9 (6.25)	18 (20.22)	3.80 (1.59-9.09)	0.001	2.29 (0.80-6.58)	0.11
Health insurance coverage	41 (28.67)	19 (21.11)	0.66 (0.35-1.24)	0.19	0.71 (0.32-1.59)	0.41
In the past 12 months the participant;						
Paid for healthcare through an exemption or insurance scheme	25 (17.7)	13 (14.61)	0.79 (0.38-1.65)	0.53		
Received a pension	11 (7.64)	6 (6.67)	0.86 (0.30-2.42)	0.78		

	Not-frail N=144 frequency (%)	Frail N=90 frequency (%)	Crude OR	P value	Adjusted OR (by age, sex and education)	P value
Was financially dependent on others	33 (22.92)	70 (77.78)	11.77 (5.56-24.91)	<0.0001	5.72 (2.61-12.50)	**<0.0001**
In the past 12 months members of the participant's household;						
Reduced their paid employment to spend time caring for the older person	16 (11.11)	30 (33.33)	4.00 (1.97-8.11)	<0.0001	2.91 (1.24-6.81)	**0.009**
Stopped their paid employment to spend time caring for the older person	7 (4.86)	17 (18.89)	4.55 (1.76-11.79)	0.0006	3.29 (0.86-12.51)	**0.006**
The cost of healthcare for the older person has affected the ability to pay for other things like school fees	12 (8.33)	14 (15.56)	2.02 (0.88-4.63)	0.08		
Electricity in the home	68 (47.22)	37 (41.57)	0.79 (0.46-1.35)	0.40		
Wood or charcoal as cooking fuel (vs gas/kerosene)	133 (92.36)	88 (97.78)	3.63 (0.77-17.04)	0.07		
Agriculture the main source of income	110 (76.39)	71 (78.89)	1.15 (0.61-2.18)	0.65		
Participant's lifestyle factors						

	Not-frail N=144 frequency (%)	Frail N=90 frequency (%)	Crude OR	P value	Adjusted OR (by age, sex and education)	P value
Current alcohol intake	60 (41.67)	24 (16.67)	0.50 (0.28-0.90)	0.002	0.64 (0.29-1.42)	0.27
Current or former smoker	51 (35.43)	40 (44.44)	1.45 (0.84-2.50)	0.16	1.25 (0.54-2.84)	0.59
MUST malnutrition “high risk”	51 (35.42)	53 (58.89)	2.61 (1.49-4.56)	0.0005	**2.00 (1.02-3.90)**	**0.03**
BMI >20Kg/m^2	102 (70.83)	51 (56.67)	-		-	
BMI 18.5-20	15 (10.42)	21 (23.33)	2.80 (1.30-5.99)	0.005	2.38 (0.84-6.67)	0.08
BMI <18.5	27 (18.75)	18 (20)	1.33 (0.67-2.65)	0.41	1.09 (0.40-2.97)	0.85
Eats < 3 meals per day	45 (31.25)	26 (28.89)	0.89 (0.50-1.59)	0.70		

4.3.2 CGA Problem lists

To further illustrate the characteristics of frail and non-frail older adults, problem lists were formulated for each participant during their CGA, and a score given according to the CFS (Rockwood et al., 2005). Examples have been provided in *Table 4-4*. These illustrative problem lists highlight that even the least frail among the sample lacked access to primary healthcare for problems such as hypertension. As the level of frailty increased, increasing multimorbidity, financial issues and concerns about nutrition were recorded. The most severely frail were also the most disabled by conditions such as stroke and dementia. The qualitative results in the following chapter will return in more depth to the issues raised here, in order to more fully characterise the lived-experience of frailty in this context.

Table 4-4 Selected examples of problem lists formulated from the CGA

Clinical Frailty Scale score	**Total N=236 frequency (%)**	**Example problem lists for each category of the Clinical Frailty Scale**
1 Very Fit	*7 (2.9)*	*63 woman: Hypertension. Looks very robust- still farming every day. Fully independent with ADLs. Lives with husband and one grandchild who is 13 years old and attends school.* 1. Unable to afford to re-fill hypertension medications so poorly managed.
2 Well	*60 (25.4)*	*60 man: BPH with nocturia and occasional urinary incontinence, urgency. Right knee stiffness and bony swelling, likely osteoarthritis. He eats two meals per day and occasionally fruit. He skips lunch usually because he is working in the field, and he has noticed some unintentional weight loss although he does not appear underweight. He worries about providing for himself and his family* 1. Untreated symptomatic conditions 2. Poor near vision, although this does not impact on his daily routine as he does not regularly read 3. The main breadwinner for three grandchildren and his wife.
3 Managing well	*38 (16.1)*	*65 man: HIV positive, has regular check-ups but told he doesn't need medication yet. Not sure of current CD4 count, no frequent or opportunistic infections. Type 2 diabetes, diagnosed 6 years ago, initially on medication but stopped taking and changed to traditional medicines. Walked independently to clinic today (walks up to 1km). Does not work in the farm now but every day he is outside caring for cattle or chopping firewood. Lives with his second wife and two children.* 1. Likely poorly controlled diabetes 2. Visual impairment, likely secondary to diabetic retinopathy 3. Two falls in last year when tripped on stones at night when mobilising to toilet. 4. HIV positive, not on ARVs.

4 Vulnerable	*41 (17.3)*	*74 man: Prostatic symptoms, hypertension, arthritis of knees and hips. Welcoming, helped get chairs for us to sit.* 1. Significant symptoms of nocturia, urinary frequency and incontinence, likely undiagnosed BPH 2. Untreated hypertension 3. Malnutrition due to food insecurity and poverty. Counselled to try to increase dietary protein with milk and eggs. Unintentional weight loss, mostly eats once per day, thinks he is losing weight due to his prostate problem. 4. Gets tired and sleeps every afternoon after feeding the cows and farming a little.
5 Mildly frail	*23 (9.7)*	*94 man: BPH with previous indwelling catheter, long distance vision is impaired bilaterally, binge drinks alcohol when he can afford. Very cachexic and has to walk with a stick for long distances. Still farms every day but has help from a grandchild. Can't walk to go to church. Significant financial worries. Poor housing.* 1. Poor vision limiting daily activities and how far he can travel 2. Significant financial worries leading to malnutrition, poor housing and social isolation 3. Still only farming through necessity as little social support 4. Alcohol binges, looks very cachexic, only eats one meal per day because he cannot afford to eat more. No meat or fruit for the same reason.
6 Moderately frail	*35 (14.8)*	*72 woman: Arthritis, likely dementia. Son states the family have financial worries. They take their grandmother to the farm and she can use the farming tools and help a little, but the main reason is so that they can watch her.* 1. High risk of social isolation and worsening cognition because she is very rarely taken to social events, family don't see the value and it is difficult for them to accompany her. 2. Malnutrition, at risk of weight loss because she needs to be cooked for and prompted to eat. 3. Chronic pain in her joints, but has no health insurance.

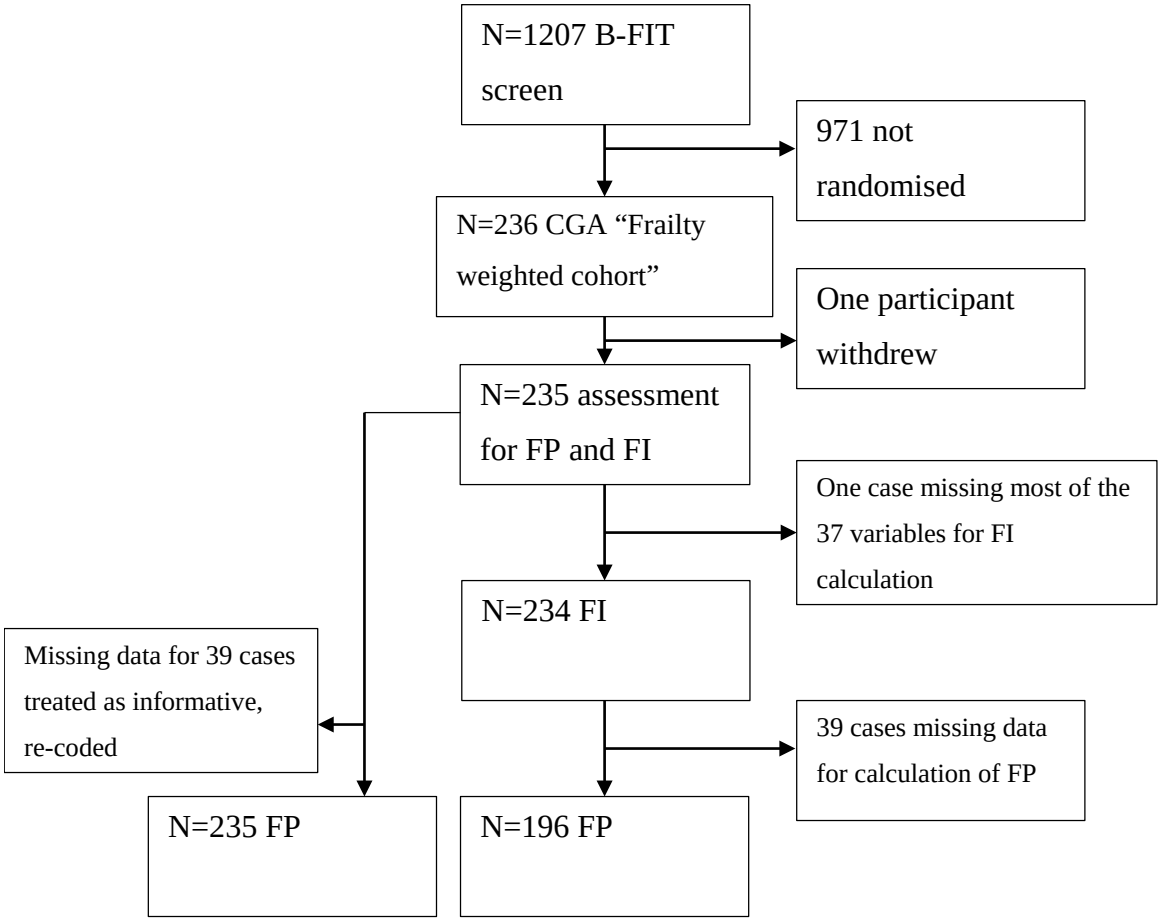
7 Severely frail	*25 (10.5)*	*79 woman: COPD, haemorrhoids, Fractured neck of femur two years ago following fall, but not operated, lipoma, urinary and faecal incontinence, probable bilateral cataracts. Son lives next door, with cognitive and psychological problems.* 1. All daily activities limited by shortness of breath from untreated COPD, poor mobility and ill-fitting crutches. 2. Depression and social isolation 3. Financial difficulties, cannot afford food, reliant on relatives and neighbours
8 Very severely frail	*7 (2.9)*	*89 man: Hypertension, asthma, stroke right hemiparesis, rheumatoid arthritis with hand deformities* 1. Looked after full time by an employed live-in care-giver. Denies pressure sores despite being bed-bound since January 2015 2. Has problems getting healthcare, due to lack of transport there 3. Immobile because of a stroke, sits or lies in bed, dependent for ADLs 4. Care-giver says has accepted his situation, doesn't cry, good appetite and sleep.

ADLs: Activities of Daily Living, ARVs: Anti-retroviral medications, BPH: Benign Prostatic Hypertrophy, COPD: Chronic Obstructive Pulmonary Disease, HIV: Human Immunodeficiency Virus

4.4 The prevalence of frailty by Frailty Phenotype

Following assessment by CGA and CFS, one participant withdrew from the study leaving a total frailty-weighted cohort of 235. *Figure 4-2* illustrates the numbers included for each stage of the analysis, and the reasons for data trimming where necessary. The CGA was the most inclusive assessment, given that it required no minimum level of physical functioning, compared with the FP, which required participants to be able to stand, walk, and follow instructions.

Figure 4-2 Flow diagram of sample size included at each stage of the analysis



4.4.1 Impact of missing data on estimated Frailty Phenotype prevalence

The prevalence of frailty by Hai District FP, calculated from complete data for 196 participants, was 9.09% (95% CI 4.22 to 13.95). However, the FP requires a certain minimum level of functioning in order to complete the assessments of walking speed and hand grip strength (HGS). The number of assessments where data for walking speed or HGS were missing were 37 and 18, respectively. Given the ability to cross-reference against CGA data, it was found that 11 of the 37 missing walking speed assessments were due to immobility following a stroke, suggesting that these data were not missing completely at random, and that

these missing data were informative. Overall, of the 39 participants missing data for calculation of their FP, 36 (92.3%) were deemed frail by CGA (Lewis et al., 2018b). The CGA-derived frailty diagnoses for participants with missing data have been included in Appendix M.

In secondary analyses, except for two erroneous walking speed recordings which were deleted, all other missing data were presumed missing due to being unable to complete the assessment (i.e. due to frailty rather than missing at random), and thus categorised as meeting the frailty criterion. When the Hai District FP was calculated using this approach (from N=235) the prevalence of frailty increased to 11.21% (95% CI 7.10 to 15.31). Below, the numbers of FP frail, and the weight-adjusted prevalence by each category are tabulated demonstrating that where data were missing and assumed to be informative (N=235), the prevalence of frailty was increased over all categories (*Table 4-5*).

Table 4-5 Frailty prevalence by FP stratified by age group and sex

	Frail by FP (N=196) and B-FIT	Percentage frail by FP (N=196) (95% CI)	Frail by FP (N=235) and B-FIT	Percentage frail by FP (N=235) (95% CI)
Total sample	6	9.09 (4.22-13.95)	30	11.21 (7.10-15.31)
Men	2	8.24 (3.16-13.31)	9	10.40 (5.98-14.81)
Women	4	10.15 (3.33-16.96)	21	11.90 (4.90-18.89)
60-69 years*	0	-	1	2.45 (-)
70-79 years	2	8.95 (-0.64-18.54)	8	10.46 (0.81-20.10)
≥80 years	4	28.41 (18.34-38.47)	21	32.67 (24.86-40.47)

*Unable to calculate due to very low numbers

4.4.2 Correlates of frailty by Frailty Phenotype

The mean walking speed was 0.65 m/s, (Standard deviation (SD) 0.40, range 0.04 to 4.29 m/s), 0.72 m/s in men and 0.60 m/s in women. The mean dominant HGS was 21.9Kg (SD 8.5, range 4.3 to 51.3), 18.92 Kg in women and 26.02 Kg in men. The mean BMI in women was 25.01 (SD 5.2, range 13.9 to 47.2), and in men was 21.21 (SD 5.5, range 13.4 to 53.3). *Table 4-6* reports the frequencies and percentages of each of the five FP components, and the frequencies and proportions meeting these criteria, stratified by sex. Around one third of participants had no FP components (n=63, 32.1%), while roughly one third had one FP component (n=67, 34.2%) and two participants fulfilled all five components of the FP criteria.

Table 4-6 The Hai District FP components by sex

Frequency (%) of frailty components	Total n= 196	Men n= 82	Women n=114
Exhaustion	82 (41.82)	32 (39.02)	50 (43.86)
Weight loss	53 (27.04)	23 (28.05)	30 (26.32)
Low physical activity	48 (24.49)	15 (18.29)	33 (28.95)
Slow walking	39 (19.90)	10 (12.20)	29 (25.44)
Weakness (HGS)	29 (14.80)	22 (26.83)	7 (6.14)
Number of frailty components			
0	63 (32.14)	31 (37.80)	32 (28.07)
1	67 (34.18)	23 (28.05)	44 (38.60)
2	32 (16.33)	15 (18.29)	17 (14.91)
3	18 (9.18)	4 (4.88)	14 (12.28)
4	14 (7.14)	8 (9.76)	6 (5.26)
5	2 (1.02)	1 (1.22)	1 (0.88)

4.4.3 Demographic and health characteristics by Hai District Frailty Phenotype

Frailty by Hai District FP was associated with chronic pain, poor or very poor self-assessed health and comorbidity (*Table 4-7*). Survey methods included routinely asking participants whether they had previously been diagnosed with any conditions from a list of common diagnoses, which included HIV-infection. Four individuals from 196 disclosed their HIV-infected status in this manner. Being assessed at home, rather than at a local centre was strongly associated with frailty. This finding is most likely due to their frailty/impaired mobility, but nevertheless seems congruent with the previous finding that frailty was associated with difficulties using transport. High numbers considered themselves to be ill (n=119, 60.7%), or living with frailty (n= 116, 59.1%). Depression symptoms, as reported by the EURO-D screening tool (Guerra et al., 2015), and cognitive impairment according to the IDEA cognitive screening tool (Paddick et al., 2015), were only significantly associated with frailty before adjustment. Around a fifth of participants were found to be underweight, according to BMI, while almost two fifths were either overweight or obese (*Table 4-7*), yet BMI was not found to be associated with frailty on univariate analysis.

Table 4-7 Health characteristics of the study sample according to Hai District FP

Health characteristic	Total sample N=196	FP non-frail N=63	FP pre-frail N=99	FP frail N=34	Crude OR FP frail	P value	Adjusted OR by age, sex and education	P value
Location where assessed								
Elsewhere (e.g. local health centre)	139	52 (82.54)	76 (76.77)	11 (32.35)				
Home	57	11 (17.46)	23 (23.23)	23 (67.65)	7.87 (3.25-19.04)	<0.0001	**5.32 (2.26-12.54)**	**<0.0001**
EURO-D score								
Depression symptoms ≤4/12	115	46 (73.0)	55 (55.5)	14 (41.1)				
Depression symptoms ≥5/12	81	17 (26.9)	44 (44.4)	20 (58.8)	2.36 (1.10-5.08)	0.02	2.12 (0.84-5.08)	0.08
IDEA cognitive test score								
8-12 (good cognitive function)	139	55 (87.3)	68 (68.6)	16 (47.0)	1.00			
5-7 (moderate cognitive function)	37	6 (9.5)	22 (22.2)	9 (26.4)	2.47 (0.97-6.24)	0.04	0.94 (0.34-2.58)	0.91
0-4 (poor cognitive function)	20	2 (3.1)	9 (9.0)	9 (26.4)	6.28 (2.14-18.48)	0.0001	3.32 (0.74-14.89)	0.09
Instrumental activities of daily living (IADL)								
≥1 IADL disability	60	8 (12.7)	24 (24.2)	28 (82.3)	18.95 (6.15-58.42)	<0.0001	**10.38 (3.35-32.16)**	**<0.0001**
"Do you consider yourself currently ill?"								

Health characteristic	Total sample N=196	FP non-frail N=63	FP pre-frail N=99	FP frail N=34	Crude OR FP frail	P value	Adjusted OR by age, sex and education	P value
No (not-ill)	77	46 (73.0)	30 (30.3)	1 (2.9)	1.00	-	1.00	-
Yes (Ill)	119	17 (26.9)	69 (69.7)	33 (97.0)	29.16 (3.40-249.61)	<0.0001	**26.16 (2.29-297.94)**	**0.0001**
"Do you consider yourself to be living with frailty currently?"								
No (not frail)	80	41 (65.0)	34 (34.3)	5 (14.7)	1.00	-	1.00	-
Yes (frail)	116	22 (34.9)	65 (65.6)	29 (85.2)	5.00 (1.78-14.02)	0.0007	2.81 (0.86-9.17)	0.07
Self-assessed health: "How is your health?"								
Good/Very good	42	24 (38.1)	16 (16.3)	2 (5.8)	1.00		1.00	
Neither good nor poor	99	35 (55.5)	51 (52.0)	13 (38.2)	3.02 (0.63-14.28)	0.14	2.96 (0.68-12.81)	0.12
Poor/ Very poor	54	4 (6.3)	31 (31.63)	19 (55.8)	10.85 (2.08-56.40)	0.0004	**6.11 (1.08-34.48)**	**0.01**
Overall in the past 30 days, how much of a problem did you have with bodily aches and pains?								
None	37	19 (30.2)	16 (16.2)	2 (5.9)	1.00			
Mild	45	21 (33.3)	20 (20.2)	4 (11.8)	1.32 (0.23-7.32)	0.74	1.70 (0.29-10.03)	0.54
Moderate	78	19 (30.2)	43 (43.4)	16 (47.1)				
Severe/Extreme	36	4 (6.3)	20 (20.2)	12 (35.3)	3.37 (0.83-13.56)	0.069	**5.69 (1.23-26.18)**	**0.01**
Self-reported medical diagnoses: "Have you ever been told you have a diagnosis of any of the following?"								
Diabetes	19	7 (11.1)	8 (8.0)	4 (11.7)	1.30 (0.40-4.22)	0.65	1.48 (0.43-4.99)	0.52
Hypertension	58	18 (31.03)	27 (46.55)	13 (22.41)	1.60 (0.73-3.50)	0.22	**2.56 (0.96-6.85)**	**0.005**
Cataracts	15	3 (4.7)	6 (6.12)	6 (17.6)	3.61 (1.17-11.18)	0.01	1.65 (0.53-5.13)	0.37
Stroke	8	1 (1.5)	3 (3.0)	4 (11.7)	5.23 (1.20-22.69)	0.01	**14.13 (1.48-134.29)**	**0.002**
Heart disease	11	4 (6.3)	4 (4.0)	3 (8.8)	1.86 (0.46-7.46)	0.37	1.36 (0.29-6.24)	0.68

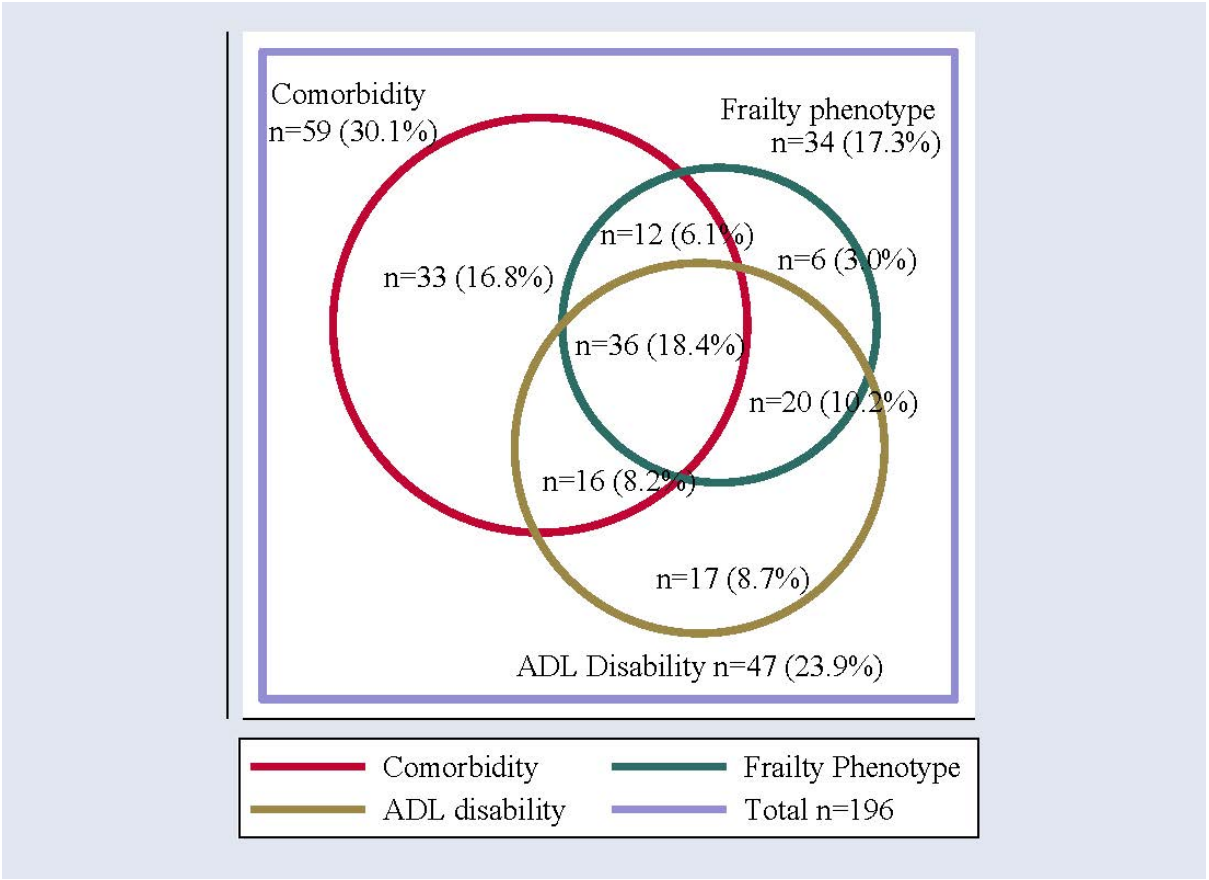
Health characteristic	Total sample N=196	FP non-frail N=63	FP pre-frail N=99	FP frail N=34	Crude OR FP frail	P value	Adjusted OR by age, sex and education	P value
Arthritis	44	7 (11.1)	24 (24.4)	13 (38.2)	2.59 (1.15-5.83)	0.01	**2.59 (0.98-6.85)**	**0.045**
Depression	12	2 (3.1)	8 (8.0)	2 (5.8)	0.95 (0.19-4.56)	0.94	1.30 (0.20-8.11)	0.77
Respiratory condition	13	4 (6.3)	6 (6.0)	3 (8.8)	1.47 (0.38-5.68)	0.57	1.11 (0.23-5.39)	0.89
Number of self-reported chronic diseases*								
0	70	27 (42.8)	40 (40.4)	3 (8.8)	1.00			
1	67	24 (38.1)	30 (30.3)	13 (38.2)	5.37 (1.39-20.70)	0.0061	**6.20 (1.78-21.61)**	**0.001**
≥2	59	12 (19.0)	29 (29.2)	18 (52.9)	9.80 (2.47-38.84)	0.0001	**17.20 (2.21-133.89)**	**0.0002**
High blood pressure (measured)	107	32 (50.8)	50 (50.5)	25 (73.5)	2.71 (1.17-6.25)	0.015	2.46 (0.93-6.44)	0.058
BMI kg/m^2 (2 values missing)								
Normal weight (18.5-24.99)	79	21 (33.3)	41 (41.8)	17 (51.5)	1.00		1.00	
Underweight (<18.49)	40	11 (17.4)	24 (24.4)	5 (15.1)	0.52 (0.17-1.55)	0.23	0.52 (0.13-2.07)	0.35
Overweight (25.00-29.99)	54	22 (34.9)	24 (24.4)	8 (24.2)	0.63 (0.25-1.60)	0.33	0.64 (0.21-1.96)	0.43
Obese (≥30.00)	21	9 (14.2)	9 (9.1)	3 (9.0)	0.60 (0.15-2.33)	0.46	0.80 (0.10-5.87)	0.82

P values in bold were significant (significance level α= 0.05). *The number of chronic diseases was derived from self-reported diagnoses of any of the following; (diabetes, hypertension, stroke, cataracts, arthritis, heart disease, respiratory disease, HIV, TB, anaemia, depression, dementia, other mental health conditions, gastro-intestinal conditions, prostatic/urinary conditions, renal failure, or cancer).

4.5 The overlap between frailty, disability and comorbidity

Frailty, ADL disability and comorbidity were found to be distinct, but overlapping entities. The frequencies and percentages are shown in *Figure 4-3*. Notably, almost a fifth overlapped in having all three (n=36, 18.4%). Twenty (10.2%) overlapped in having both disability and frailty, while 12 (6.1%) overlapped in having dual diagnoses of comorbidity (≥2 diseases) and frailty.

Figure 4-3 The overlap between frailty by FP, ADL disability, and comorbidity



4.6 The characteristics of the Frailty Index

The FI analysis included data for N=234 participants from the frailty-weighted cohort (*Figure 4-2*). The response frequencies for each of the 37 variables included in the FI have been included in Appendix N. Missing data could be assumed missing completely at random, therefore an expectation maximisation (EM) approach to data imputation was taken (Little's MCAR test Chi 2=415.527, DF=386, Sig=.144.)

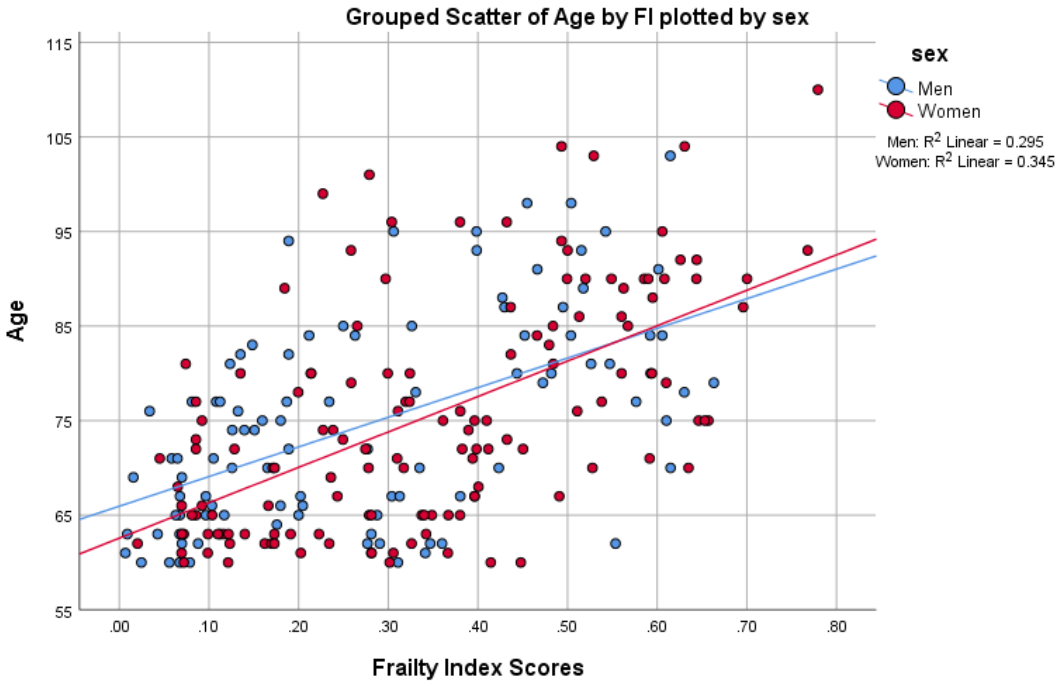
Descriptive statistics for the 37-variable FI produced after EM imputation were: Median 0.30, IQR 0.34, range 0.01-0.78. When ROC analysis was conducted using CGA-diagnosed frailty as the diagnostic standard, and the co-ordinates of the curve were used to assess the most

accurate cut-off point for detecting frailty. The highest accuracy for detecting frailty was a FI score=0.385 (sensitivity =0.81, specificity =0.91, and accuracy =0.72).

4.6.1 The correlation between Frailty Index scores and demographic characteristics

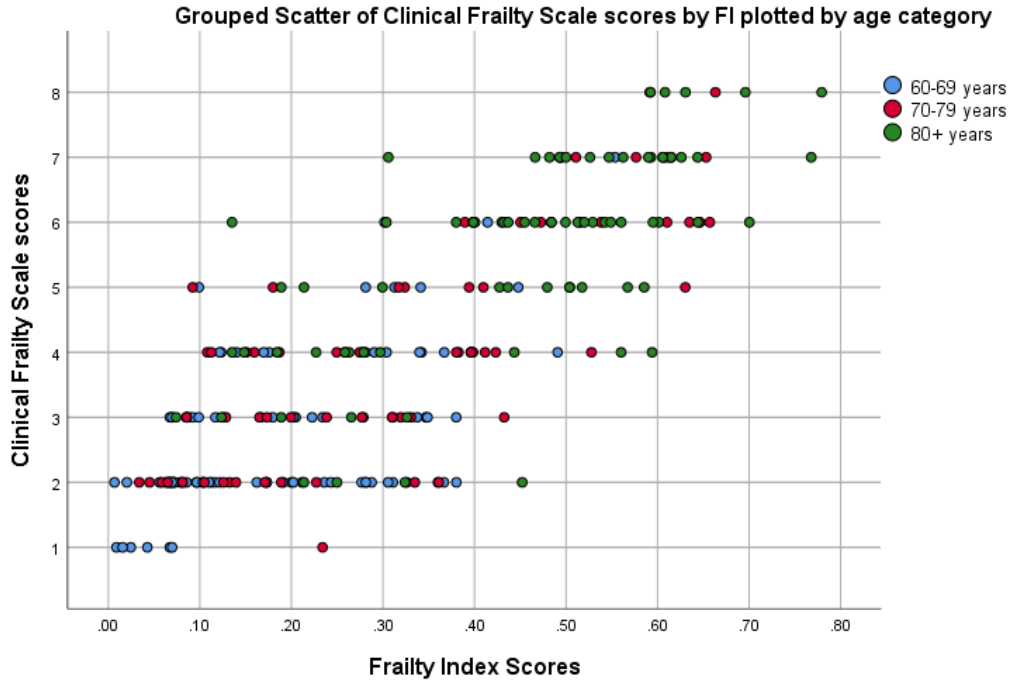
Mann-Whitney U testing demonstrated a significant difference by sex in the mean rank FI scores (Mann-Whitney U 5290.00, p value= 0.006). When investigating the association between sex and FI through binary logistic regression however, female sex non-significantly increased the odds of frailty according to FI (using the accuracy cut-off), when controlling for age and education status (OR 1.73, 95% CI 0.86 to 3.50, p=0.123). The scatter plots below illustrate the correlation between FI and age, by sex, and education status. The R^2 linear shows a stronger correlation between age and frailty in women as compared with men (*Figure 4-4*).

Figure 4-4 FI scores plotted against age by sex



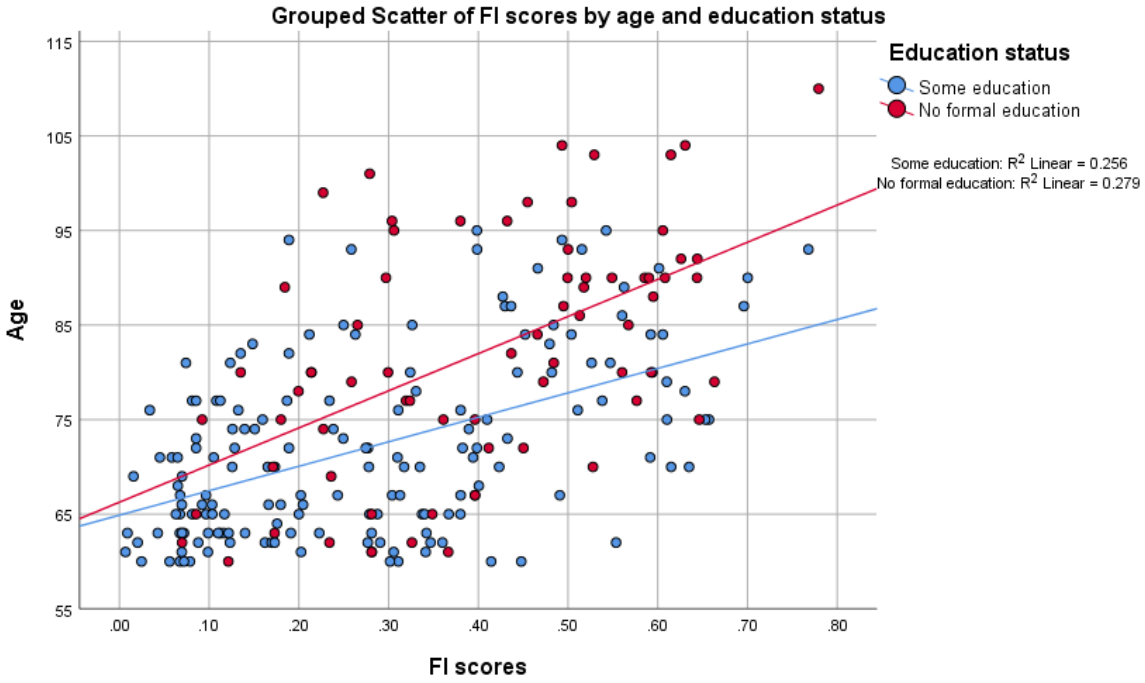
The FI was also strongly correlated with the CFS scores produced at CGA assessment with an R^2 Linear= 0.639. The distribution of CFS scores and FI scores have been visually represented (*Figure 4-5*) where the extremes of fitness (CFS score=1 “very fit”) and frailty (CFS score=8 “very severely frail”) are represented predominantly in the youngest and oldest age categories respectively.

Figure 4-5 FI scores plotted against CFS scores by age category



The following scatter plot (*Figure 4-6*) illustrates the stronger correlation between frailty by FI and individuals without a formal education. The strength of this relationship (R^2 Linear 0.279), is lost when binary logistic regression is employed for the odds of frailty by FI (when adjusting for age, sex and education status), and increasing age was the only significant variable; 70-79 years, OR 6.11 (95% CI 2.42 to 15.44, p<0.0001), ≥80 years OR 24.80 (9.62 to 63.95, p<0.0001), suggesting that increasing age confounds this relationship between education status and frailty.

Figure 4-6 FI scores plotted against age by education status



4.7 The prevalence of frailty by Frailty Index

The FI was transformed into a binary outcome variable based on the highest accuracy cut-off of 0.38, and was also re-coded into quartiles using the 99th centile as the upper limit, as per the methods of Clegg et al. (2016). This produced four categories; "fit" (lowest score to FI 0.1362), "mild frailty" (FI 0.1363 to 0.3005), "moderate frailty" (FI 0.3006 to 0.4709) and "severe frailty" (FI 0.4710 to highest). A FI cut-off of 0.2 or 0.25 has commonly been used to define frailty in the literature (Song et al., 2010), therefore a binary cut-off at 0.249 was produced. The prevalence of frailty according to the FI was calculated by sex, age-group, marital and education status (*Figure 4-8*). The prevalence was also estimated for the four categories formed from the FI (fit, mildly frail, moderately frail and severely frail), adjusting for frailty-weighting (*Figure 4-7*). The number of cases categorised as frail by FI, and by each B-FIT category is shown in Appendix O.

Figure 4-7 The prevalence of frailty by FI quartiles

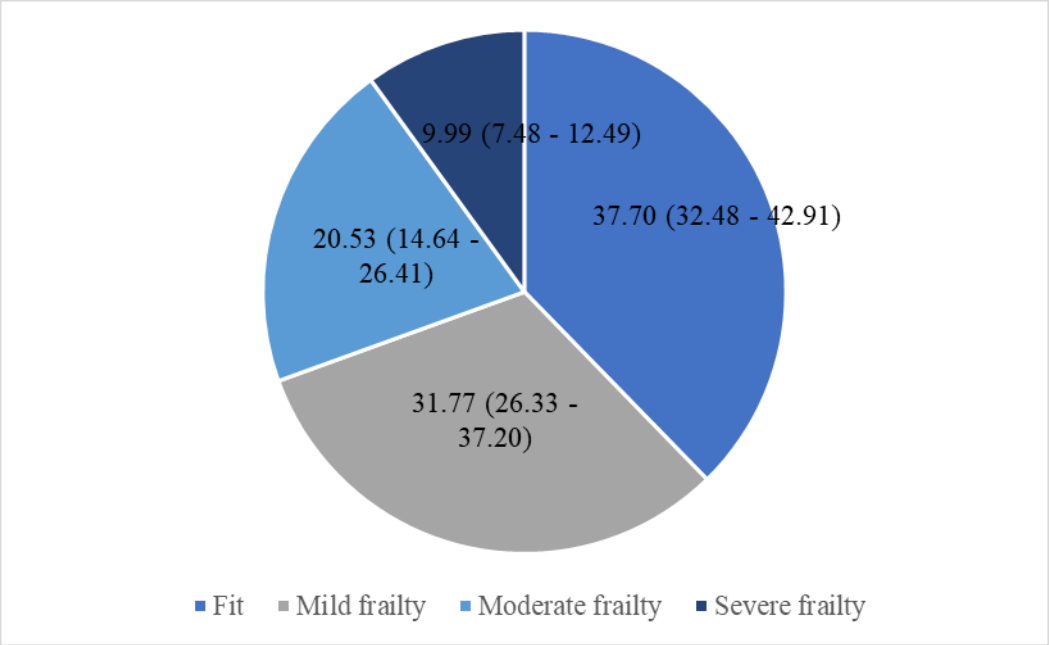
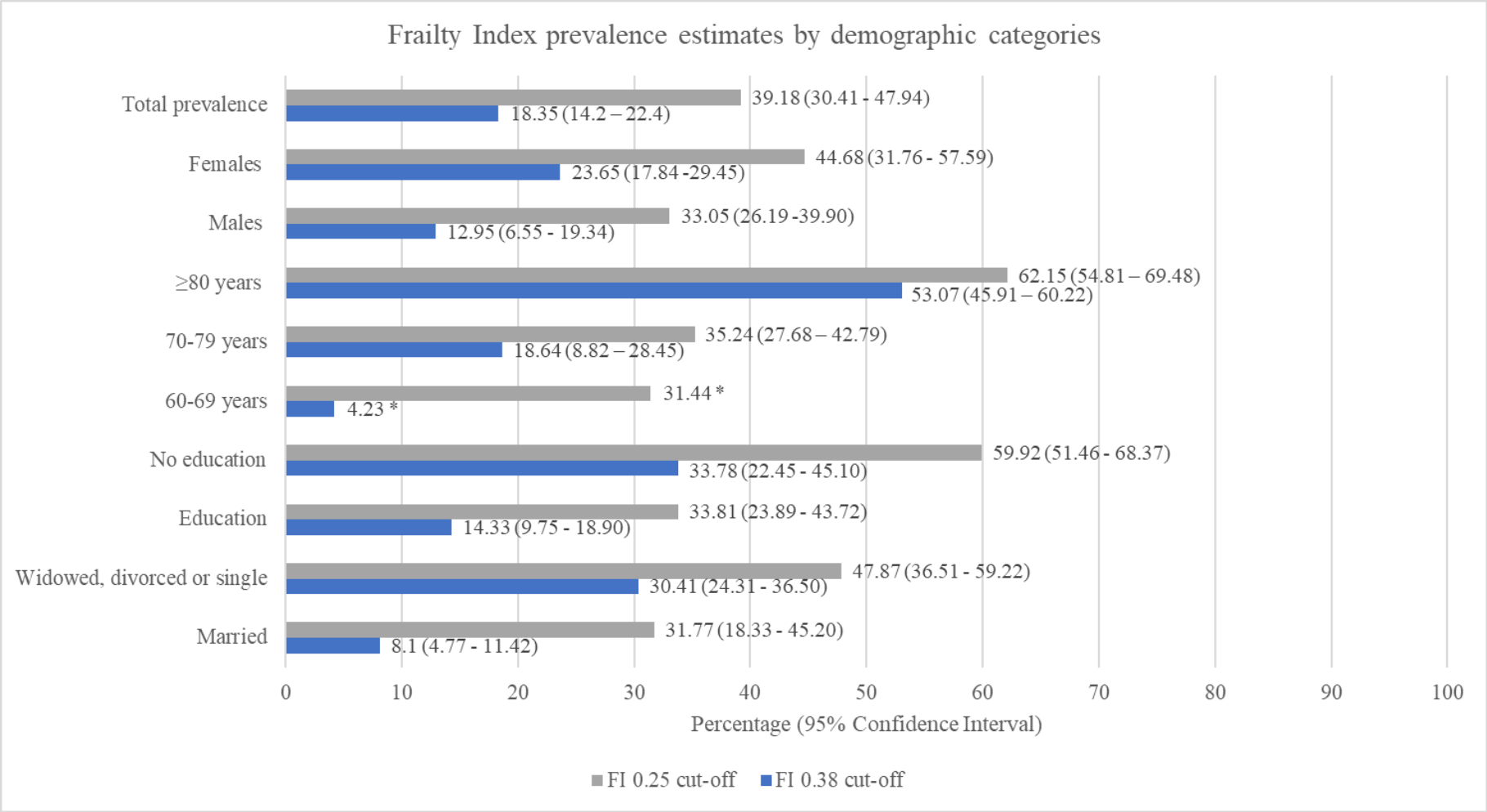


Figure 4-7 demonstrates that when the FI was categorised by quartile, and adjusted for frailty-weighting, the majority (almost 40%) could be considered "fit", and 9.9% considered severely frail, a similar prevalence to that estimated by FP (Section 4.4). However, the degree to which the two measures identified the same individuals as frail is illustrated in the next section (*Figure 4-14*).

Figure 4-8 FI prevalence estimates by demographic categories



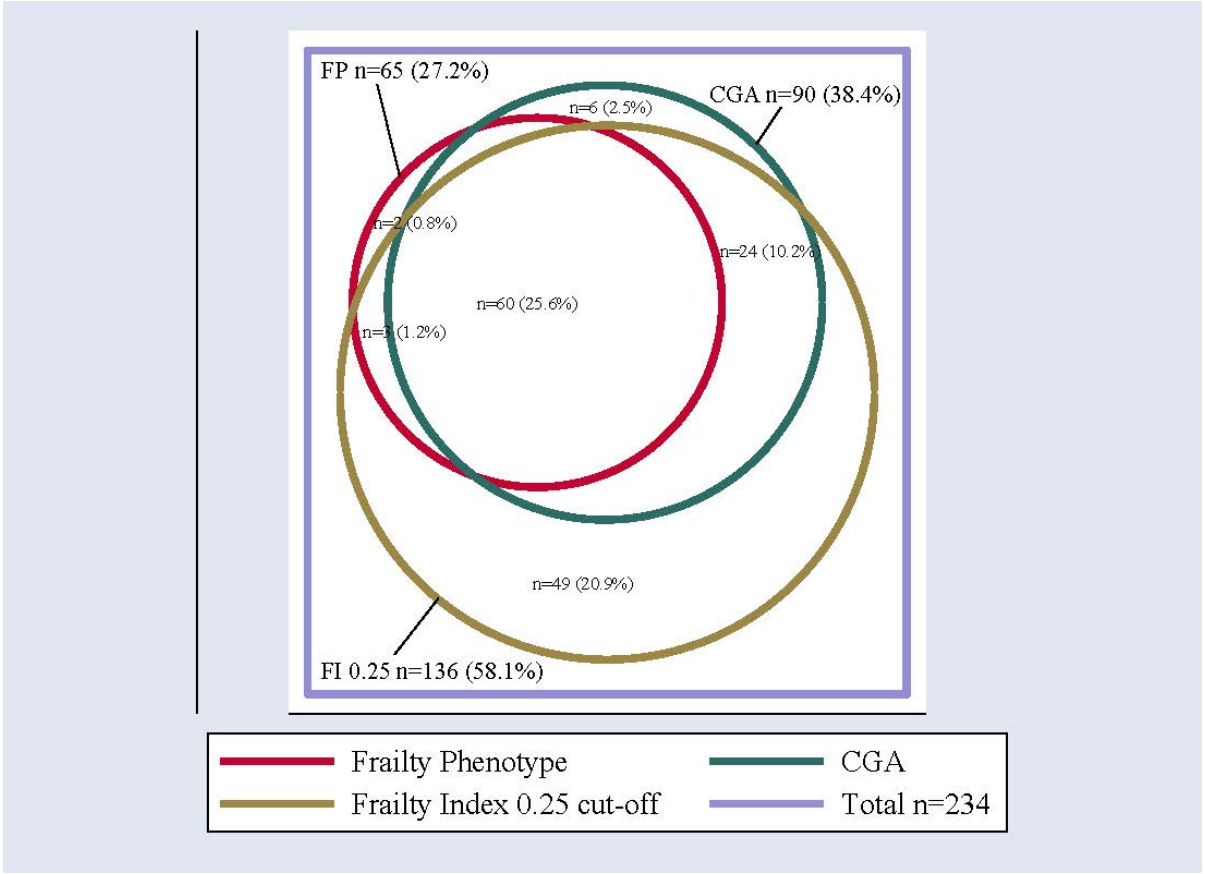
*Unable to calculate standard error because of stratum with single sampling unit.

The proportions identified as frail were highest in women, in older age categories, and in those who were widowed, divorced/separated or single and without a formal education. These patterns were seen across both cut-off points, however the higher accuracy (0.38) cut-off point produced prevalence estimates closer to that of the CGA.

4.8 Comparison of the operational frailty measurements

In order to compare the relationships between each frailty operationalisation visually, proportional Venn diagrams were produced. Frailty according to the FI (by each cut-off), CGA, FP, and B-FIT have been plotted below in proportioned and positioned 3-circle Venn diagrams, surrounded by a rectangle which proportionally represents the total population size (N=234). The largest sample size possible was used, so the secondary analysis FP data were included. If the CGA diagnosis of frailty is taken as the “gold standard” against which the others are to be measured, then the FI 0.38 cut-off and CGA converged the most (unsurprisingly, given that the cut-off point was derived from the CGA through ROC analysis).

Figure 4-9 The overlap between frailty by CGA, FP and FI (0.25 cut-off)



This Venn diagram (*Figure 4-9*) illustrates that the FI with a lower cut-off for frailty, (0.25) identified 49 additional cases as frail, compared with those identified as frail by CGA and FP. There were 90 individuals (38.4%) from the total N=234 who were not categorised as frail by any of the operationalised models.

Figure 4-10 The overlap between frailty by CGA, FP and FI (0.38 cut-off)

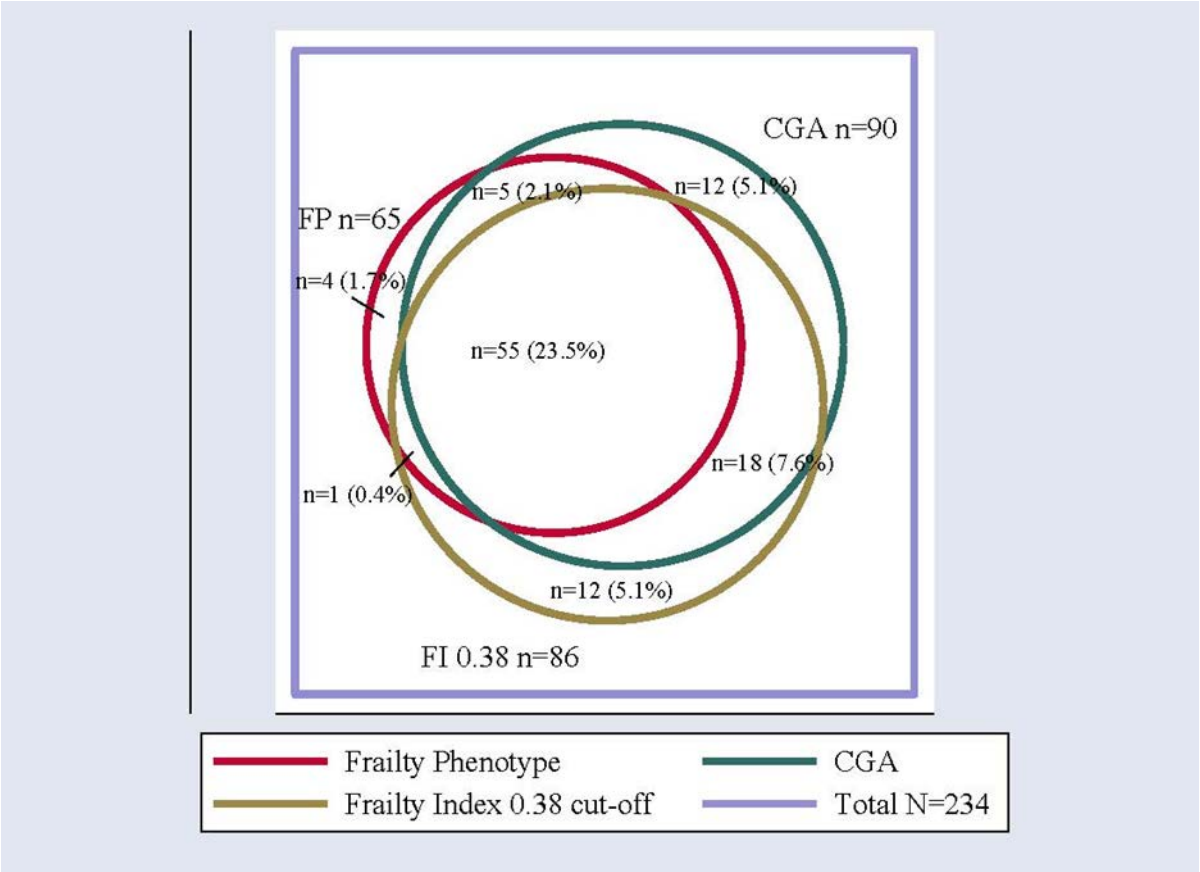


Figure 4-10 shows that although the proportion of complete overlap between frailty methods is slightly reduced (23.5%) compared with the previous 25.6% overlap across all methods, the FI using the 0.38 cut-off is more specific, with only 12 individuals identified by the FI as frail who were not identified as frail by the CGA or FP. Using this more specific FI cut-off meant that 127 individuals (54.2%) were not categorised as frail according to any method.

Figure 4-11 The overlap between frailty by FP, CGA and FI "fit"

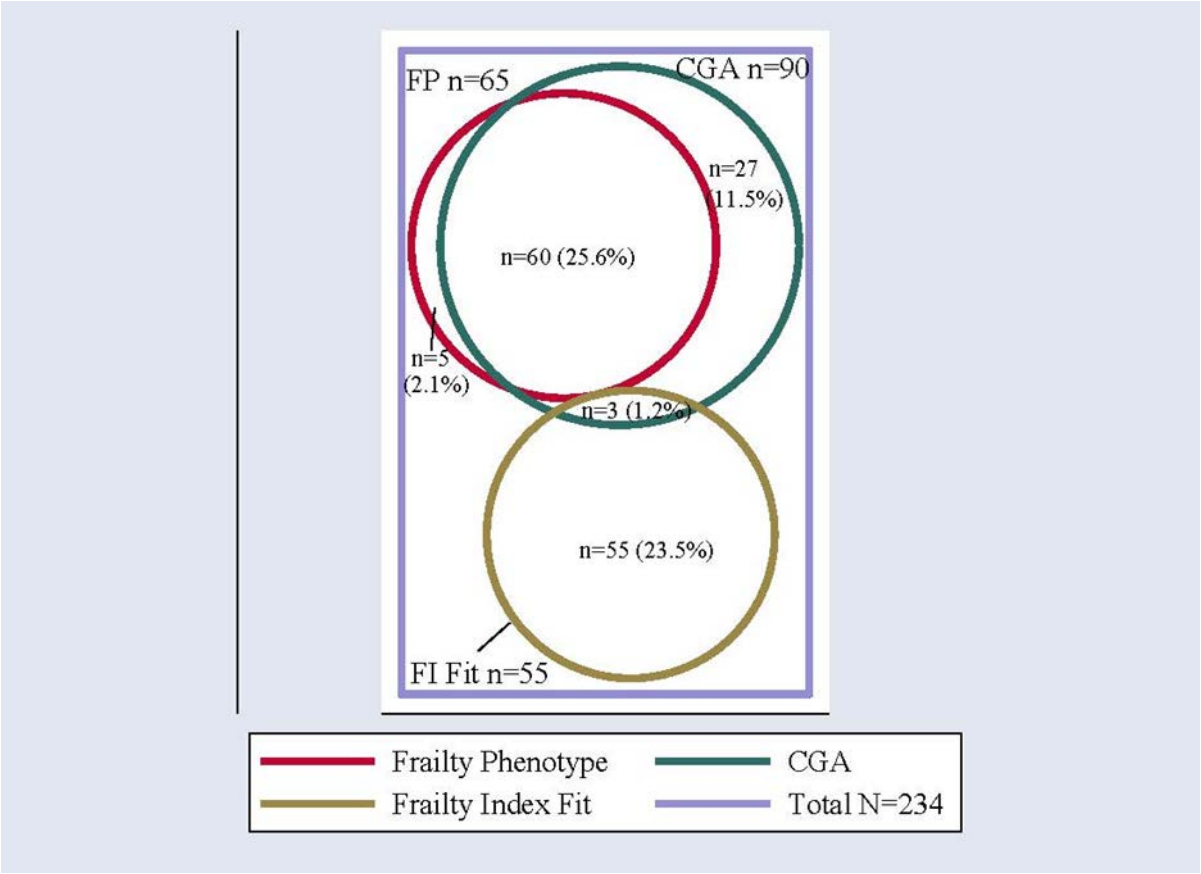
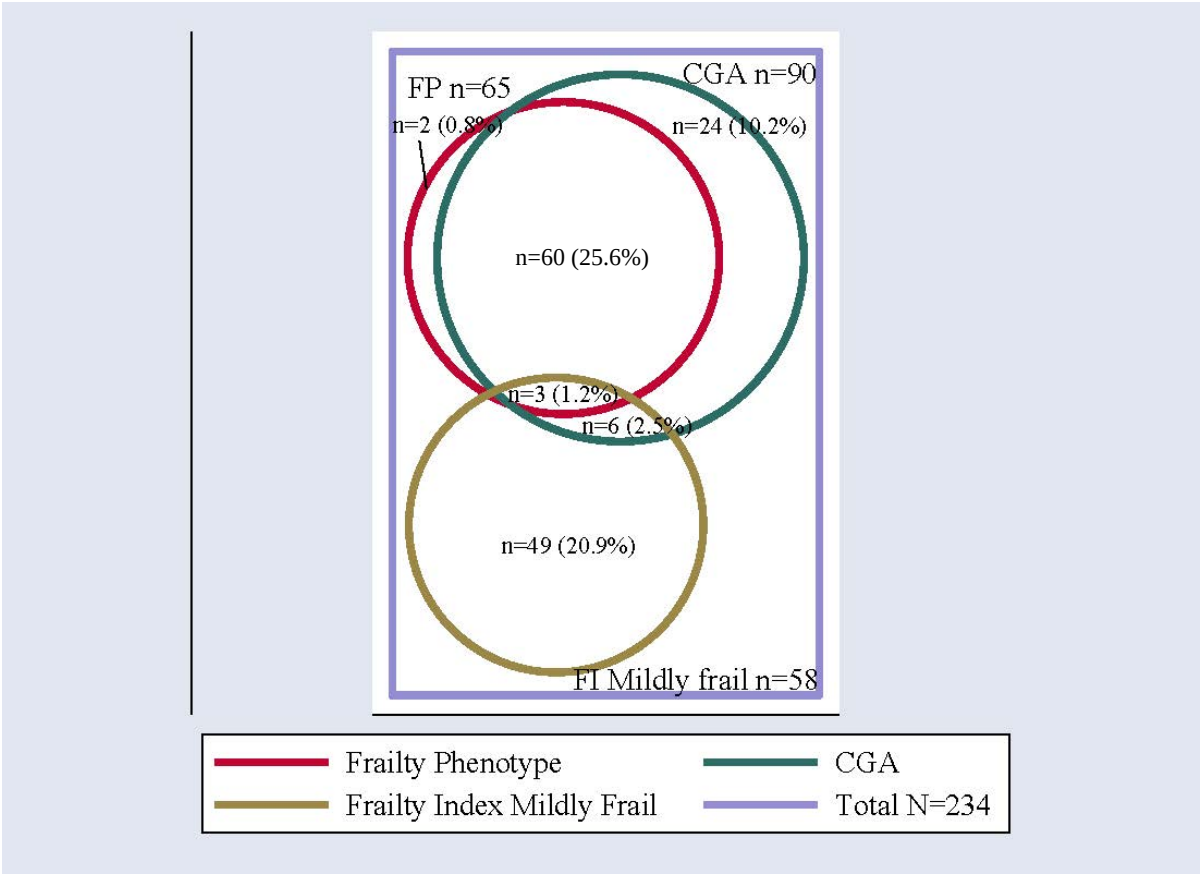


Figure 4-11 shows an overlap of only three individuals who were deemed frail by CGA but were categorised as "fit" based on their low FI scores. This suggests that in a minority of individuals, the CGA's ability to take into account social, economic and psychological factors allowed individuals to be categorised frail despite having a low FI score, and not meeting the physical FP criteria. This illustrates the unique benefits of the CGA, and limits of the FI as a model, despite its multi-component approach.

Figure 4-12 The overlap between frailty by FP, CGA and FI "mild frailty"



When the FI was categorised by quartiles, there was only an overlap of 9 individuals who were deemed "mildly frail", and who were also categorised frail according to the FP or CGA. No cases overlapped across all three methods, highlighting that the different underlying theoretical models may lead to identifying different individuals with different manifestations of frailty.

Figure 4-13 The overlap between frailty by FP, CGA and FI "moderate frailty"

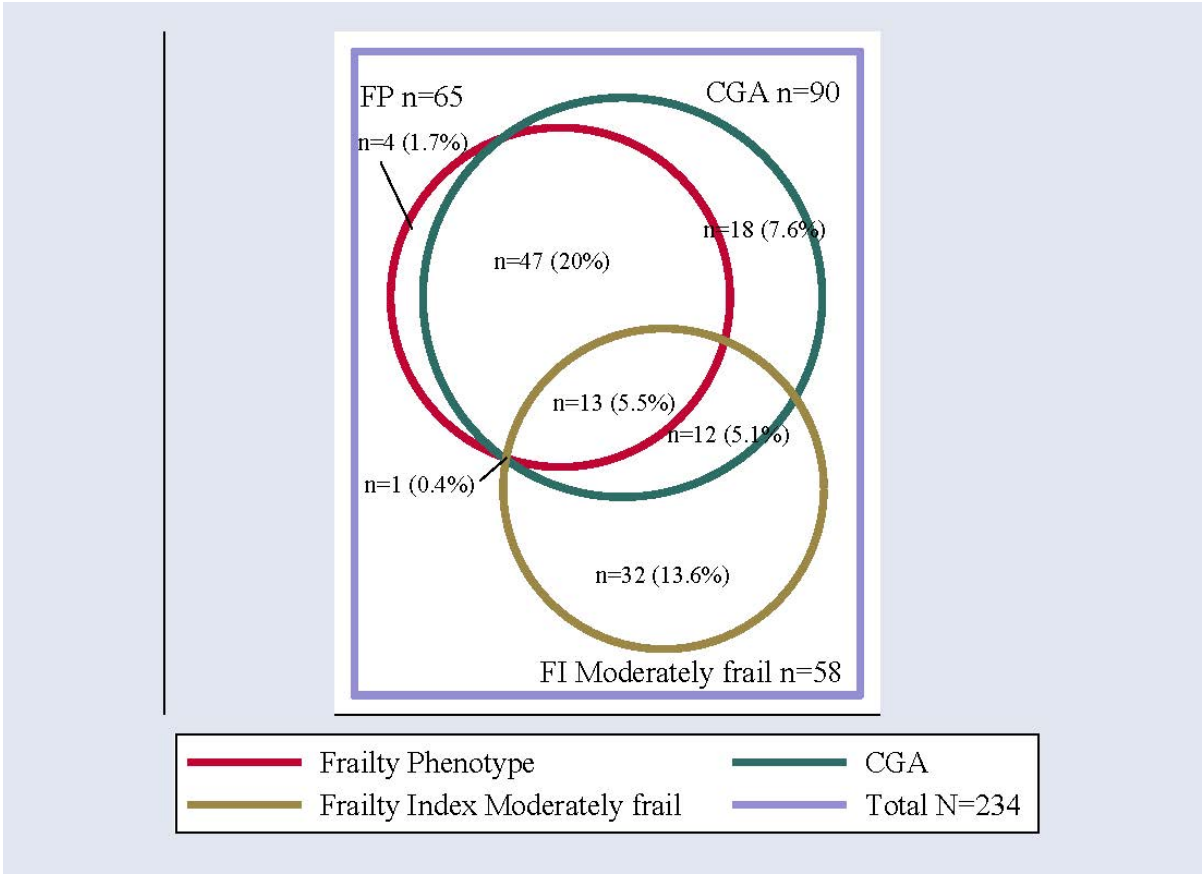


Figure 4-13 shows that those categorised as "moderately frail" now start to overlap across all three models (5.5%). Yet, there are a considerable proportion (13.6%), that despite being categorised "moderately frail" based on their FI scores, were undiagnosed by either the FP or CGA.

Figure 4-14 The overlap between frailty by FP, CGA and FI "severe frailty"

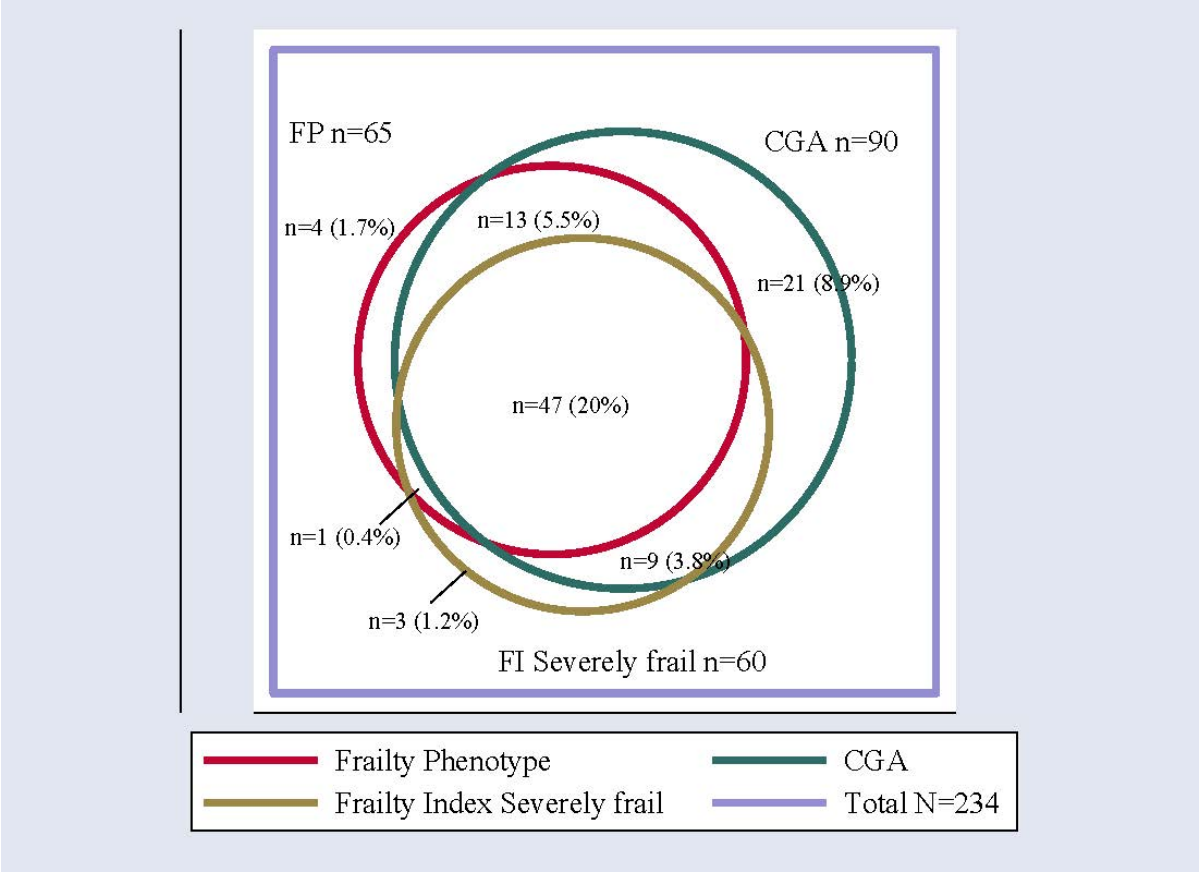
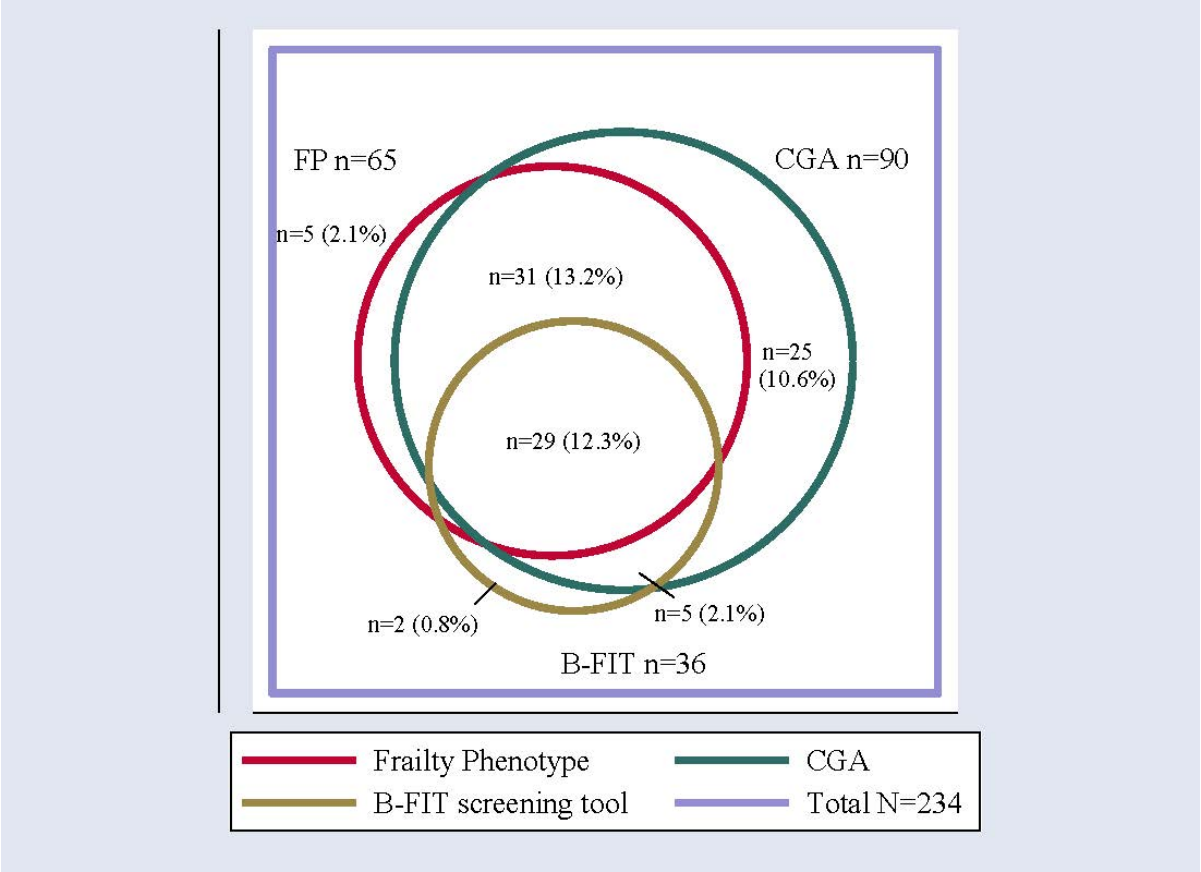


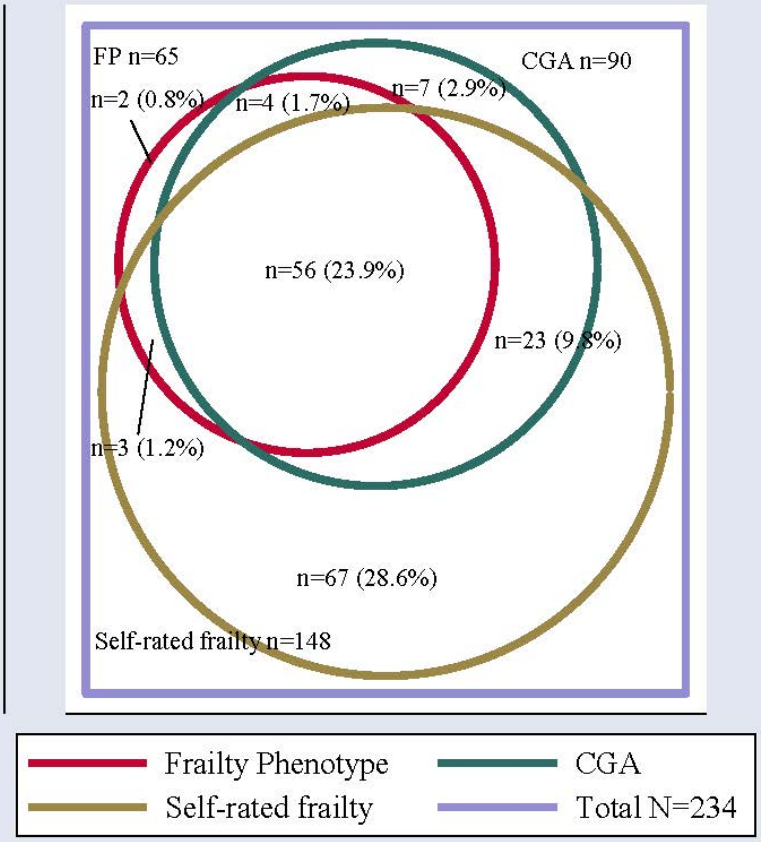
Figure 4-14 illustrates the convergence of all three methods of frailty identification, now with only three individuals deemed "severely frail" according to their FI scores but not categorised as frail by either of the other methods. This diagram is similar to the overlaying of the FI 0.38 cut-off (*Figure 4-10*), although that produced a higher concordance of 23.5% across all three models, compared to the 20% agreement in this Venn diagram.

Figure 4-15 The overlap between frailty by B-FIT, FP and CGA



This Venn diagram highlights that the B-FIT screening tool was highly specific for frailty, overlapping the most with the FP. This may be due to the fact that both measurements focus on physical components of frailty. The B-FIT incudes an assessment of ADL functioning (the Barthel Index), similarly, the FP includes measures of immobility, weakness and reduced activity. A formal assessment of the diagnostic accuracy and validity of the B-FIT screening tool is outwith the aims of this thesis, yet this diagram suggests that when compared with the "gold standard" CGA, the B-FIT screen was sensitive but too specific.

Figure 4-16 The overlap between frailty by FP, CGA and frailty by self-report



When participants were asked "do you consider yourself to be living with frailty?", a large proportion, (n=148) answered "yes". This was equivalent to a prevalence of 45.42% (95% CI 38.2 to 52.5) adjusting for the frailty-weighted cohort. This seems to over-estimate the prevalence of frailty when compared with the "gold standard" CGA, given that this question identified 67 individuals (28.6%) who were deemed frail neither by CGA nor FP (*Figure 4-16*). The pattern is similar to that of the FI 0.25 cut-off, which also produced an estimate of frailty that identified 49 individuals (20.9%) that did not overlap with the other methods (*Figure 4-9*).

4.9 Summary of findings

This chapter has reported results previously published elsewhere, including the first and only published study of frailty prevalence in rural SSA using the CGA (Lewis et al., 2018b), and the second study employing the FP (Lewis et al., 2018a). These results show that frailty prevalence varies markedly depending on the theoretical model used, as well as its operationalisation. We have also confirmed the finding that different individuals within a population are identified as frail when the different operational measures of frailty are employed (Cigolle et al., 2009). In this study, the prevalence of frailty in the population

ranged from 9.09% (95% CI 4.22 to 13.95) when measured by Hai District FP calculated from complete data for N=196, to a prevalence of 39.18% (95% CI 30.41 to 47.94) when the 0.25 cut-off point was applied to the FI. This variation within the same study population can be attributed to the difference between the methods used, and their underlying conceptualisation of frailty as either a multidimensional entity of increased vulnerability (as measured by the FI and CGA), or a physical syndrome underpinned by physiological ageing-related processes such as sarcopenia (typified by the FP). Across all measures of frailty used here, the prevalence increased with age and was higher in women compared with men. This finding of increased frailty, despite a higher mean life expectancy in women is termed "the male-female health-survival paradox" and is consistent with previous findings in both high and low and middle income countries (LMICs) (Harttgen et al., 2013, Gordon et al., 2017). This concept will be returned to in more depth in section 8.13 of the Discussion Chapter.

4.9.1 The Comprehensive Geriatric Assessment

Among LMICs outside of SSA, the use of CGA assessment in the published literature is rare, with a recent review identifying a small Iranian study which used a CGA comprising of ten domains to produce a FI (Teymoori et al., 2009), and a Romanian study which used general practitioners' assessments as a criterion standard for frailty (Olaroiu et al., 2014). The attributes of the CGA, (particularly its requirement for multidisciplinary expertise) means that there are very few large-scale community epidemiological studies which have used it, although crossover occurs where studies have used multi-domain CGA data to produce a FI in order to estimate community prevalence of frailty, for example in the China Comprehensive Geriatric Assessment Study (Ma et al., 2018). This crossover highlights the close conceptual relationship between these two measures of frailty. This Chinese study was the largest epidemiological study in a LMIC setting to nominally employ the CGA. However, in practice this was a survey administered door-to-door by trained assessors, and was used to develop a 68-item FI (Ma et al., 2017). Their estimated frailty prevalence of 9.9%, based on a cut-off score of 0.25 for adults aged ≥60 years, is considerably lower than was found in the present study using the 0.25 FI cut-off (Ma et al., 2018). However, prevalence was significantly higher in rural compared with urban-dwelling adults; estimated at 12.9%, which comes closer to this thesis's 15.8% age-standardised estimate by CGA.

4.9.2 The Frailty Phenotype

According to the current study, the prevalence of frailty according to the FP was between 9.09% (95% CI 4.22 to 13.95) and 11.21% (7.10 to 15.31), depending on data trimming and imputation methods. This is consistent with the weighted average prevalence of frailty by FP,

which was 9.9% (95% CI 9.6 to 10.2) calculated from 15 studies for a sample of 44,894 participants (Collard et al., 2012). All of these studies were from high-income country (HIC) settings however and the prevalence by FP varied widely from 4.0% to 17.0%. This variation was even wider in studies from LMICs ranging from a prevalence of 5.2% in a small study of older care-givers in urban Brazil, to a prevalence of 39.2% in urban Mexico (Gray WK, 2016). Very few studies have reported the prevalence of frailty by FP in rural community-dwellers, however one study of 1,878 older Columbians living in the Andes Mountains found that 12.2% could be classified as frail by FP (Curcio et al., 2014).

The present study has contributed the second known study of frailty according to the FP conducted in SSA (Lewis et al., 2018a), the first being a study from Agincourt, rural South Africa (Payne et al., 2017). Despite being a study based in rural SSA, key population characteristics limit the ability for comparison, these being that the South African study was a younger adult population (aged ≥40 years with a mean age 61.7), and with a high proportion of HIV-infected individuals (21%) (Payne et al., 2017). Nevertheless, these authors found a prevalence of frailty ranging between 3.0 and 13.2% depending on their operationalisation of the FP criteria, which is consistent with the present study's findings (Payne et al., 2017). Interestingly, participants who were unable to complete part of the FP assessment were shown to have a higher hazard ratio for death (published in supplementary data). This adds weight to the assumption that data missing from FP assessments in this thesis were most likely missing due to more severe frailty and not missing at random. This thesis has also corroborated Fried's finding that the FP is distinct, and overlapping with ADL disability and comorbidity (*Figure 4-3*) (Fried et al., 2001).

4.9.3 The Frailty Index

The FI produced in this study, yielded a Median 0.30, IQR 0.34, range 0.01-0.78. However due to the frailty-weighting of our cohort these statistics will have been artificially elevated making direct comparison with other studies more difficult. The frailty prevalence according to FI followed the same patterns as have been found when the FI was used in LMICs including in Ghana and South Africa (Harttgen et al., 2013), these being that the prevalence of frailty increased with age, was higher in women, and was higher in those with lower educational attainment. The community prevalence of frailty by FI varies considerably based on population characteristics (e.g. age distribution), and the cut-off points used to define frailty. In a systematic review of frailty in LMICs, 20 studies used the FI to define frailty with a prevalence ranging from 11.6% to 27.8% (Gray WK, 2016). The present study found the community prevalence of frailty by FI ranged from 9.99% (7.48 to 12.49), when the highest

quartile of FI scores were categorised as “severe frailty”, to 39.18% (30.41 to 47.94) when the FI cut-off point of 0.25 was used. These prevalence estimations are therefore within the expected range for LMICs. Indeed, for adults aged ≥50 years using a 40-item FI with a cut-off point of 0.2, the prevalence of frailty was reported as 38.0% (95% CI 34.9 to 41.0) in South Africa, and 37.9% (95% CI 35.2 to 40.4) in Ghana (Biritwum et al., 2016).

When comparing these results with that of HICs a systematic review found a frailty prevalence varying between 4.2% and 59.1% (Collard et al., 2012), with a weighted average prevalence of frailty of 13.6% (95% CI 13.2 to 14.0) for broad multidimensional measures of frailty such as the FI (Collard et al., 2012). However, although this estimate took into account eight studies, with a total of 24,072 participants, only one study had reported the prevalence of frailty strictly according to the FI. For comparison, in a study of community-dwelling adults aged ≥65 years in Canada the community prevalence of frailty was 22.7% (95% CI 21.0 to 24.4%) using a cut-off point of 0.25 (Song et al., 2010). Considering that the current study included a younger study population, the prevalence of frailty was higher (39.18%) for the same cut-off point. The difference between a FI cut-off of 0.25 and 0.38 is approximately the difference between having 9 and 14 deficits (for a 37-item FI). The higher cut-off point was the point of highest specificity and sensitivity for frailty when ROC analysis was used comparing with CGA. If we accept the CGA measure of frailty as a criterion “gold standard”, given its unique ability to apply expert clinical judgement within a particular context, this suggests that older people may have more “deficits”, compared with older community-dwelling adults in HIC settings (e.g. Canada), but do not develop frailty due to those deficits until they have accumulated in higher numbers (in this case ~14 or more, as opposed to 9).

One of the particular advantages of the manner in which the CGA was employed in the current study is that it was applied with reference to local norms. That is, for example where the majority of older people had either moderate or severe pain (n=141, 60.5%), but most were able to continue to work or remain independent in their ADLs, the presence of pain may not have been judged to be an important contributor to frailty when they were assessed by CGA. Yet, pain would have been recorded as a “deficit” according to survey responses when calculating the FI. Thus, this explains the requirement for a higher cut-off point when the point of highest sensitivity and specificity was chosen following ROC analysis against criterion standard of the CGA. Reliance on self-report, will also have possibly underestimated the prevalence of “deficits” in the study population. A lack of access to adequate or affordable primary and secondary healthcare may have led to an underestimation of age-associated chronic conditions. These “deficits” may have been considered to contribute to frailty only in

the most severely multimorbid and symptomatic individuals, or in the minority with access to healthcare, and thus to screening and diagnosis (Vellakkal et al., 2015). Conversely self-rated health questions may have led to increased proportions of deficits for some variables (for example high frequencies of self-reported frailty), given that many of the undiagnosed chronic conditions would have nevertheless produced bothersome symptoms and led to poorer evaluations of health status.

4.10 Conclusion

These results have demonstrated that frailty as a biomedical entity can be quantified and assessed through the operationalisation of frailty models found in the literature, namely the CGA, the FP and FI. These biomedical frailty models have been successfully applied in the rural Tanzanian setting with frailty according to the physical FP producing lower prevalence estimates than that of the broader multidimensional FI and CGA. Frailty by all measures increased with age, was higher in women than men, and was associated with lower educational attainment. The consistency of these findings with the wider literature supports the assertion that these biomedical models of frailty can be applied to measure and characterise frailty across cultures. Nevertheless, the challenges encountered in applying these models will be debated in section 8.3 of the Discussion Chapter. The upcoming qualitative results chapters will explore the cultural context, which will lead to discussion about the concurrence between these biomedical models and the lived-experience of frailty.

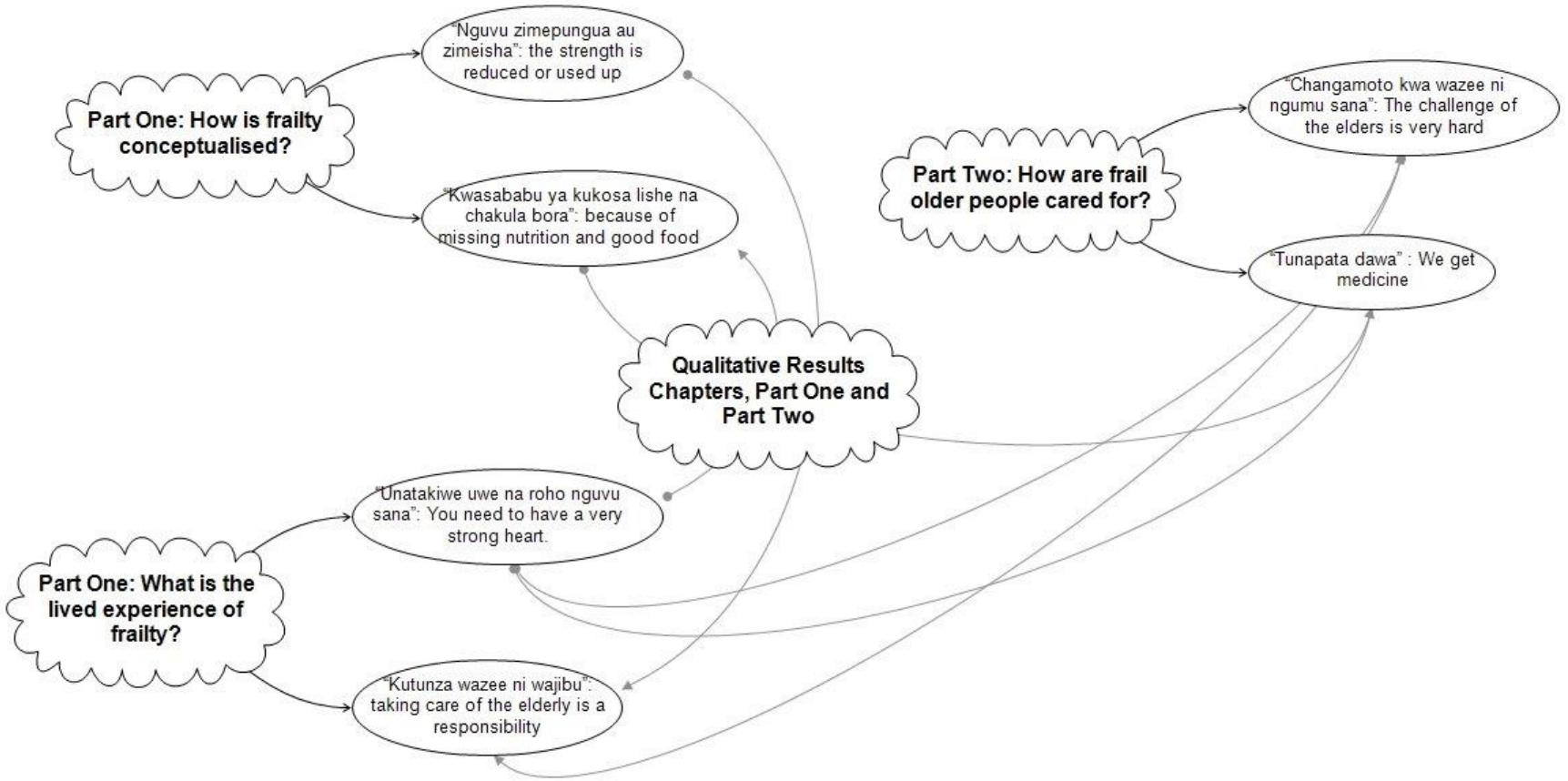
Chapter 5 Qualitative Results Part One: The conceptualisation and lived-experience of frailty

5.1 Introduction

The qualitative results have been presented in two parts in order to best answer the qualitative research questions: Part One seeks to answer the first two questions, examining how frailty in old age is conceptualised, as well as the lived-experience of frailty in this Tanzanian context. Part Two, answers the research question; how are frail older people cared for in this context? Data were taken from semi-structured interviews (SSIs) and focus group discussions (FGDs) and are presented according to theme and sub-theme. Illustrative quotations have been included throughout these chapters in English with any additional commentary on the translation or cultural aspects included in footnotes. Names given are anonymised pseudonyms. As discussed (section 3.21), theme and sub-theme titles were coded using Swahili spoken words or phrases. This was with the aim of representing the authenticity of participants' voices, and adding to the richness of these data by enabling an investigation of multiple levels and interpretations of meaning.

Part One presents four themes, and Part Two presents two further themes. A graphical illustration of the themes, sub-themes and their relationships are shown below, including which research question they pertain to (*Figure 5-1*).

Figure 5-1 The themes presented in Qualitative Results Chapters (Part One and Part Two)



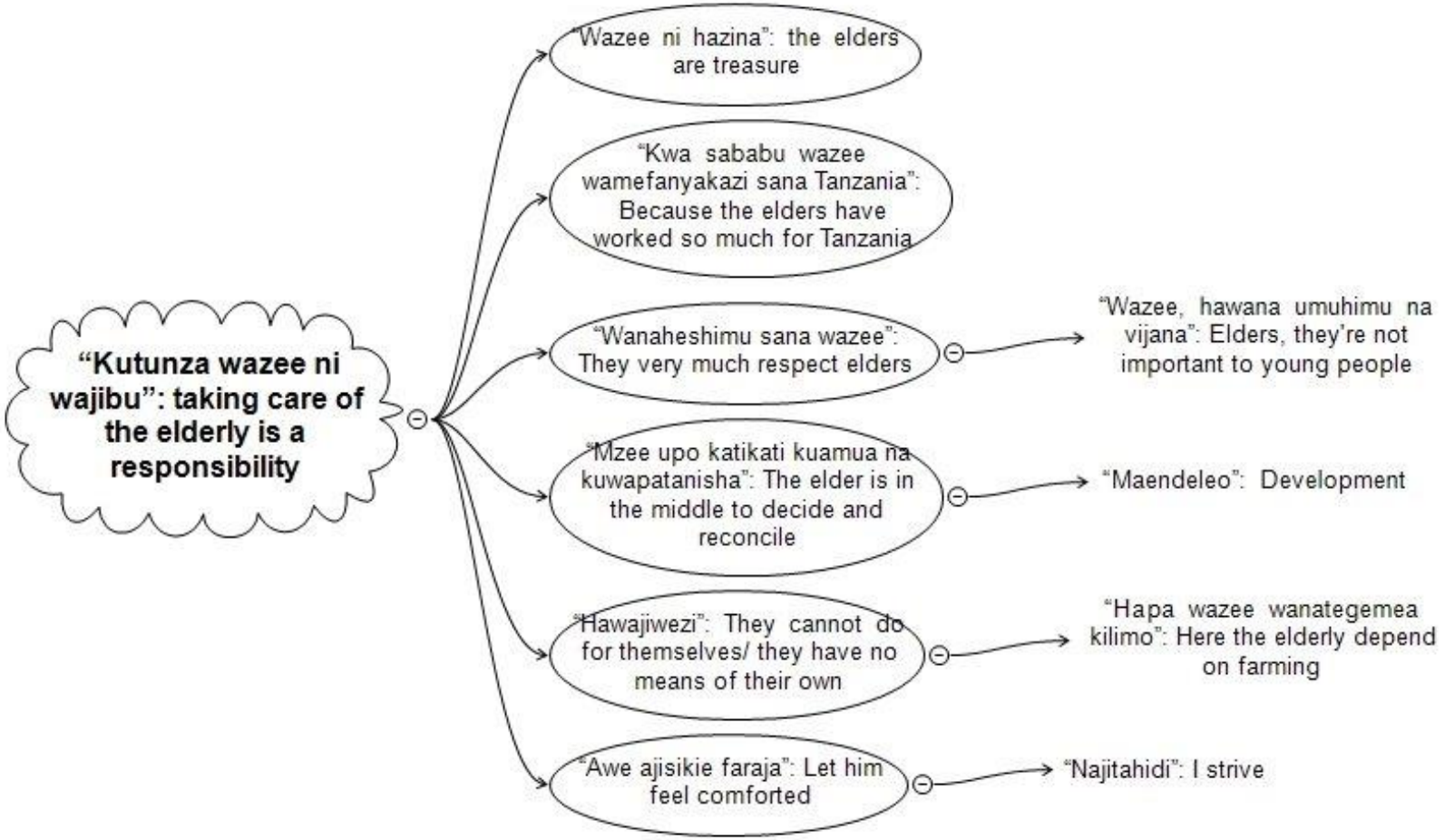
5.2 Overview of Part One and Part Two themes

Part One of these qualitative results includes four themes, summarised in brief here. The first theme, *"Kutunza wazee ni wajibu"*: taking care of the elderly is a responsibility, provides a cultural context and introduction to Tanzanian ideas and ideals around ageing. This is followed by the theme *"Nguvu zimepungua au zimeisha"*: the strength is reduced or used up, which introduces the conceptualisation of frailty in this context. The third theme, *"Kwasababu ya kukosa lishe na chakula bora"*: because of missing nutrition and good food, develops these ideas for a deeper understanding of frailty, examining explanations given for the causes of frailty. The fourth theme, and last presented in Part One, *"Unatakiwe uwe na roho nguvu sana"*: You need to have a very strong heart, represents the lived-experiences of frail older adults. Two conceptualisations of frailty were developed based on these data, and will be presented and discussed in Part One; these are the concept of frailty as returning to "childlike" dependency, and frailty as "being in scarcity".

Part Two, which examines care and healthcare for frail older people includes two themes: The first theme "Changamoto kwa wazee ni ngumu sana": The challenge of the elders is very hard, provides an understanding of frailty from a community perspective, discussing the challenges of providing care for frail older people. The second theme is "Tunapata dawa": We get medicine, which provides an analysis of frail older people's ability to access healthcare, conceptualised here as a form of care. Themes from both Part One and Part Two will be drawn together in order to answer the research questions, with some preliminary discussion during both chapters which will help consolidate the concepts raised by the findings presented. Above, *Figure 5-1* provides a visual representation of the six themes and how they relate to the research questions.

5.3 Theme “Kutunza wazee ni wajibu”

Figure 5-2 Mind-map illustrating the theme “Kutunza wazee ni wajibu” and its ten sub-themes



5.4 "Kutunza wazee ni wajibu": Taking care of the elderly is a responsibility

The theme *"Kutunza wazee ni wajibu"*: taking care of the elderly is a responsibility, reflects traditional attitudes towards older people and their care (*Figure 5-2*). The theme places the investigation of frailty in its cultural context. Older people, especially as they become frail are seen as people for whom the younger generation, and society in general, has a duty of care towards. In many respects this concept of responsibility of care for older people is an idealised notion. It might also be described as the expression of conservative attitudes, which are being challenged in today's changing Tanzania. This care is felt to be a responsibility because of a debt of care owed by the younger generation towards the older generation. This has been termed "inter-generational reciprocity" (Schatz and Seeley, 2015, Schatz et al., 2018), and as previously introduced (section 2.25.1), is an important value explaining the meaning and motivation for care across African countries. Conversely, the concept of inter-generational reciprocity may also explain why some older adults do not receive care in their old age.

The following excerpt gives an example of how this traditional inter-generational reciprocal care was expected, with 'Bibi[10] Eliaika', explaining it as an automatic expectation.

Bibi Eliaika: They help, elders take care of children and children come to take care of their elders.

JR: Anhaa! Elders take care of children and later they come to take of them?

Bibi Eliaika: Eehee, Elders.

JR: So she is saying the elders are taken care of by the children. First the elders take care of their children then the children take care of the elders.

Bibi Eliaika: The child is this one, (Mama Kilala), I took care of her and now she cares for me. (109 years, 1st August 2017)

Sub-themes of "Kutunza wazee ni wajibu"

5.5 "Wazee ni hazina": The elders are treasure

The proverb *"wazee ni hazina"*, was used frequently in FGDs and SSIs. The saying was often used to emphasise to the researchers that "older people are valued here" (in Tanzanian

[10] Bibi=grandmother. The research team followed local convention, addressing research participants by their family pronouns. Family names are generally used, even for strangers, based on one's age and gender, therefore my anonymised confidentiality coding often includes family pronouns. Babu=Grandfather, Mama=Mother, or Mzee= a respectful and formal prefix e.g. Mr or Sir.

society). The meanings, as discussed with my Tanzanian colleagues (John Kissima 'JK', Prosper Regnald, Lucy Mariki, and Jane Rogathi 'JR') during the translation and analysis process, are multiple: Firstly, older people *should* be valued highly, becoming old itself being seen as a virtue due to the accruing of a life-time of experience. Indeed reaching old-age is itself seen as a blessing, a gift bestowed by God, understandable in a context where childhood and young adult mortality are high. Secondly, older people will bring the younger generations blessings if they are treated well and with the deserved respect. Therefore the treasure is both figurative and representative of good fortune. The blessing or curse of an older person is considered powerful, and is a commonly held belief in many African cultures. For example, the Gusii tribe of South Western Kenya believe in the ancestrally-derived authority of elders, and that their words should be *"awed and feared"* (Okemwa, 2002, p185). From wider discussion on this topic, it seems these beliefs are prevalent among young and old today in Tanzania.

Thirdly, *"wazee ni hazina"* can be understood as saying that older people's knowledge is a form of treasure, which should be respected and valued. For example, it was suggested that older people could impart a treasure-trove of knowledge about farming practices such as irrigation. In a rural, largely subsistence-farming community, this knowledge would be highly regarded as it could mean a more successful harvest for one's household or village. However, although this sentiment was still expressed, older people's valued knowledge was limited to certain spheres of life, which may be becoming increasingly irrelevant to younger people. Rapid urbanisation and migration is likely be an important factor in this (Aboderin, 2004b). According to traditional thinking, elders were keepers of valuable wisdom, which could bring prosperity to the younger generation, however, as van der Geest's work in Ghana implied, the knowledge which is currently valued, and which brings employment and wealth to the youth could no longer be found with older people (Van der Geest, 2011). Rather, education was the source of valued knowledge, not experience, making older people, and their treasure of knowledge worthless. Yet, this sub-theme is evidence that publicly and in some rural areas at least, these views still prevail.

In addition we consider that the elderly are treasure, so we depend on their advice a lot. (Mama Lema, ten-cell-leader and subsistence farmer, 55 years, 13th June 2017)

The following quote frames the old adage in the context of Tanzania as a "Nation". The wisdom of the older generation should be respected and listened to, it was argued, in order for the country as a whole to benefit from the elders' treasures of peace and love. While most

literature on the role and place of older people in sub-Saharan Africa (SSA) has focused on older people within their families and smaller social groups, this framing of treasuring older people as a national issue may be a particularly Tanzanian perspective. The nationalism of the first Tanzanian president, Julius Nyerere also known as *"Baba wa Taifa"* (Father of the Nation) (Omari, 1995), is likely to have deeply influenced the older generation, and Tanzanian culture generally.

That he saved for this nation and at the end of the day this should be returned, because they say "the elderly are treasure", yes elders are treasures. If all the elders got finished the youth will remain. If they just remain the youth, where will the wisdom be? It will disappear. But if we care for the elders in the country (it) will have peace and love, and those who will continue to live, will live in love. (Mama Alhafose, 48 years, Subsistence farmer with experience of caring for her father and mother-in-law, 23rd May 2017).

5.6 "Kwa sababu wazee wamefanyakazi sana Tanzania": Because the elders have worked so much for Tanzania

This theme discusses the sentiment that care is conditional on having worked during one's youth. Care should be reciprocated when either elders have worked hard to raise and educate the younger generation, or because they have worked hard for the "Nation" of Tanzania in their adult years. These important principles underpinning care for older people have previously been studied in rural Ghana (Van der Geest, 2002a). These principles also explain the lack of care for older people who are judged not to have raised and educated their children well. The consequence being that there are "deserving" and "undeserving" poor elderly. In Accra, Ghana, where the younger generation were struggling to find work, remittances sent back to older parents did not meet older people's expectations of the care they felt was deserved, which was limited by economic hardship and unemployment (Aboderin, 2004a).

The encompassing idea is that there should be a dividend earnt from planning for the future, by investing in one's children, and in the future of the family. Those without family to care for them in old age somehow deserve their lot, as they have not been wise enough to keep their family together in a state of co-operation[11]. This conditional inter-generational reciprocity is illustrated by the following quotation;

[11] Shirikiana to share together or co-operate. This is a hugely important concept to Tanzanian society and which it could be argued, is a concept which is embedded within the grammar of Swahili. Most verbs have a reciprocal form. For example -shirikiana (v)= to co-operate. The verb uses the reciprocal form of the verb -shiriki= to share, so by adjusting the endng to the root verb, co-operation is produced (sharing reciprocally). The implication being, that in Swahili-speaking culture, if you can do something, you can do it for one another, reciprocally.

A good life in old age is possible when the family is in a state of co-operation and sharing together. In having love it means that the father, the father and his family have become a community which has good co-operation and those elders will live with good understanding, because those children will like to care for and help the elders, because they will know that that my father raised me, cared for me therefore, me, I am supposed to look after him so as to pay back the goodness.

But if he was living a life not of harmony, at the end of the day the family will be scattered, when it is scattered it means that at the end of the day, the elder will not have someone to look after them because they failed to believe. The family, (failed) to organise well so (they) will not get help. But if he would have organised a good family at the end of the day he will live well in old age. (Mama Alhafose, 48 years, subsistence farmer, 23rd May 2017)

Family solidarity and inter-generational reciprocity are important values, which have been studied in-depth in African gerontology (Van der Geest, 2002a, Macia et al., 2015, Whyte, 2017, Oppong, 2016). Reciprocity has also been conceptualised in SSA as "interdependence" and described as *"a sense of mutual dependence expressed in give and take over time"* (Schatz et al., 2018). Interdependence of this sort encompasses both a sharing of resources and of care. These data provide a new perspective on this concept, demonstrating that inter-generational reciprocity extends beyond the family or household, to the "Nation" of Tanzania. Older people who served their country in their youth and through their working adulthood, should be served in return in their old-age, for example it is suggested, through the government providing a state pension.

When Nyerere became the country's first president in 1962 he emphasised that the country's unity was a priority, wanting to avoid the potential destabilising influences of tribal loyalties (Omari, 1995). Nyerere emphasised the importance of identifying as Tanzanian first, and one's tribal identity second (Nyerere, 1973). The unity of language was one method of promoting a sense of the "Nation" of Tanzania (Omari, 1995). President Nyerere taught that independence had been achieved through the unity of the people, fighting against colonialism, and that Tanzanian national unity would be important for the next fight, against poverty (Nyerere, 1973). In the words of the historian Omari; *"Nationalism was the weapon. After independence the common enemy shifted from colonialism to the challenges of development"* (Omari, 1995, p25). It is likely that when national solidarity is cited as a reason for deserving and expecting care in old age, it is the legacy of Nyerere's ideology. Particularly for the older

generation, who would have been young adults in the 1960s. For example, this ten-cell leader, 'Mzee Martin' a 65 year old subsistence farmer describes what he sees as the government's duty to provide a universal state pension.

Honestly it's difficult to take care of the old people here in the village, because the ones who take care of the old person is the family, which might not have anything, it is inferior. So they face a lot of difficulties, but myself, I request if possible the government should look after the old people because the elders have worked so much for Tanzania, at least they should get a small portion in order to encourage them in their lives. (Mzee Martin, 65 years, 13th June 2017)

The next quotation has the rousing echoes of a political speech. Spoken by a 78 year old resident of the government-run 'Amani Residential Home' (Amani) for older people. He refers to the government as one might refer to a personal relationship, or family bond.

We are depending on our government, because it is our government. The government of Tanzania is a peaceful and loving government, it's a peaceful government, so now increase your love. They should increase their love towards the elders as we elders loved you. We are the ones who gave birth to you, who fed you, we farmed for you, we tried by any means for you to go to school, we made every effort, so now you should remember us when you have put us in this place. (Mzee Eliakimu 78 years, retired civil servant, 18th February 2017)

In summary, the older generation feel they are owed care by the younger generation, first by the family to which they provided care, but there is also a sense that they should be provided for according to their Tanzanian citizenship. The form of reciprocal care described here is expressed both in terms of provision of resources and regard.

5.7 "Wanaheshimu sana wazee": They very much respect elders

Regard or respect towards older people is the focus of this sub-theme and its counter *"Wazee, hawana umuhimu na vijana"*: Elders, they're not important to young people. Respect is conceived of as a form of care, as a traditional right, and as an earnt privilege. Respect as an older person's traditional right is illustrated by the well-known saying, "elders are treasure", discussed previously. However, there is a tension in the fact that according to most of the interviewed participants, respect is reciprocal, earnt in the same way as care is earnt reciprocally across one's lifetime. The argument goes, if an older person respects himself and shows respect to others through honourable behaviour, relationships and lifestyle, they will be

respected in return. Here, a resident at Amani gives their perspective on the conditionality of respect.

You behave respectfully it will give you a way to pass. If you go and fall down, the community will say "let's help that elder to get up" he has respect. But if you pass and you are aggressive and abusive anyhow, they will say "let him die"! (Mzee Elias, 87 years, manual labourer, 16th February 2017)

In the next quote, another resident 'Mzee Ali' argues that the traditional right of respect in old age has been lost in favour of the earnt privilege of respect for wealth. This reflection is poignant coming from his perspective as an older man who lost his family and livelihood when he lost his sight, and was forced to shelter in the local mosque before being given a place to live at Amani. Thus, there are intersecting privileges at play in old age; old age and also wealth are respected as indicators of an honourable life lived. While older people living in poverty, it is implied, cannot be guaranteed respect as their low material status could be taken as a sign of poor judgement and foolishness.

An elder in a society, you are respected when you have wealth. The wealth which you look for from when you were young, a house, a farm, and the community will respect you. If you spend your youth opening the zip[12], you will be very poor of course. (laughter) (Mzee Ali, 50 years, sisal factory worker, 16th February 2017)

As mentioned, there is a tension within this sub-theme between idea that respect is not automatic with age, but relies on behaving in a manner worthy of respect. This tension may be resolved, by remembering that becoming an older person in Africa, the youngest continent, may be held in high regard in and of itself. Life expectancy at birth in Tanzania 65 for females and 63 for males (Kassebaum et al., 2016), therefore it takes a certain amount of fortune and fortitude to reach old age, and to survive the major killers of younger people (such as infectious diseases, accidents and childbirth) (Agyepong et al., 2017). Indeed, this fortune was often framed as a "blessing" or gift from God in the sub-theme *"Maisha ni Mwenyezi Mungu akiamua"*: Life is how Almighty God decides.

5.7.1 "Wazee, hawana umuhimu na vijana": Elders, they're not important to young people

Many interviewees felt that the attitudes of the younger generation toward older people, were changing and becoming less respectful. This may be framed as part of a wider "complaint

[12] "opening the zip" refers to spending money

discourse", where complaining about their mistreatment by the younger generation is part of what older people do, to unify, empower, and reinforce traditional values (Sagner, 2002). Alternatively, this narrative may reveal Van der Geest's "drying up" of genuine reciprocity (Van der Geest, 2011), and in these data, evidence of a lack of polite respect towards older people. In Ghana, following customs such as using respectful greetings was described as a way for both young and old to maintain dignity and honour in the absence of a relevant and valued form of reciprocity between generations (van der Geest 2011). In Tanzania, the performance of respect is certainly found in the custom of greetings, with the respectful greeting "*shikamoo*" used for all older people, and anyone of higher status. The next quotation illustrates an instance of where even this face-value performance of respect may have been lost, as described by 'Mzee Joseph' during a FGD at Amani;

In the past, they were kneeling for elders, or you help them a with a little luggage and escort them. But right now, this generation if you are not careful they can push you away saying "have I made you old?"(Mzee Joseph, 91 year old, Kilimanjaro Native Co-operative Union worker, 16th February 2017)

Cattell's anthropological work among the Samia of rural Kenya challenges this finding whereby the ideology of respect for elders is said to have underpinned the care of frail elders during pre-colonial times (Cattell, 2008). The author attributes the perception of a lack of respect for the older generation, to families "*struggling to meet their felt obligations*" brought about by multiple economic and social changes, yet the duty of care was still felt as a *"strong moral and cultural force"* (Cattell, 2008, p196).

The next quotation illustrates the sense of injustice felt at being disrespected, and feeling that this lack of respect was undeserved. Emphasising the importance of the values of sharing and co-operation, refusing to share was perceived as a disrespectful action. In this example, a neighbour "has forgotten" and failed to share their cabbages when their harvest was good. It was a particularly bruising show of disregard according to 'Baba Thomas' a 63 year old retired accountant whose case is described in more detail (Appendix Q).

Baba Thomas: I have carried them, I have educated them, I did what I could, they lived a happy life at that period.

JR: They've forgotten?

Baba Thomas: They have forgotten mother. You can already fall down and see him, he could pass by here like the day before yesterday selling cabbages. He's got nearly two million, but he doesn't say you can take one even! (63 years, 14th August 2017)

Thus, in this and the previous sub-theme a tension exists between respect as an earned privilege and respect as a traditional right, both of which were being denied or ignored by the younger generation. There was also a tension between the true feeling of respect and regard, and a performance of showing respect, both of which were perceived as a form of care. These findings are corroborated by an extensive anthropological study in rural Ghana (Van der Geest, 2002a, Van der Geest, 2011). In Ghana, respect was evident through caring actions, as well as in etiquette. Rather than frail older people inherently being deserving of respect and care, there is a reciprocal exchange of respect across the generations. If an older person has lived a "successful life" where they have secured the future of their children by providing them with education, land, and property, the older person should expect to be respected as they become frail (Van der Geest, 2002a). Conversely, a lack of respect by younger generations was evident by a lack of care and neglect. The strength of the value of reciprocal care is such that it has been described as a metaphorical "inter-generational contract" (Whyte, 2017). Hence the breaking of this contract was experienced as particularly painful by older people, and forms the basis of much of the distress described in *"Unanyayasika"*: You are harassed or humiliated.

5.8 "Mzee upo katikati kuamua na kuwapatanisha": The elder is in the middle to decide and reconcile

"The elder" as a social role is described in this sub-theme, placing older people in important positions of leadership and decision-making, both at a household and local community level. Older people as "elders" it was argued, should be fully involved and at the heart of decision-making, and dispute-solving within the family, and could help to reconcile neighbours within the village too. Older people were deemed most appropriate to take on leadership roles for the economic development of Tanzania, and to show discernment in maintaining positive traditions. Elderhood in its traditional African form has been described as intrinsically linked with grandparenthood and a culmination of adult social maturation (Sangree, 1992). It has also been described as an inherently powerful and authoritative position, so that paradoxically, as the body deteriorates and becomes frail, an elder's power increases (Van Wolputte, 2002). The "elder" role has traditionally included dealing with the affairs of the extended family, as well as carrying out ancestral supplications (Sangree, 1992, Stroeken, 2002). However, while there was very little mention in this study's data about ancestral

beliefs, the authority, leadership, and decision-making roles of elderhood were very prominent.

When the family want to have a misunderstanding, you old person, you are within the family to solve the problem and to make peace again. (Mzee Elias, 87 years, temporary manual labourer, 16th February 2017)

Reflecting on these concepts, it was evident that JK, a retired clinical officer, took on an "elder" social role within the research team. For decisions regarding which village to visit, and which route to take, the team deferred to JK. When disagreements occurred within the research team, JK cast in the "elder" role, facilitated a reconciliation meeting. This was a strikingly different working relationship, to what would be the norm in the UK, yet for JK this was both an expectation and a pleasure to fulfil this "elder" role.

This may be an example of stereotype embodiment theory (Levy, 2009), which claims that both positive and negative age stereotypes may be internalised throughout a life course. Reinforced by psychological, and social factors these age stereotypes influence individuals' functioning and wellbeing (Levy, 2009). These positive age stereotypes evident throughout this sub-theme, were also seen in our day-to-day working as a team, under the wise authority and leadership of an elder.

Notably, the "elder" role doesn't necessarily require physical strength, but rather requires higher cognitive functions, such as problem-solving and advising. That is to say, older people may be valued for having honed these leadership skills over a lifetime, despite developing physical weaknesses, and perhaps frailty.

Its true elders are treasure, they have a very big importance, of their assets of wisdom, in addition to that they are guardians of the family according to the best way of bringing up the family, they help to leave the modern system and return to the better ideals of being respectful. These elders are of great value for the nation which wants to know where they are headed for. (Mzee Temba, 60, cattle keeper 24th July 2017)

As illustrated by the previous quote older people were seen as the upholders of important traditional ideals and values. On one hand, their role was expressed as helping younger people to leave *"the modern system"* and return to traditional ideals. This aspect of their role could be regarded as conservative or past-facing with older people seen as guardians of tradition. However it was also framed as important for a secure and prosperous future, as described next.

5.8.1 "Maendeleo": Development

Older people in their "elder" roles were seen as valued advisors on younger people's "development" projects and plans in their local villages. That older people were seen as being able to contribute in an important way to the future of Tanzania was a powerful message, suggesting that elders were not perceived as irrelevant or disengaged (as has been suggested by anthropological work in Kenya (Cattell, 2008), and Ghana (Van der Geest, 2002a)).

Nyerere developed the concept of rural development (seen in his writing, speeches and in the Arusha Declaration), as a means of addressing rural poverty in Tanzania (Nyerere, 1973). The concept has been defined thus; *"where the community's initiative, self-reliance and leadership for active and voluntary participation, and external modernising assistance, are integrated in such a way that the local community still takes the lead and directs the movement for development, on its own terms and for its own benefit"* (Komba, 1995, p33). The fact that older people today were identified as being important in leading this process at a village level, is likely to be due to the persisting influence of Nyerere's ideologies.

The role of elderly here at (the village) first and foremost are advisors, they advise on different sorts of projects of development, they have visited many places, they have learnt a lot, so they are advisors, they can give us encouragement, us youngsters so that we can continue bringing development to our village. (Mzee Ndenfoo, 39 years, subsistence farmer, 24th July 2017)

This may seem to completely counter the previously described conservative aspect of the "elder" role in upholding traditions and values of the past. However, one could argue that the real skill of elderhood today in Tanzania, is in having the discernment to preserve the enduring values and ideals of the past, as well as adopting and promoting the potential benefits and virtues of the present day, for the sake of the country's economic and social development. An interesting example of this was when older people described themselves as educators who could help dissuade others from practicing harmful traditions, such as female genital mutilation.

We elderly are the big advisors for these our youth who are growing up these days, so that they can follow the ethics which as a nation we fight for, also we fight for (ending) female genital mutilation, which is the national agenda. Whereby if elders enter into the centre and advise our fellow elders that they should not do those acts of long ago, yes that is the biggest wisdom, because elders of long ago they have been

doing things which our government doesn't like. (Mama Omari, 62 years, owner of a small shop, 24th July 2017)

Modernisation theory (introduced in section 2.24), suggests that older people's status reduces in line with technological advances in the economy and medicine, as well as with increasing urbanisation and availability of formal education (Cowgill, 1986b). Interestingly, this sub-theme seems to contradict these assumptions, in that older people are seen as leaders in bringing about "modern" changes in mechanised farming techniques, and in teaching new ways of thinking about older traditional practices. While modernisation theory positions older people as being usurped by modern technology and knowledge, here older people position themselves at the vanguard of these modernising changes.

5.9 "Hawajiwezi": They cannot do for themselves/ they have no means of their own

The double meaning of the expression *"hawajiwezi"* expresses the layers of dependency that this theme conveys. Older people are described as unable to depend on themselves any longer (physically, financially or both).

Talking about older people in this way could be interpreted as a perpetuating of negative stereotypes of older adults as dependent and needy, however it is most likely to be an accurate description of the situation which many older people in this context are facing. This PhD study's quantitative findings have shown that health insurance coverage was low and being in receipt of a pension was unusual among older people in Hai District (*Table 4-3*). Old age is a time of financial dependency due to a lack of social security, increasing risk of healthcare costs as well as diminishing earning potential. These qualitative results corroborate the finding that frailty increased the odds of financial dependency five-fold (*Table 4-3*). Given that the term *"hawajiwezi"* refers both to being financially dependent, and also physically dependent, being unable "to do for yourself" refers to activities such as washing and dressing, and also to one's ability to subsist, which in this rural setting requires manual labour.

One particularly striking metaphor used in this sub-theme, is that of the older people becoming like children in their dependency and helplessness.

For sure we say that an elder's life is like the life of a young child. So when a young child gets somewhere to be placed and brought up well and you make sure that he has a person who raises him up[13], has a person to feed him, to get all the services, like a

[13] -lea (v) = to bring up; to raise or to educate. The Swahili verb used to discuss caring for an older person was often the exact verb used to describe caring for children, emphasising the parallel notion linguistically. The choice of this verb also suggests that care for an older person should be approached with the same tenderness and compassion as caring for a child, and without expectation that the person should be more capable or "independent".

child. Also when an elder gets old, starting from seventy five years and above now they return to become completely like a child again so the family itself fails to take care of them because they have nothing to give to this person. (Mzee Terewandumi, 69 years, subsistence farmer, 5th July 2017)

This image of the older person becoming "childlike" contrasts with the traditional notion of elders fulfilling the roles of authoritative teachers and leaders within their communities (as discussed in the previous sub-theme). This finding of dependency in old age being likened to the social role of a child was also described by Cattell in their work on ageing and work in Western Kenya (Cattell, 2002).

In discussing this dependency and helplessness, it is as if the alternative role to "elder" is the role of "childlike" dependent. 'Bibi Felista' illustrates this well, having (in her words) "failed" to do manual work at the age of 93, her new role in the household is to be waited-upon and cared-for. There was no sense that she was encouraged to carry out any small activities, or that she herself resented not being able to participate more in household activities. Her new role was to accept this dependency with gratitude. In performing these acts of care, her family of six children, met their idealised notion of inter-generational reciprocal care.

Bibi Felista: Yes, like I used to cut the grass for the cows, I looked for cow food, I looked for my food to eat. I failed. Until they bring it for me here where I have stayed. When I am brought the food I say thank you. (93 years, 5th July 2017)

The following quotation uses the same analogy and evokes the image of an African mother carrying her child in a kanga[14] on her back.

Elders return to childhood, they are like a young child being carried, so as a young child being carried what activities can they do? So that one is an old person and cannot do anything, they cannot do anything. (Mzee Masana, 76 years, secondary school teacher, 16th February 2017)

This imagery and concept was used in the development of the first conceptualisation of frailty as returning to "childlike" dependency. It is helpful to consider this concept in the context of role identity theory. According to this theory, people derive their individual social identities from their roles within society, based on the shared meanings associated with those roles and their performance. The role identity of frailty as a form of "childlike" dependency was

[14] Kanga (n) 1. Kanga cloth; kanga wrapper 2. Guinea fowl The decorative fabric worn by women across the Great Lakes region of East Africa, earnt its name from the spotted background patterns which looked similar to a guinea fowl's pattern. Today it is usually worn wrapped around the waist, over a dress or other loose layer of clothing.

defined here relative to its counter-roles "adulthood" or "elderhood" (Burke and Tully, 1977). The theory also claims that in order to take on a particular role identity, one must perform the identity, and individuals *"monitor their own behaviour in terms of the implied meaning of that behaviour, where the relevant dimensions of meaning are those that distinguish the individual's role identity from the counter-role identity"* (Burke and Reitzes, 1981, p90). Here 'Bibi Felista' enacts the role identity which is expected for a frail person, distinguished by an inability to work. This conceptualisation has also been returned to in section 8.6.1 with reference to the "western" concepts of the "third" and "fourth ages" which were introduced in the literature review (section 2.21).

5.9.1 "Hapa wazee wanategemea kilimo": Here the elderly depend on farming

The focus of this sub-theme, is the meaning of work in old age in this context. Farming was a means of sustenance but also represented being in responsible and caring social roles for most of my study participants. It is helpful to keep this fact in mind when considering the first conceptualisation of frailty; frailty as "childlike" dependency. The ageing, failing body, was not only a reminder of one's mortality, and a source of pain and unpleasant symptoms, but it caused a loss of identity as "a worker" and as an adult. Cattell and Freeman in their work in Kenya and Malawi respectively, also found that working in a caring capacity for others was defining of adulthood (Cattell, 2002, Freeman, 2018). Being less able to work caused a loss of pride in one's labour, and an important reduction in income and food for the sustenance of the whole household. The following health committee member uses the term strength to refer to financial wealth or means. Developing frailty in the absence of a retirement period meant keeping working, taking up one's hoe for digging, and bringing home diminishing harvests.

Eeh, another way that elderly get weakened early is they do not have capital for crop cultivation. You know here the elderly depend on farming, now you find they do not have strength[15] to buy good seeds, manure, therefore he is farming a small plot, you find (their) income is like that, the harvest there at home is little to say he has a big plot. (Mzee Gunda, 58 years, construction worker, 28th July 2017)

Productive ageing, may be a relevant construct to consider here. Productive ageing seeks to support and recognise the contribution of older people to work in paid and unpaid roles (Butler, 2010). While productive ageing highlights that older adults remaining productive is the norm globally (Butler, 2010). These data do not suggest that this is from choice, or

[15] Nguvu (n) 1. Strength 2. Power, as illustrated in this quotation, power and strength was also sometimes financial.

desired. Working into older ages was often an unquestioned necessity for survival in Hai District.

5.10 "Awe ajisikie faraja": Let him feel comforted

Here, respondents describe the quality of care which is required by those "who cannot do for themselves". Caring for older people was described in terms of caring "closely" for them; the word "close" (in Swahili karibu[16]) is used often in this sub-theme, to describe care that is fitting for an older person. "Close" care refers to care provided attentively, by close family members, with a warm, inclusive attitude, with someone physically by their side, ideally on family-owned land, "close" in place to one's community[16]. The sub-theme highlights the fact that good care provides comfort to the older person. This finding is corroborated by a study examining elder-to-elder care in Dar es Salaam and Rufiji District, Tanzania (van Eeuwijk 2018). The author identified meaningful care activities which were seen as being important for the emotional state of someone living with frailty. These were talking, socialising, consoling, comforting, encouraging and praying together (van Eeuwijk, 2018).

It is important to look after the elders because they need our care, we who have strength, because their strength has reduced. They cannot help themselves therefore our help to them is important so that they feel comforted. Because elders they like it when you are close to them, they like conversation, they like…, not to be lonely we are supposed to be with them, to speak to them often, encouraging them so that they can feel they are with people who are caring for them. (Mama Nuru, 53 years, farmer 13th May 2017)

The following quotation, by a staff member at Amani gives even more importance to the idea of providing "close" care and comfort, highlighting that this form of care can prevent psychological distress and other illnesses. The term "thinking too much" is a common idiom of distress in this setting; in a systematic review of the term, which included 138 papers, 60 (43.5%) related the term to use by African research participants (Kaiser et al., 2015). Furthermore, a qualitative study investigating the conceptualisation of depression in Hai District, found the remedy for "too many thoughts" was comfort, love, and reassurance (Howorth et al., 2019).

Yes it is a very big problem, because once you are alone, you are likely to encounter other problems. But if you live with other people who even come to visit you or assist

[16] Karibu 1. (n) welcome 2. Close person/thing 3. Adj close (to) 4. Next (to) These are all translations, which are relevant to the description of the care older people should receive.

you, they will help in even carrying you outside from time to time, you are getting washed, given someone to tell stories with, in reality you are better off. You will become better, and your thoughts won't be too much. In addition, some illnesses won't affect you because you are close to people. (Mama Magreth 47 years, care assistant at Amani, 27th May 2017)

5.10.1 "Najitahidi": I strive

This sub-theme comes from many interviews where care-givers used the term "I strive" to describe their struggle to provide care as they felt it was deserved for their older dependents. For example, the excerpt below where the adult son 'Baba Jumanne' kept repeating that he was striving, in order to balance his responsibilities of care to his children and his father 'Babu Elirehema', seemingly, with nobody else to assist in supporting them. He felt strongly that it was his duty to care for his father (according to the overall sentiment of the theme *"Kutunza wazee ni wajibu"*: taking care of the elderly is a responsibility), yet he admitted that he was failing to care for him well. His father's house was a small, poor quality, mud-and-wattle shelter which resembled a cooking outhouse or a barn for animals.

I just strive, I really strive because the responsibilities are difficult and are a lot and when you look at his age for now, he is someone who you cannot tell, maybe to do this or maybe to do a certain activity. Yes, meaning that if you look here, for example the children are at school, it is me who is here and he is the way you can see him here, the mother has left and all the children are at school. (Baba Jumanne, 44 years, subsistence farmer and motorbike taxi driver, 4th July 2017)

His eighty year old father describes developing a sore on his leg and being threatened with requiring an amputation, and 'Baba Jumanne' was pained to admit that he was sometimes unable to provide appropriate healthcare (discussed further in Part Two as a form of care provision for frail older people). This illustrates well that the burden of care, and responsibility of providing care falls with the younger generation.

I strive and strive, in whichever way I can and whichever way I cannot…So there are some of the services you may find maybe the way he is sick there, you find that I don't have the ability to get him treated. (Baba Jumanne, 4th July 2017)

The staff of Amani described going beyond their usual duties, and needing to depend on God and take strength from their faith in order to provide the right care for their residents. The striving of the staff at Amani was not so much for food and other essentials (which were provided by the government) but to provide the "close" care as described in *"Awe ajisikie*

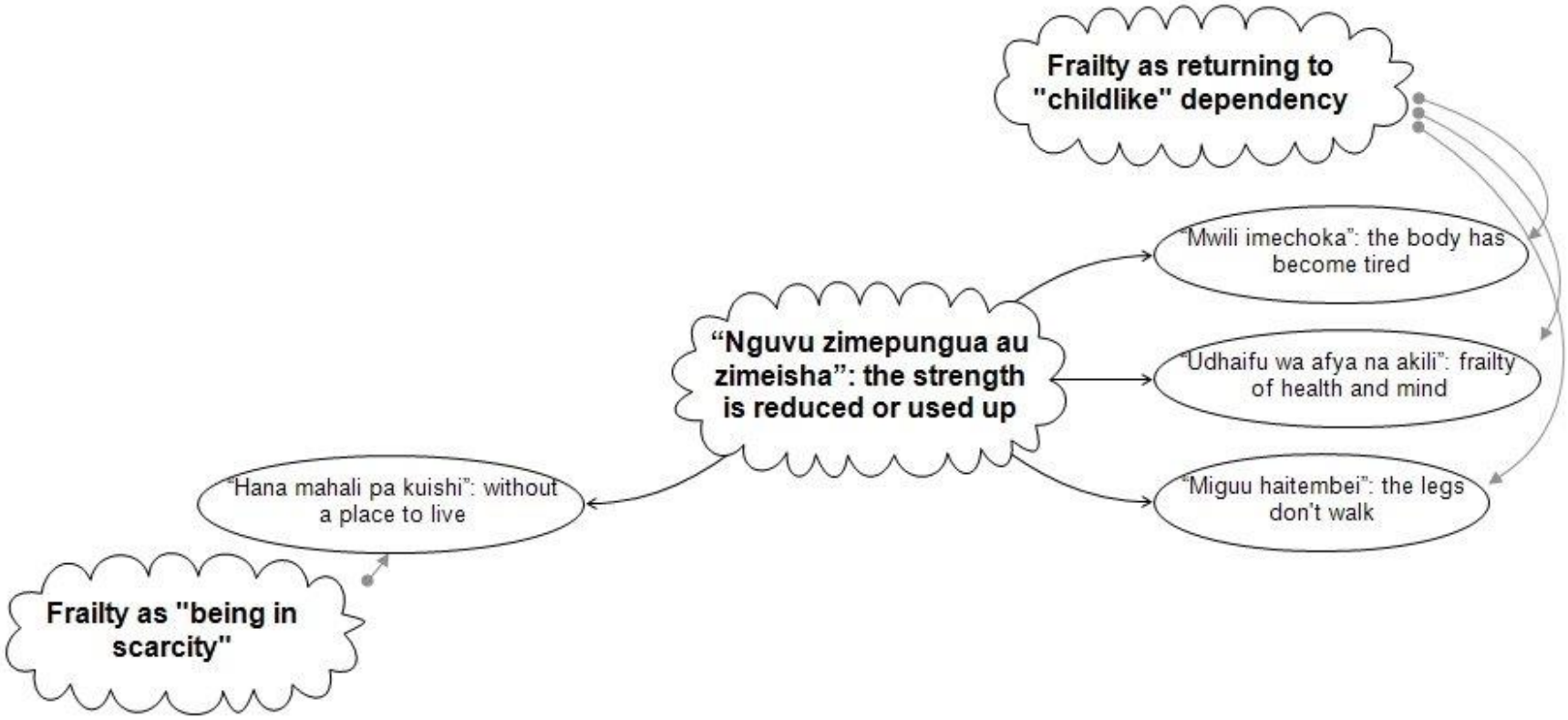
faraja": Let him feel comforted. The attentive, loving, and respectful care which is idealised, is strived for despite having to balance priorities and demands on time.

It is true, despite work being tough, but for a person to work here they must have the fear of God in their hearts and depend on Him. That's to say, I was employed but you can't just do this work as arranged by the government, we must do more. We usually extend our working hours whenever there is an immediate need that we must meet, maybe a grandmother has pain in her side which needs to be looked at, you can't go home and leave her in pain but the first intention should be to take care of that need, let them be well yes, then you leave. (Mama Magreth, 47 years, female care assistant, 27th May 2017)

In summary, *"Najitahidi"*: I strive, represents the narrative that the younger generation do their best to provide the idealised "close" care which they feel their older people deserve. They are required to balance household and family needs, limited financial resources, and time in order to provide this care which they feel duty-bound to provide.

5.11 Theme: Nguvu zimepungua au zimeisha

Figure 5-3 Mind-map illustrating the theme "Nguvu zimepungua au zimeisha" and its four sub-themes



5.12 "Nguvu zimepungua au zimeisha": The strength is reduced or used up

This theme describes the conceptualisation of frailty in old age. It is described primarily as a loss of energy, or using up of strength. There is no direct translation for frailty in Swahili, so it was translated as *"udhaifu wa wazee"* literally meaning the weakness/es of the elderly. Taking this translation into account, it is understandable that, frailty was often described as a lack of energy, strength or power. To avoid circularity of meaning, we asked broad questions such as "What do you hope for in your old age?" or "How do you feel about getting older?" "what is it like being and older person in your village today?", or "what are the challenges older people face?" (Appendix F) and also "real-life" vignettes (Appendix G).

When we say frailty it means the loss or inadequacy of strength. Once you have already reduced in strength it means that then you are frail. (Mzee Godfrey, 36 years, subsistence farmer, 13th June 2017)

As mentioned in section 2.27, Brigit Obrist, in researching the place of care for older people in coastal Tanzania, has previously discussed physical frailty in old age (Obrist, 2018). A simple definition was used, where frail participants were those who described themselves as; *"sina nguvu"*, "I don't have strength". The author described this as a *"health condition marked by a series of critical moments due to old age, illness and injury, leaving the older men and women frail and no longer able to perform their gendered routines"* (Obrist, 2018, p98). A high proportion of older adults participating in the quantitative aspect of the study self-identified with having frailty 45.42% (95% CI 38.2 to 52.5) (*Figure 4-16*). The willingness to self-identify as frail or as having "weaknesses of the elderly" is an interesting finding, which suggests that older people in this setting did not resist or fear the description. In contrast, the term "frail" has become highly feared and resisted in "western" settings, as discussed in section 2.22. To illustrate this further, Appendix P shows that only five from 25 participants interviewed by SSI, did not self-identify as frail, with a supporting quotation explaining their perspective.

As seen in (Appendix P) participants' expressions often suggest a progressive process of the body weakening. While corroborated by Obrist's work, this theme is also subtly different, suggesting a finite amount of energy, which is expended throughout one's life, so that it is used up and finished by old age. The gradual development of frailty was emphasised rather than it being a state of "no energy" occurring suddenly. In its conceptualisation it is the product or accumulation of a lifetime's activities.

This idea is conceptually similar to the deficit accumulation model of frailty, whereby deficits, diseases, and symptoms which increase with age, are counted up, to produce a frailty index (FI), which express an estimation of an individual's vulnerability to external stressors (Rockwood and Mitnitski, 2007). The concept of a using-up of a finite resource of energy was also described in Freeman's work in Balaka, Malawi: The author describes how Malawians thought of body fluids as containing a "life force" or energy, so that the body's energy may be referred to as "blood". The life course was explained as a *"linear trajectory of diminishing blood (power/strength) until death"* (Freeman, 2018, p119). The same explanation for frailty was described by some of my study participants, and this rationale was used to explain why older women might become more frail compared with older men. 'Bibi Abraham' explains that loss of one's life "blood" during childbirth contributed towards increased frailty in women.

Bibi Abraham: Yes, by then she is powerless. As you know between a man and a woman, it's very different us mothers we must get tired.

JR: mmh, is saying the women, and is saying the women because the women they get tired very easily compared with men.

EGL: ok, any other reason?

JR: Why do you think women get tired easily as compared to men?

Bibi Abraham: (laughing) I don't know, maybe my advice is childbirth, you give birth.

JR: Anhaa maybe because of giving birth, it's the reason as why they get tired?

Bibi Abraham: Yes, it is because they reduce their blood. (Age unknown, 28th July 2017)

This is a fascinating explanation for a paradoxical finding which has been consistently described in the biomedical literature; "the male-female health-survival paradox", where women have higher levels of frailty compared with men at any age, but better survival compared with men (Gordon et al., 2017).

The frailty of the body due to old age, it's when you are already aged, the blood decreases. (Babu Materu, 93 years, subsistence farmer, 4th July 2017)

While overall, frailty was described as a gradual using-up of a finite amount of life "blood" or strength over the course of a lifetime, until a state of frailty was reached, the following sub-themes describe the phenomenon happening in the body, legs and mind.

Sub-themes of "Nguvu zimepungua au zimeisha"

5.13 "Mwili imechoka": The body has become tired

The body becoming tired was an integral component of the description of physical or bodily frailty, in addition to the reduction of strength. Frailty according to the frailty phenotype (FP) includes a description of self-reported exhaustion, measured by self-report using questions taken from the Centre for Epidemiological Studies-Depression (CES-D) scale (Orme et al., 1986)[17]. Needing to rest and having to stop one's usual activities due to fatigue fits very closely with the biomedical FP model of frailty, developed in the United States as part of the Cardiovascular Health Study (Fried et al., 2001).

In order to understand the meaning attributed to the tiring of the body in the context of developing frailty, one must appreciate the importance of the body to an older Tanzanian. In the context of rural subsistence farming using manual techniques, a person's body is a tool for working, and its capital is production on the farm. As the body is experienced as tiring, and its capabilities for working reduce, this challenges the individual's role identity as an adult and here, led 'Babu Obadia' to admit to having the problem of "weakness of the elderly" or frailty.

JK: She asks, as you can still work, why do you say you have frailty of old age?

Babu Obadia: Frailty of the elderly, because I cannot work the way I used to be able to work. I have failed. But I just work a bit, like for half an hour.

Clarifying, which symptoms or problems were limiting his ability to work, he responded;

Babu Obadia: For sure tiredness, it comes from being tired, when I work, I just work for two hours or just one hour, then I come to rest, being tired is in front of it. (82 years, subsistence farmer, 5th July 2017)

[17] Using the CES–D questions, the participant is asked to grade how often in the past week did they feel that (a) "everything I did was an effort", and (b) "I could not get going". Subjects answering "a moderate amount of time" or "most of the time" to either of these questions were categorised as meeting the criterion for exhaustion.

‘Babu Shuma’, an 87 year old cattle herder was no longer able to work, due to being blind and suffering severe joint pains. He relied on his younger wife to provide for him, drawing a parallel between becoming frail and becoming “childlike”.

Babu Shuma: The body is starting to tire mother, especially these heels are painful, these muscles are painful (showing his ribs) they are not hurt but because I am pulling them, they are tired.

JR: They are tired?

Babu Shuma: They are tired not because of pulling them… they are tiring, that’s it they are weakening, you become like a child you wish to crawl, the body hasn’t got much strength. (87 years, 14th July 2017)

This vivid description of becoming like a crawling infant, in one’s dependency and frailty was seen previously in the sub-theme *“Hawajiwezi”*: They cannot do for themselves/ they have no means of their own, and forms an important aspect of the first conceptualisation of frailty.

A qualitative investigation of older adults’ experiences of ageing and care in rural Malawi, analysed older adults’ perceptions of their aging bodies, and their subsequent changing social roles (Freeman, 2018). Freeman found the same emphasis on the body’s ability to work being a crucial part of the “adult” social role, and discussed ageing and dependency as a threat to that “adulthood”. Older people resisted the return to “childlike” identity by emphasising their body’s past productivity, and by doing as much as their bodies would allow them, in order to emphasise their “adulthood” as much and for as long as possible (Freeman, 2018). This can be referred to in relation to identity control theory (Burke, 2006), which describes how individuals match their self-perceptions with the identity standard in order to have this standard socially reinforced. For example, maintaining a perception of oneself as an adult in the Tanzanian context would involve working productively on the farm and being recognised as a productive worker by others. These Tanzanian data contribute additional nuances to these ideas:

First, “elder” social roles require less physical capability, and may be a means of avoiding the loss of “adult” status. An example of this may be ‘Bibi Eliaika’, the 109 year old grandmother of an Mchagga household, who despite being dependent for all her care needs, and identifying with having body tiredness, was still capable of her “elder” role in decisions-making about land inheritance.

Bibi Eliaika: For example, if you leave them some farmland, this is yours and the others, the other one should take care of this. They (her daughter) should be like me and leave some portion of the farm to them (the grandchildren) (1st August 2017).

These data show that although the "childlike" frail role may dominate, a person's status as "elder" may not be completely lost, even if its scope is reduced to matters closer to the home.

Secondly, these data point to the importance of relational identities and roles in this context, which also brings worth when one's "adult" capabilities are threatened by a tiring body. Throughout all of my interviews older people were referred to using possessive pronouns ("my/our/their"), older people belonged either to individual or collective family members, or to their village communities. Older adults were also always referred to and addressed using family pronouns. Even as a research team, our relationship with older study participants was given a certain intimacy by addressing them with the conventional "Bibi" and "Babu" (grandmother or grandfather respectively in Swahili). In turn I was usually called "mwan'angu" (my child). These familial role identities, it could be argued, give meaning to an otherwise potentially undignified or belittling state of "childlike" dependency. Indeed, in visiting them at home, the research team (the author, JR and/or JK) were able to activate this positive role identity of parent/grandparent, visiting them as adult children would, checking on their wellbeing, listening to their problems, and offering a small gift of sugar[18].

Doing as much as possible, and highlighting one's past productivity were interpreted as means of resisting frailty and dependency in rural Malawi (Freeman, 2018). These behaviours served to counteract the meanings of the changing situation, and resistance to the role identity change, from adult to the possible "childlike" dependent self (Burke, 2006, Freeman, 2018). However, the third way in which this sub-theme adds a new perspective is through the interpretation that working into late old age was not usually through choice in this context. Rather, work was out of necessity for survival, as per 'Babu Obadia'. And describing one's past productive work could be regarded as a way of justifying and explaining their current frailty, that is, their current physical exhaustion was evidence of their past work. According to this study, while "childlike" dependency was not desired, there was little evidence for older

[18] We gave each participant a bag of locally produced sugar as a gift for participating in the study. Sugar was decided upon collectively by the research team as a valued commodity, usually taken daily in the morning with black tea. A 1Kg bag was worth around 1 USD, yet it was well-received particularly as it had to be bought, while most other produce would be available from one's plot e.g. maize, bananas, vegetables, seasonal fruits. This act of giving a gift of sugar would also be reminiscent of the remittances and gifts of flour, rice and other commodities that adult children give or send home to their ageing parents.

people *resisting* frailty. Frailty was an inevitable approaching the end of a finite supply of life strength and energy.

The social and cultural devaluation of a person from adult to frail "childlike" dependent has been discussed in the context of disability and its erosion of a person's adult social role in a study of adults living with disability due to polio (Luborsky, 1994). However, it can be argued from these data that no such devaluation occurred, despite an undesirable loss of adult social identity. There was a socially acceptable time to stop working, and a sense that it was just as undesirable to be forced to work past one's bodily capabilities. Additionally, as one moved from the responsible, working "adult" role identity, and returned to the "childlike" dependent role identity, one's familial and relational role identities became more important and prominent, perhaps preventing the social and cultural devaluation which has been associated with physical disability (Luborsky, 1994).

5.14 "Miguu haitembei": The legs don't walk

These are examples of where poor mobility were given as evidence of frailty and as a description of physical or bodily frailty. In this sense, the conceptualisation of frailty was complementary of the FP, which includes slow walking speed and reduced physical activity as integral components of frailty (Fried et al., 2001). In these data, the legs were referred to as disobedient, refusing to obey their owner and function as they should, thus there was a separation created between the frail body, and the self. This disjunction was similarly described in an exploration of the emotional experiences of older Canadian women (Grenier, 2006). Grenier discussed how medical models of frailty have focused on the body's functioning, however the failing body was only one reason for "feeling" frail, while there was often a disconnect and tension between participants' bodies, and identities. For example, one study participant, Alice distanced her "self" from her body, saying *"My body didn't used to do this"*, in reference to her incontinence (Grenier, 2006, p302). This distinction was also made by frail community dwelling adults in England, who used a similar strategy to resist self-identifying as frail (Warmoth et al., 2015).

Having difficulty walking was particularly troubling in this sub-theme, considering that walking was the main form of mobility. In fact, almost all activities in this rural subsistence-farming setting require walking: Cutting grass to feed the cattle, fetching water, collecting firewood, cattle herding, farming by hoe, and going to the market to sell or buy food, all require walking. This illustrative quotation, shows how a difficulty walking had a considerable impact on the daily activities required for subsisting, as well as for taking part in community activities.

Bibi Felista: Because of the legs I cannot. The legs are refusing. To want, I want, I want even to go church, I want to go but I fail because of the legs. (93 years, 5th July 2017)

In summary, there is a notable concordance between the sub-themes *"Mwili imechoka"*: the body has become tired, and *"Miguu haitembei"*: the legs don't walk, and the biomedical FP model of frailty. Further comparison and discussions of which, will be taken up again in section 8.10.

5.15 "Hana mahali pa kuishi": Without a place to live

Data discussed during this sub-theme will shed light on the complex interaction between poverty and frailty, and it will be argued that poverty may be seen as part of the cause, consequence and experience of frailty. In these data frailty was described as having the appearance of a life lived in extreme poverty. According to this sub-theme, one recognises a frail older person by their poor housing, poor clothing or homelessness. This ten-cell leader 'Mzee Temba' described the situation in strong terms.

That elder even if you just see them with your eyes, you know they have needs. It's different from those elders who receive their needs. It appears that their health is good, different from that other elder which if you see them, they have poor health due to missing assistance. They differ in health, you can see the environment of their shelter, their house. If you already see the environment of their house and their sleeping quarters, you just know their life is worthless[19] and also their health is used up…Because of their economics one can become a useless person[20] and get frailty. (Mzee Temba 60 years, farmer and cattle keeper 24th July 2017)

Kilimanjaro region in fact has the lowest level of "extreme poverty" outside of Dar es Salaam according to the multidimensional poverty index (MPI) (UNDP, 2015). The MPI is used to measure a wide range of deprivations that individuals and households may face in the domains of health, education and living standards (Alkire and Santos, 2010). For example, the MPI includes the following indicators of poor housing; dirt flooring, using wood or charcoal for cooking fuel, and not having electricity in the home. This measure of poverty fits with participants' descriptions of the visible and public aspects of deprivation, which, in Hai District also represented the visible and public appearance of frailty. Although Tanzania as a country is classified as a low income country, (World Bank, 2018), Kilimanjaro region, is

[19] Duni (adj) 1. Low 2. Inferior 3. Mean 4. Worthless. The term "duni" was also sometimes translated as "poor" by LM and JR.
[20] Bovu (adj) 1. Bad 2. Rotten 3. Useless 4. Immoral (in this translation, a prefix m- refers to a person)

comparable to countries with medium human development (UNDP, 2015). But despite this region being one of the most affluent areas in Tanzania, it seems that for older people, physical frailty and extreme poverty are closely associated, as exceptional extremes of both health and wealth. This relationship is likely to be even more prominent in poorer regions of Tanzania, and in other poorer regions of SSA.

You find someone frail does not have income, does not have development, the means at their home is difficult which disturbs them very much. When you yourself look at their home you will know that this person is frail. (Mama Hawa, 54 years, village executive officer 4th July 2017)

Above a health committee member suggests that frailty is the opposite of economic and social "development". The importance and meaning of this concept was discussed in sub-themes *"Maendeleo"*: Development, and *"Hawajiwezi"*: They cannot do for themselves/ they have no means of their own.

5.16 "Udhaifu wa afya na akili": Frailty of health and mind

In this sub-theme frailty was conceptualised as having both physical and psychological or cognitive components. A "reduction in thoughts" was described by participants as a form of frailty, as though mental capacities reduce in line with physical energy or strength (*"Nguvu zimepungua au zimeisha"*: the strength is reduced or used up). The fact that frailty according to the FI and CGA, both include assessment of mood and cognition highlights the appropriateness of these models for application in rural Tanzania, where it is accepted that one may be frail in either or both, the mind and body.

In addition to a form of frailty being a "reduction of thoughts", one of the underlying psychological causes of frailty was also expressed as "thinking too much", a common idiom of distress in Africa (Kaiser et al., 2015). Other causes were being bereaved, feeling abandoned by children, or having financial worries, all of which were also highlighted as possible causes of depression in older people in Hai District (Howorth et al., 2019). One of the forms of frailty that affected the mind, and which was also described as "reduced thoughts" was dementia. For older people and their families, this type of frailty may be particularly difficult, given that it would take away the many "elder" roles that older people perform, which involve higher cognitive processing, and which may still be carried out, albeit in more limited ways, even with physical frailty (*"Mwili imechoka"*: the body has become tired).

Myself how I understand about frailty, frailty is tiredness of the body because of coming across various different diseases or other problems that can appear later. But it's a shortage of thoughts and body weakness. (Mzee Kulaya, 67 years, coffee farmer and health committee member, 4th August 2017)

The following health committee member made the distinction between frailty of the body and mind when reflecting on his mother, who was prone to wandering due to advancing dementia.

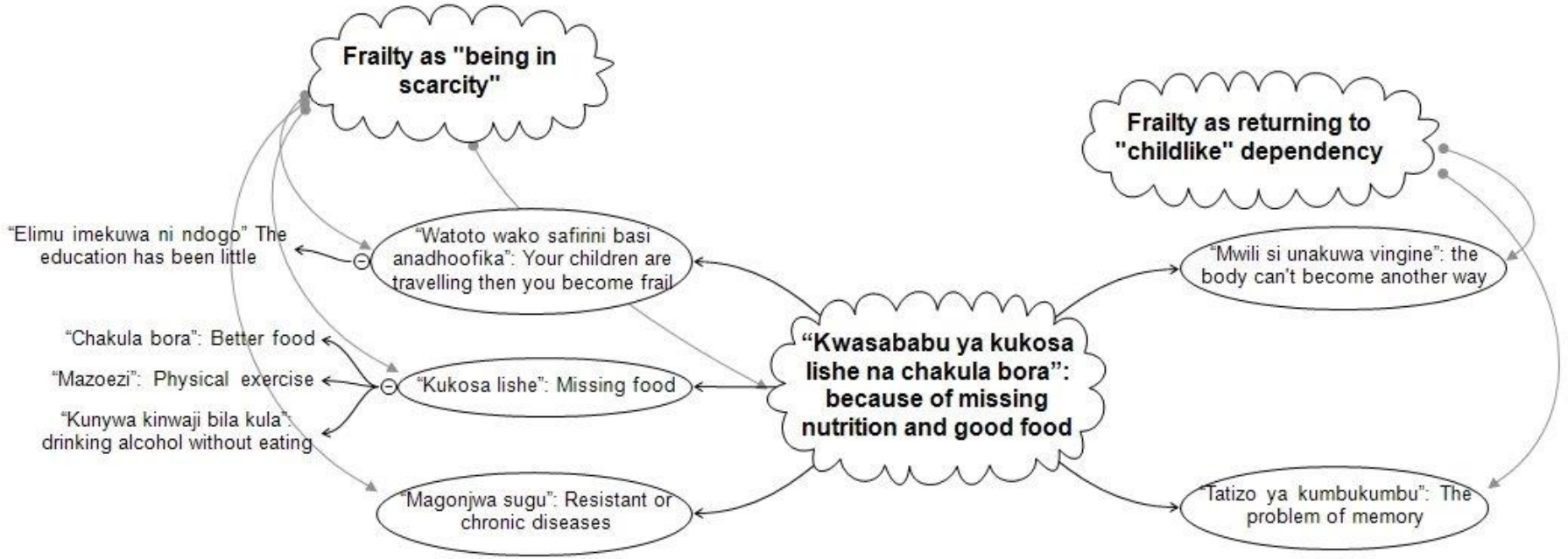
Baba Munuo: Afterwards, if you put her food there, but she does not remember, she says "not yet, still a little time to eat", but later she completely forgets. Maybe by chance we have all gone to the farm, when you come back you find the food is there or the tea is the same. So it is dementia, a problem, although she is hungry! And when you ask her why? she says, "I am hungry but why have you not given me food now?" That is the memory problem, and many things like that. Also she may forget to take the clothes and even forget to get dressed. Maybe she may come with a kanga[14] only and thinks she is dressed already and all good. That is a problem.

JK: Do you think your mother is frail?

Baba Munuo: The health is not frail, but I see the frailty is in her mind only, memory. (70 years, subsistence farmer and small business-holder 13th June 2017)

5.17 Theme: Kwa sababu ya kukosa lishe na chakula bora

Figure 5-4 Mind-map illustrating the theme "Kwa sababu ya kukosa lishe na chakula bora" and its nine sub-themes



5.18 "Kwa sababu ya kukosa lishe na chakula bora": Because of missing nutrition and good food

Within this overall theme are the causes given for frailty. *Figure 5-4* illustrates how the nine sub-themes relate to the two conceptualisations of frailty. Except for *"Mwili si unakuwa vingine"*: the body can't become another way, and *"Tatizo ya kumbukumbu"*: The problem of memory, frailty is framed as being due to *scarcity*. As will be described at the conclusion of this chapter, the first conceptualisation of frailty is of frailty as a gradual using-up of one's finite life energy as part of a natural life course, until one becomes a dependent "childlike" older person. The sub-theme *"Mwili si unakuwa vingine"* translated as "the body can't become another way" is concurrent with this sentiment. Frailty in this instance is not to be resisted or reviled, rather it's a matter-of-fact unavoidable outcome of living into late old age. Likewise, caring for (or "raising") a frail elder was not associated with feelings of shame on the part of the older person, or resentment on the part of the care-giver. However, the second formulation is frailty as an aberration from this expected life course. The following three sub-themes; *"Kukosa lishe"*: Missing food, *"Magonjwa sugu"*: Resistant or chronic diseases, and *"Watoto wako safirini basi anadhoofika"*: Your children are travelling then you become frail, describe a particular insufficiency or deprivation, which lead to a loss of strength and tiring of the body or mind, or the development of extreme poverty (see *"hana mahali pa kuishi":* without a place to live).

The causes of frailty and frailty itself were so closely linked in peoples' minds that very often when asking for descriptions of the causes of frailty, examples of *living with* scarcity were given. Therefore, it could be said that frailty was a form of *being in* scarcity, and that this theme seeks to describe the ways in which this is the case. This "being in scarcity" conceptualisation, led to becoming old "too early" and "too suddenly", thus implying the potential for prevention or some degree of reversibility in this form of decline.

The three sub-themes of *"Kukosa lishe"*: Missing food, lists "lifestyle" factors which could be regarded as modifiable and largely within the individual's control. These being, missing meals and not getting a nutritious diet, not enough physical exercise and harmful alcohol intake. These sub-themes will be returned to in section 8.17 with critical reflection on the "successful ageing" discourse of Rowe and Khan, which claims that "successful ageing" consists of three components; "avoiding disease", "maintaining high cognitive and physician function" and "engagement with life" (Rowe and Kahn, 1999).

Sub-themes of "Kwa sababu ya kukosa lishe na chakula bora"

5.19 "Mwili si unakuwa vingine": The body can't become another way

In this sub-theme, frailty was discussed as a consequence of old age, an accepted and insurmountable part of ageing. Widower 'Babu Materu', aged 93 distinguished between disease and frailty, and attributed his weaknesses to the expected changes which come with age. He didn't seem troubled by feeling frail, perhaps because he felt well cared for; living in a house on the same compound as his daughter-in-law, who provided meals and cleaning. Additionally a grandchild slept at his house to assist him to the toilet, and provide company and security overnight.

My health is good. Due to old age yes, I have frailty, I feel frail but I do not have much disease, normal illnesses for example those sicknesses of the day, for example I suffer from malaria, I go to the hospital then I get better. (Babu Materu, 4th July 2017)

The 47 year old last-born daughter and care-giver for her 93 year old mother reflected that she hopes to be in the same physical condition as her mother, if she reaches her nineties. She believed her physical frailty was only to be expected given the years of hard manual work she had worked on her family's behalf.

For sure where she has reached old age, you know the joints, she has been working, the joints cannot work, also even me, if God helps me I will reach that age of ninety the legs also will have failed, they will fail to work because it is old age, I have reached[21] into old age. (Mama Agnes, 5th July 2017)

This is the form of frailty, which was expected as a normal part of the life course, and was expressed earlier as a returning to the role identity of "childlike" dependent. There is a matter-of-fact acceptance of this form of frailty, especially where the younger generation are able to meet the needs that this dependency produces. This acceptance of "usual ageing" is in contrast with the discourse of "successful ageing" which promotes ways of maintaining and enhancing physical and cognitive function (Rowe and Kahn, 1999), in order to maintain the characteristics of youth for as possible and resist the ("usual") aging process. This acceptance that frailty was "usual" was not a fatalistic attitude, rather expectations of becoming frail in old age, were realistic. Particularly given that access to healthcare was limited (see section 6.9). Conditions which would be treatable in a high-income country setting, for example

[21] Nimefika=I have arrived, an alternative translation. Reaching or arriving implies getting to a place at the end of a journey. Thus the language used also conveys a life course approach to ageing, with frailty the culmination of a "successful life" of productive work.

osteoarthritis which would be remedied by a joint replacement, may lead to frailty in this setting, through reduced mobility and chronic pain leading to muscle deconditioning, reduced income, and increased social isolation.

In addition to this realistic view, “the body can’t become another way” signifies the meaning of frailty according to the first formulation frailty (returning to “childlike” dependency). Becoming frail in late old age is seen as evidence of a life and body spent in service of others. It signifies having worked hard and raised a family, and thus a life lived successfully. Taking this concept further, the frail body does not exempt a person from ageing successfully, rather ageing successfully according to the Tanzanian view of success, is to receive care in one’s dependency. Rowe and Khan’s “successful ageing” model has been compared with the Tanzanian view of “success” in ageing in order to shed further light on the meaning of frailty, and is discussed in (*Table 5-2*).

5.20 “Kukosa lishe”: Missing food

Within this sub-theme frailty was described as developing because of missing meals and going hungry. This was talked about both objectively and subjectively, with FGD respondents describing how older people may miss meals and be forced to rely on luck or charity for their next meal. Frail participants meanwhile, for example ‘Babu Shuma’, described needing “sustenance” to give himself a “boost” of energy as he was losing weight and walking at a slower pace, both being components of the FP, and previously described as important physical characteristics of frailty.

Missing meals was a very common explanation for becoming frail. This thinking is also supported by the theoretical framework which underpins the FP, termed the “cycle of frailty” (Fried et al., 2001). According to this hypothesis, chronic undernutrition due to an inadequate intake of protein, energy, and micronutrients, contributes to skeletal muscle loss, and reduced energy expenditure, which in turn leads to a cyclical downward spiral towards increasing frailty, dependency and death (Fried et al., 2001). Participants described in stark terms how frailty may be caused by subsisting on one meal per day, or often going hungry. ‘Babu Shuma’, a blind cattle herder described difficulty getting enough to eat or drink. When JR gave him his gift of 1Kg sugar to thank him for his time in participating, he kissed the bag of sugar and started to pray with gratitude.

…I want to get a little sustenance, to get food so as to help me otherwise without this the body is getting weak, it’s not that I have fever, my body is becoming completely weakened, like a donkey, a donkey. If I want to go get up I have to cling to the staff, I

look for anyone to give me even some tea to drink but I don't get any, I have problems mother we are in difficulty, yes that's my problem. (Babu Shuma, 87 years 14th July 2017)

This form of inadequate intake is clearly different from "the anorexia of ageing" which is hypothesised to lead to frailty through chronic undernutrition as part of the "cycle of frailty" underlying Fried's FP (*Figure 2-2*) (Fried et al., 2001). The anorexia of ageing has been defined as an age-associated reduction in appetite and hunger which occurs due to multi-component interactions of physiological, psychological, social and medical reasons (Malafarina et al., 2013). Undoubtedly, physiological changes in the hormones that regulate appetite, hunger and satiation play a role in this sub-theme as a factor contributing to reduced food intake, but most often this "missing food" was due to a scarcity of resources (food or money).

This 64 year old ten-cell leader 'Mzee Mrema', when asked whether frailty was an expected part of old age responded;

It's not normal for all elders, because when you are in old age and you only get one meal per day, you become twice older unexpectedly. (Mzee Mrema, 14th July 2017)

Thus, this form of frailty, caused by going hungry and skipping meals caused a sudden and aberrant form of ageing and frailty.

Another striking example of loss of appetite was seen in 'Bibi Martha' (93 years), who suffered dementia and consequently forgot mealtimes forgetting to eat unless prompted. Her daughter-in-law 'Mama Upendo' (55 years) felt this attribute was both a hallmark and cause of her mother-in-law's frailty;

JR: And you say that Bibi has frailty, what makes you see it this way? What makes you say that she is frail, how do you see it?

Mama Upendo: As I see she has really lost her appetite, she eats very little.

JR: She eats a little amount?

Mama Upendo: Eeeh, Yes, she eats very little. (14th August 2017)

5.20.1 "Chakula bora": Better food

Poor diet was attributed to causing frailty in this sub-theme. It was a common belief that certain foods provided the body with energy and strength and could delay the onset of frailty.

What constituted "better food" varied considerably, with some blaming frailty on chemicals in food and cholesterol in cooking oil. Others described a lack of softer foods, appropriate for older people to be able to chew and digest easily, conversely "watery" foods were described as "useless". There was also an acknowledgement that a lack of protein, fruits and vegetables in the diet could contribute to frailty, with the poorest and most frail among participants living on the staple carbohydrate *"ugali"* (a stiff porridge) and beans.

Myself its eight months I haven't known meat, not even fish, you can ask her it's just beans mother, today it's beans we get. (Baba Thomas, 63 years, accountant, 14th August 2017)

In the following quotation, 'Babu Materu', cared-for by his daughter-in-law describes becoming frail due to being unable to chew nutritious and flavoursome foods properly.

JK: Now it is just old age bringing you frailty?

Babu Materu: It is old age, and for example these foods here are useless, useless, for example teeth, look here I haven't any so to chew and chew I cannot, yes it brings me my deficiency[22]. After these things of chewing and chewing, yes, are the things which bring flavour, the teeth they bring starch to the body. After, the blood receives it and becomes satisfied. You see yeah? Now if the things of chewing, chewing you don't get, only the liquid watery food, it's useless. (93 years, widower, 4th July 2017)

Therefore, taking a multi-component approach to the concept of the "anorexia of ageing" in this setting these findings provide examples of physiological, psychological, social and medical reasons for reduced quality and quantity of food intake. Material constraints due to household financial difficulty, exacerbated by the frail older person's physical and financial dependency are likely to be the most important factors in the construct of frailty caused by a lack of (or scarcity) of adequate nutrition.

5.20.2 "Mazoezi": Physical exercise

Physical work was discussed as a way of maintaining your ability to work into old age in this sub-theme. This was based on the understanding that there is a wide variation in individual functional capabilities with age. Here, two residents of Amani agree that continuing to do hard physical work enables one to maintain these abilities for longer.

[22] -pungufu adj 1. Lacking, 2. Incomplete 3. Deficient the original translation by LM was "it brings me to reduce myself" which would be another valid translation, as weight loss is often described in similar terms -punguza v 1. To reduce 2. To trim

You know there is a way you can live which will make yourself elderly. If you do not do heavy work you must get old. Because you are used to simple or light things… (Mzee Elias 87 years, temporary manual labourer, 16th February 2017)

Being of old age is because of what? A person is to do with the person's experience of work, even if they have one hundred years, but are used to working they will make an effort, they will do everything a bit, but if you are lazy or weaken yourself you will get old. (Mzee Joseph, 91 years, worker for Kilimanjaro Native Co-operative Union, 16th February 2017)

This narrative to some extent concurs with the "successful ageing" discourse which frames the physical decline of old age, termed "usual ageing" as a choice (Rowe and Kahn, 1999). Physical exercise in the rural Tanzanian context however was rarely a leisure activity or choice, but due to a reliance on non-industrialised farming practices, physical exercise means manual labour and strenuous daily tasks such as chopping firewood.

When referring to work as exercise, it diminishes its importance culturally. Being able to carry out productive work in order to feed others is the activity of an adult. Cattell conducted an anthropological study focused on older people in the Abaluyia culture and society of rural Kenya, and wrote about the concept of work. Given the challenges of rural subsistence life (in contrast with the convenience and ease of urban "modern" life), work was seen as vital for life and in producing the social role of adulthood: *"A responsible adult is one who works hard and feeds others"* (Cattell, 2002, p161). It was observed that *"work…validates an individual's personhood and place in family and community"* while conversely *"old people don't work they just sit and eat"* (Cattell, 2002, p161). Hard physical work was seen as necessary for subsistence and survival, and was discussed as a means of being a socially valid "adult" person in a grounded theory study of older people in Malawi (Freeman, 2018). Importantly, this work was conceptualised as a form of care, given that work was not only for the individual's subsistence, but for the sake of family (Freeman, 2018). The performance of care through productive physical work for the subsistence of one's dependents was what constituted a social "adult". Therefore in recommending hard physical work as a means of avoiding frailty, 'Mzee Elias' and 'Mzee Joseph' are framing frailty in moral terms. If you are lazy, and are not productive for the sake of others when you are capable and healthy, you will deserve to become "old early".

5.20.3 "Kunywa kinwaji bila kula": Drinking alcohol without eating

In another example of frailty as an aberration from normal ageing, this sub-theme recognises that frailty is not exclusive to older people, rather it's argued that alcoholism can lead to frailty, even in younger people.

The most common alcoholic drink in Hai District is known as *"Mbege"* (banana beer), which is traditional to the *"Mchagga"* ethnic group. It is made through a laborious process of sun-drying then grinding millet to make a flour, and boiling, mashing and straining banana, before leaving both to ferment together. More affordable than bottled beers, *"Mbege"* is ubiquitous in Hai District. It is socially important, shared from the same traditional calabash vessel at celebrations and ceremonies, but it is also drunk on a regular basis (most often by men), when gathering with friends to socialise after a day of working in the field. This sub-theme constituted warnings against alcohol consumption outside of these socially acceptable norms, stating that it destroys the body, mind, and finances, leading to frailty. In suggesting that frailty is not an inevitable consequence of ageing this sub-theme is more consistent with biomedical models of frailty, which emphasise the diversity of health states in advanced chronological age.

There is also the implication that alcohol consumption outside of socially accepted drinking is irresponsible as it will impact on one's ability to work and care as a responsible "adult" ought, so there is also a moral dimension to this cause of frailty. This 69 year old, health committee member hopes that by making responsible decisions, he will still be able to work at age 75;

But also to the age like seventy five, for many we see that those with seventy five years old are not very elderly. There are elders who can cultivate, there are elders who are able to walk except for an elder who has not exercised himself through life, maybe alcoholism since he was a youth. If they reach the age of seventy five he becomes a person who has failed for himself completely, and the diseases like stroke can develop easily. But if you were a person who was responsible for your activities especially of cultivating well and walking, and physical exercise from being a youth, the age of seventy five is still not very elderly to say it disturbs you. (Mzee Terewandumi, 5th July 2017)

5.21 "Magonjwa sugu": Resistant or chronic diseases

Descriptions in this sub-theme are of diseases slowly affect the body, remaining untreated until they lead to frailty. That chronic or untreated diseases build-up leading to frailty over

time fits with the biomedical "accumulation of deficits" model of frailty (Rockwood and Mitnitski, 2007). This ten-cell leader with no medical background observed;

Eee, frailty in the older people, the biggest problem is illnesses that come inside you slowly and affect the lower limbs and the back, and they don't get treatment at the appropriate time, so the illness gets worse until you find that person limping with a stick, then you find that person just lying down. (Mzee Kimaro, 54 years, church curate, 14th July 2017)

This description of frailty also fits well the biomedical understanding of frailty as overlapping with multimorbidity and disability (Fried et al., 2001). However, the key distinction is that in this context, frailty occurs due to not receiving "treatment at the appropriate time", this is a form of scarcity. It is the medical problems which are left undiagnosed, unchecked and symptomatic which lead to frailty. An experienced village chairman described the injustice of the situation vividly;

If it is the service for the elder then it should be meant for that, and not that the elder goes there limping for half an hour and when he reaches there he is given Paracetamol and returns home with the same disease, it adds to the problem until the disease doubles. (Mzee Mrema, 64 years, subsistence farmer 14th July 2017)

From the perspective of older people themselves, living with chronic diseases was an indignity and source of suffering. For 'Babu Elirehema', whose son struggled to provide the healthcare he required, the consequence was chronic urinary symptoms. The most troubling for him was the development of incontinence. According to Van de Geest's study of older people's care and toileting in rural Ghana, incontinence was generally regarded as one of the most "painful" and "humiliating" consequences of old age (Van der Geest, 2002b). It was also believed that rich people don't suffer with incontinence, because medicines can be bought to treat it. Therefore, for 'Babu Elirehema', these chronic symptoms may have been an indication of the family's poor status and means, and an marker of frailty through scarcity.

…it's the problem of the bladder. There is a problem of letting the urine pass freely. Now it is like when we are here and I feel ready to urinate I have to run first to turn it away, if not, and I stay here, in time you will see it just passing free! It is what?…it is bad! I do not know what is the reason that the urine is like this? (Babu Elirehema, 80 years, subsistence farmer and cattle herder, 4th July 2017)

While a lack of healthcare was seen as a cause of frailty, and part of the formulation of frailty as "being in scarcity", the provision of healthcare was arranged, organised and paid for, on behalf of frail older people by family and care-givers, thus this topic has been included in Part Two which focuses on the care of frail older people.

5.22 "Tatizo ya kumbukumbu": The problem of memory

In addition to "frailty of the mind" being a distinct form of frailty as discussed in the sub-theme *"Udhaifu wa afya na akili"*: frailty of health and mind, frailty was also discussed as a sequalae of memory problems. Cognitive impairment contributed to more widespread frailty, due to having a "childlike" mind. This ten-cell leader, spoke from his experience of providing care to his grandparents when he was 12 years old;

In ageing what I remember is that when a person is headed to old age their mind becomes like that of a small child. Then things, they start forgetting from time to time. (Mzee Asanterabi, 65 years, subsistence farmer 13th June 2017)

The pattern of cognitive impairment associated with physical frailty has been described as "cognitive frailty" by biomedical research (Facal et al., 2019). As introduced in the literature review (section 2.10.2), the concept of "cognitive frailty" has been characterised by its theoretical reversibility (Ruan et al., 2015).

In contrast, "the problem of memory" was recognised not as a potentially reversible harbinger of frailty, but as a cause of dependency. Requiring of the same care and "raising" due to cognitive impairment meant taking on the same social role as a frail person. Therefore, the dependency caused by dementia is what caused frailty. This detail adds to the conceptualisation of frailty as return to "childlike" dependency. "Childlike" could be interpreted as a return to the physical feebleness of infancy, yet it is clear through the current sub-theme and *"Udhaifu wa afya na akili"*: frailty of health and mind, that dependency for care was the key factor; so that a person might be physically robust, but frail due to their dependency.

So that's the kind of frailty that she has, meaning she can't perform anything. That's the frailty. (Baba Munuo, 70 years, subsistence farmer and small business owner, 13th June 2017)

Dementia, in these data are referred to in fairly benign terms, for example "forgetting things" and the term *"tatizo ya kumbukumbu"* (the problem of memory). However there is evidence from urban South Africa of dementia being constructed as a form of bewitchment or madness

(Ferreira and Makoni, 2002). This construction was not borne out in these data, where even aggressive or confused behaviour was excused due to the frail older person's "childlike" status. One Amani staff member describes her attitude to dealing with residents who have cognitive impairment thus.

…another time they speak with you badly but you see they are already aged, you can't get angry completely, you just laugh, you are just happy because they are elders already, a child. (Mama Magreth, 47, care assistant, 27th May 2017)

It is suggested by these data that the social expectations of this identity role, in addition to receiving care, include an innocence and lack of personal autonomy. Thus, "the problem of memory" as a cause of frailty aligns with the first construct of frailty as a return to the role of "childlike" dependency. Mushi et al. conducted a sociocultural exploration of dementia in Hai District, (2014) and found that dementia was largely normalised as an expected part of ageing. These data concur with their finding that dementia was not thought of in the same way as other diseases, which are seen as potentially treatable. It was so normalised in late old age that it was even referred to as *"ugonjwa wa wazee"* (disease of older people) (Mushi et al., 2014).

5.23 "Watoto wako safirini basi anadhoofika": Your children are travelling then you become frail

This refers to instances where psychological suffering was given as a cause of frailty. This psychological distress came about due to a lack of family material support, comfort and company. Examples from these data include a grandmother missing the "close" care of her children when they are travelling[23], and lacking financial resources (another possible sign of neglect by adult children). It may also be due participants interpreting frailty or weaknesses as a psychological state of feeling dejected, and wretched. The daughter of 'Bibi Eliaika' (109 years) describes her mother's psychological suffering in this way.

JR: Do you think grandmother has become frail?

Mama Kilala: Yes, she has become frail, there is a time if she remembers something, for example perhaps the day her children are travelling then she is weakened and becomes a wretched, wretched[24] person. Or if she wants money and she doesn't have any money in her kanga[14] she becomes frail, she says, "see how I have become so poor I have run out of it this way?" (62 years, subsistence farmer, 1st August 2017)

[23] In this context "travelling" refers to rural-to-urban migration, rather than travelling as a leisure activity.
[24] Mnyonge (n)= weak person, "down-and-out", wretched person. It is repeated for emphasis. In the original translation of the transcript, it was translated as "debased" by JR.

"Mawazo" (too many thoughts) can lead to frailty. This has been described as a "cultural concept of distress" commonly expressed in studies with African participants (Kaiser et al., 2015). The idiom may have some overlap with depression or anxiety, however the expression does not fit within the narrow categorisations of psychiatric symptoms and diagnoses. In this example, it may reflect a suffering associated with the struggle to accept socio-cultural changes such as the urban migration and "neglect" of adult children. In a review of the idiom, the sequalae of "thinking too much" were broad, including memory loss, tiredness, exhaustion and weakness (Kaiser et al., 2015). This sub-theme adds to the understanding of this concept of distress, in that frailty and memory loss were also thought to be caused by *"mawazo"*. Therefore, both too many, and a reduction in thoughts were mentioned as being closely linked with frailty.

Yes indeed… you may have thoughts that make you a fool[25] even frail in the body. Due to the things you think about today, the thoughts of today are like what to eat, what the children will eat or those elders? When an elder sleeps there, thinking "ooh my children, I was the one who helped you but right now I am tired and what do I have of any such kind?" It's frailty. (Mzee Martin, 65 years, subsistence famer, 13th June 2017)

Essentially this form of scarcity is lacking the "deserved" and "close" care (described in *"Kutunza wazee ni wajibu"*: taking care of the elderly is a responsibility), which is the traditional and idealised form of care. Whether due to active neglect and abandonment, or due to the struggle of balancing minimal resources of finances or time, this lack of care led almost to a form of existential suffering for older people. Existential because it caused older people to question the value and purpose of their life's work if it was not being recognised through the reciprocal care of their children.

5.23.1 "Elimu imekuwa ni ndogo": The education has been little

Here, frailty was conceptualised as being caused by a lack of education, both directly (through poor health education) and indirectly (through older parents not being able to rely on the better earnings of an educated younger generation). This broad inter-generational approach to thinking about the causes of frailty in older people reveals the extent to which individuals think of themselves as belonging within interdependent and inter-generational networks (Whyte, 2017). Frailty occurred in the context of a dysfunction of these interdependencies,

[25] Mjinga (n) = clown or fool, in this quotation it refers to being made to feel like a fool

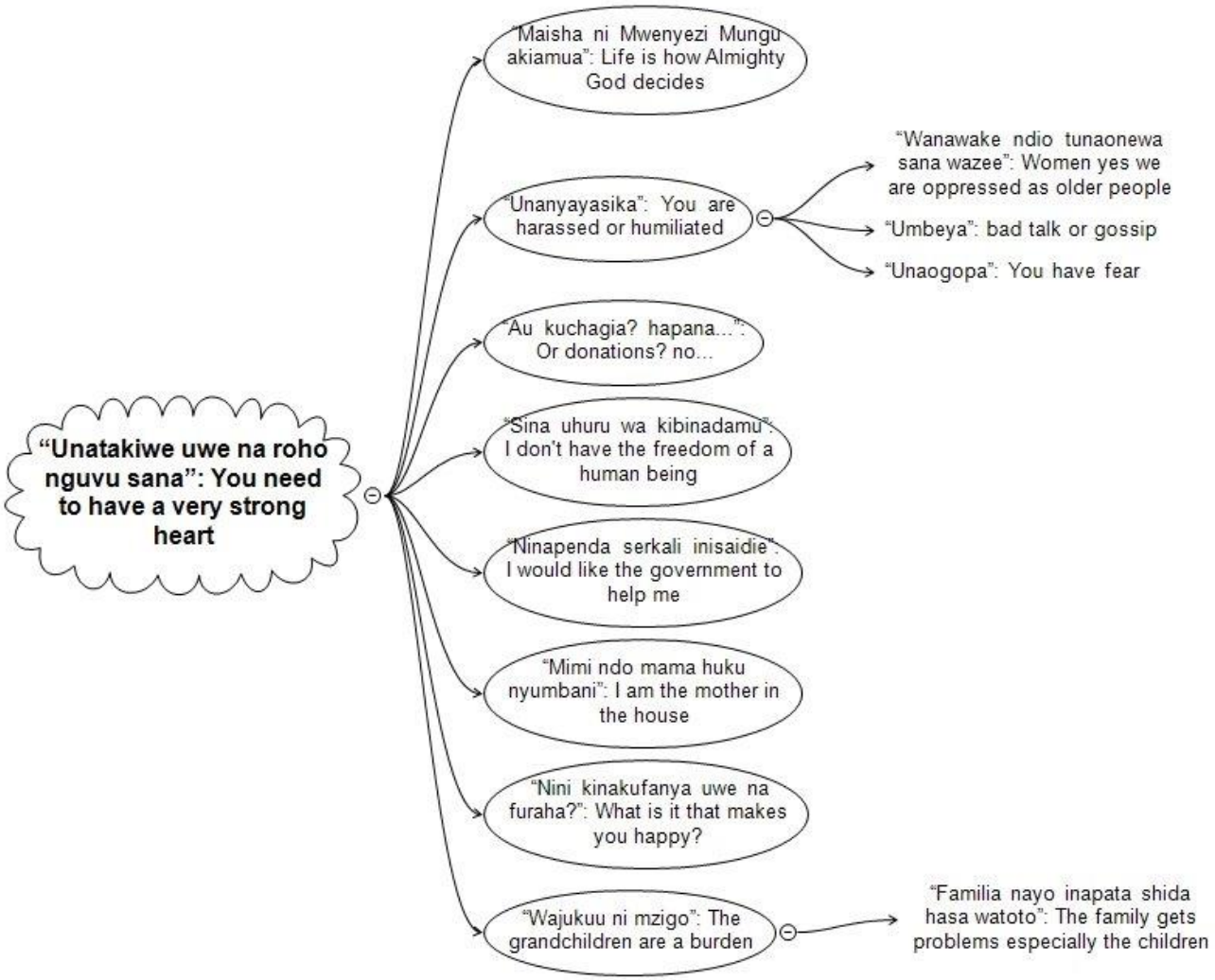
and as a scarcity of education. This argument was made by a health committee member, a 36 year old subsistence farmer:

Someone in our environment who lives with frailty? There are many and they are living in a very poor situation that are like, you find elders who do not have means of eating, and for a big percentage it is caused by education. That if someone gets education it's easy to do what? Even when they are given health education or education about anything else it becomes easy, even the elder can get the fruit (of success) from the their children… So in big percentage, the cycle comes from (the fact) that education is little, education has been little, so you find many elders and even youth are also frail. (Mzee Mfaume, 4th July 2017)

This topic will be elaborated upon further in the discussion chapter, section 8.7 when discussing the conceptualisation of frailty as "being in scarcity" also with reference to modernisation theory, which was introduced in section 2.21.

5.24 Theme: Unatakiwe uwe na roho nguvu sana

Figure 5-5 Mind-map illustrating the sub-themes of "Unatakiwe uwe na roho nguvu sana"



5.25 "Unatakiwe uwe na roho nguvu sana": You need to have a very strong heart

The focus of this theme is on the lived-experience of frailty in this context. These data come from interviews with older people and their family or care-givers, the sub-themes are illustrated above (*Figure 5-5*).

Overall, the experience of living with frailty in old age was epitomised by requiring strength of character and fortitude of spirit. This theme describes older people's experiences of the ways in which they are forced to take heart and bolster themselves (*"Unanyayasika"*: You are harassed or humiliated). The theme also describes some of the strategies employed to survive and persevere despite the challenges they face (*"Maisha ni Mwenyezi Mungu akiamua":* Life is how Almighty God decides.) Some of the hopes and expectations of older people living with frailty are also presented (*"Ninapenda serkali inisaidie"*: I would like the government to help me).

Sub-themes of "Unatakiwe uwe na roho nguvu sana"

5.26 "Maisha ni Mwenyezi Mungu akiamua": Life is how Almighty God decides

This sub-theme describes the ways in which older people relate their religious beliefs to their lives and their futures in the context of daily uncertainty over whether they will be fed or go hungry, and a longer-term uncertainty over the care they might need. Perceived good fortune was expressed as a blessing to be grateful for, and any misfortune or hardship, was expressed as being tried or tested by God. Trust in God's plan for their future was an important source of comfort and hope for older adults living with frailty regardless of religious affiliation. While all participants described a religious affiliation, this sub-theme provides evidence of personal comfort gained through these beliefs.

The quotation below, taken as the sub-theme title was the response of 'Mama Pili', a 60 year old Muslim widow, to the question of whether she worries about her future.

Life is how Almighty God decides, now why should I worry? (Mama Pili, 27th July 2017)

Older adults were reluctant to admit to fear of the future, given that their future was perceived to be "in God's hands", this was also the case when considering their death. The belief that God was the ultimate judge and executioner of justice was also a comfort for those who felt they had been wronged or disrespected, as in the following sub-theme (*"Unanyayasika"*: You are harassed or humiliated). Particularly relevant to the experience of living with frailty; God was seen as giving strength when strength was ailing.

For sure we feel, because of being unable, I have told you it is only God himself who gives us strength because you may not be able, you may not be able to wake up, then you struggle to stand up and just work by the strength of Almighty God. Because God is the one who gives strength. I have said the truth. I cannot say I have strived myself, yes God has given me the strength. When I wake up in the morning I pray to God first so as He can give me strength to work. (Babu Obadia, 82 years, subsistence farmer, 5th July 2017)

Religiosity is undoubtedly an important part of African life, but the meaning and experience of personal faith and religiosity for older Africans has been little studied (Kodzi et al., 2011). The health and psychological benefits of religious affiliation and involvement in old age have been suggested to work via several mechanisms; by providing a worldview through which successful living is defined, by providing additional social arrangements through which older people may access practical support, through increased social integration, and by enabling emotionally supportive relationships to form between people living with similar experiences (Kodzi et al., 2011). This sub-theme supports these ideas, for example, for 'Bibi Zakia' and 'Babu Shuma' the local Sheikh was a source of practical support through donations of food and money, and regularly attending the mosque was an important social event for 'Bibi Zakia', and vicariously for her husband too. Perhaps most importantly, their religious belief gave them a framework for living which gave them a hope of "blessings", and guided them away from what they perceived to be the potentially harmful influences of alcohol and gossip.

If we are getting a donation we thank Alhamdulillah! Because that donation will reduce the bad thoughts, that donation will get rid of desire… my heart will be calm. (Babu Shuma, 87 year old cattle herder, 14th July 2017)

Research has examined the influence of religious affiliation and participation and found that it contributes as an independent variable to overall wellbeing (Kodzi et al., 2011), yet this qualitative work provides a deeper insight into the influence of religion on the experience of living with frailty in rural SSA. Overall, religious belief helped older people to cope, and to "have a strong heart" in the face of their chronic suffering and hardships.

5.27 "Unanyayasika": You are harassed or humiliated[26]

This theme describes the injustices, humiliations or harassment felt by older people. All of these instances can be seen as examples of where the younger generation have not kept their

[26] -nyayasika (v)= to be harassed. Throughout many of the transcripts JR chose to use the term "humiliated", which may be more contextually appropriate.

side of the “reciprocal contract” (Whyte, 2017) and older people have been disrespected and have not received the care that they expected, upon reaching old age.

Traditionally old age imbues a certain stature and authority, and an *“Mzee”* (older gentleman) would expect children to follow his commands. Therefore, ‘Baba Thomas’ felt humiliated by children *“who are cruel and don't obey”*. In one example, ‘Baba Thomas’ who was blind and walked unsteadily with a stick, was ignored by local children when he called on them to accompany him to the bathroom. He was disgraced by being left to soil himself, and had to wait for his wife to return from the field in the evening in order to be helped.

In the following quotation, ‘Babu Elirehema’ was not humiliated by his diminishing physical ability to work productively, but more by the fact of being rejected and ostracised by members of his community.

Babu Elirehema: Yes I see myself that it is very bad, I feel very bad because I see that I am on my own and when I enter there I am told, others they will ignore me telling me “you, go away! You, do this!” so then it becomes a shame, it’s a rejection, so I return to do my activities right here.

JK: why do they tell you go away, why?

Babu Elirehema: because they see you don’t contribute together with them or you cannot do the work of who, you cannot work, if you take it (the hoe) they tell you that “you will die, move from here now!” (80 years, subsistence farmer and cattle herder, 4th July 2017)

This type of marginalisation and disrespect has been discussed through the framework of elder abuse in South Africa (Ferreira and Lindgren, 2008). The authors suggests that cultural differences may require a broader definition and expanded categories of abuse in order to include marginalisation and disrespect. Although none of the participants in this study explicitly described these instances of harassment or humiliation as a form of abuse, their distress was clearly underpinned by a sense of injustice and concern over the changing attitudes of the younger generation (see also *“Wazee, hawana umuhimu na vijana”*: Elders, they're not important to young people).

5.27.1 “Wanawake ndio tunaonewa sana wazee”: Women yes we are oppressed as older people

Following on from the previous sub-theme, these data describe ways in which older women faced a particular type of humiliation and harassment. Widowed older women in particular,

risked being disinherited, met pressures to re-marry or stay unmarried, and were also more likely to face witchcraft accusations (Bridget Sleap, 2011, Lloyd-Sherlock et al., 2015). 'Bibi Helena', who was accused of being a witch, spoke the quotation taken as the sub-theme title, when reflecting on her maltreatment and stigmatisation by her community (this will be discussed further in the sub-theme "*Umbeya"*). The following excerpt comes from an interview with 'Mama Pili', a 60 year old in relatively good health. She had been selected to be interviewed to provide the perspective of a relatively healthy and financially secure older woman. However, during the interview she became upset, revealing the vulnerable position she'd been left in after her husband's death, having had much of her plot of land "snatched". She also described her more limited life choices as a woman who would not be permitted to re-marry while living on her deceased husband's land.

> *Mama Pili: It's true when you are a woman in your compound and you are left behind[27], you get bigger problems. You know the community can disturb your thoughts you need to have strong heart. A lot of things can make you sad and fill you with a lot of thoughts, or you can completely run away, in general a woman is harassed so much.*
>
> *JR: What about men?*
>
> *Mama Pili: He is not a pillar, if he remains alone he can re-marry and bring a woman home, aren't his thoughts reduced? You, can you bring a man home? You don't have that freedom. (21st July 2017)*

The association between widowhood and socio-economic status, health and wellbeing across the World Health Organization Study on global AGEing and adult health (WHO SAGE) countries has been investigated (Lloyd-Sherlock et al., 2015). Across all five countries widowhood was associated with the lowest wealth quintile, and of particular relevance to this study's setting, widows in Ghana had significantly higher levels of household poverty and food scarcity (Lloyd-Sherlock et al., 2015). This disinheritance of land was truly a threat to 'Mama Pili', given that the land was required for her sustenance in order to cultivate food, and as previously discussed, a scarcity of food was seen as an important cause of frailty in old age (*"Kukosa lishe"*: Missing food). Similarly, in a qualitative study of Zulu widows' experiences, widows grieved both for the loss of their financial security, as well as for the loss of their husbands (Rosenblatt and Nkosi, 2007). Widowhood was also a "struggle with

[27] "Left behind" in this context means to be widowed

witchcraft" for some (Rosenblatt and Nkosi, 2007), with witchcraft framed either as a cause for the death, or an accusation faced by the widows, a finding pertinent to the next sub-theme.

5.27.2 "Umbeya": bad talk or gossip

"Bad talk" or gossip was the experience older people had of being the object of the suspicion of others in the village, or of being gossiped about. Gossip was more common than open accusations and confrontation, but was harmful to older people's sense of belonging and inclusion within their communities, leading them to harbour feelings of mistrust. In Tanzania, people commonly hold beliefs about witchcraft and curses, so "bad talk" can be potentially very harmful. Witchcraft-related killing of older people is shockingly prevalent, with an average of 350 killings on witchcraft suspicion each year from 2014 to 2017 (Wazambi and Komanya, 2019). When older people in this study expressed concern about "bad talk" in the village, they were usually already socially marginalised, and such gossip may have led to their increased social withdrawal. To a large degree the residents of Amani were socially excluded from the surrounding community, and despite denying that there were any open witchcraft accusations, it was agreed that there was probably "bad talk" about them "outside". Kinshasa's residential homes for older people were also places of social exclusion, one of the reasons being, that they were said to be places of witches (Pype, 2018).

I think that people say that people here at the residence are witches, and the government saw that these people see that, these people who are brought here, that these people who are brought here are witches. If it has happened, then I have not heard, that at the residence a certain person is a witch, but outside here they speak about witchcraft. (Mzee Masana, 76 years, secondary school teacher, 18th February 2017)

The quotation below is from an interview with a woman in her nineties who was accused of witchcraft and who had been isolated by her community. She lived alone in a single-room house made of mud and sticks, and owned only one stool, which JR and I sat on together, while she insisted on taking a bucket turned upside-down. We sat like that, under a tree as there was no room or light in her tiny house to conduct the interview. Her son-in-law had refused to offer her care in his home, due to the accusations, yet some in the community had tried to reduce the stigma of these beliefs by bringing her to the front of the church congregation to declare that she was not a witch.

JR: They say you have done which things?

Bibi Helena: "That one she curses people, she does not listen to people"
(Estimated age around 90 years, traditional birth attendant, 21st July 2017)

In Tanzania, and other countries where witchcraft beliefs are prevalent, this type of "bad talk" can become exacerbated during times of economic hardship, leading to increased victimisation, particularly but not exclusively directed toward older unmarried women (Miguel, 2005). Indeed, this older woman's poverty in the context of a generally difficult economic climate and a recent poor harvest might have led to an worsening of the discrimination against her.

5.27.3 "Unaogopa": You have fear

"Unaogopa" describes the fearful the experience of becoming older and living with frailty in Tanzania. In particular, older people and their care-givers experienced fear of crime. This was seen as a gross violation of the respect which older people desired and expected. Examples of fear of crime includes 'Mama Upendo' was afraid of leaving 'Bibi Martha', a 93 year old woman with dementia alone, for fear that people could come and *"do something bad without her knowing"*. The social officer in charge of Amani spoke about a break-in at the residential home. That residents' government-provided food supplies could be stolen despite having a guard, highlighted their vulnerability. A perimeter wall was then built with fundraising support from the UK-based NGO.

In the past there was a problem, before having the wall, the things of the elders were stolen. The thieves came and broke in and took the elders food, but after having the wall we give thanks that the theft has decreased. We have not seen that again. No thieves again. (58 years female, social officer in charge 16th February 2017)

The finding that physically and cognitively frail individuals experienced fear in their daily lives is important, and gives weight to the "General Vulnerability Model" as a theory for fear of crime (Lloyd-Sherlock et al., 2016). This conceptual framework states that older individuals with particular physical vulnerabilities, such as frailty or with social vulnerabilities such as poverty or low educational attainment are more likely to live with a fear of crime. From the analysis of the large WHO SAGE dataset (comprising a total population of over 35,000 older adults living in six different LMICs), the authors found that frailty (by FI) was a more important determinant of fear of crime than chronological age or sex (Lloyd-Sherlock et al., 2016). Stiles et al. suggested that thinking of yourself as "weak", or an "easy target" may lead to increased fear of crime, and found an association between fear

of crime and physical disability (Stiles et al., 2016), a concept which overlaps considerably with frailty.

These data suggest that not only are older people in Hai District more comfortable and willing to describe themselves as frail or as having weaknesses, but that care-givers and relatives also perceive older people to be more at risk of victimisation. The "Experiential Model" theorises that fear of crime is closely related to actual risk of crime and experiences of such (Lloyd-Sherlock et al., 2016). Although there is much evidence of older people in Tanzania facing violence, and even killing due to accusations of witchcraft, (Kibuga and Dianga, 2000, Ministry of Labour Youth Development and Sports, 2003, Wazambi and Komanya, 2019) our data did not provide any examples of this except for malicious rumours of witchcraft accusations which led to an increased isolation of the older person within the community (*"Umbeya"*: bad talk or gossip).

5.28 "Au kuchagia? hapana...": Or donations? no...

Frail older people did not have the financial capabilities to contribute to the community in the ways expected of other people. This was experienced as an indignity by older adults who, due to a lack of income, were not able to participate in society as they would wish. This indignity may have been more bothersome than being dependent for physical care. For example, this title comes from the fact that people are generally expected to contribute a small donation when they attend a wedding, funeral, or church service (Case et al., 2013). However, older adults without means faced the indignity of going to these gatherings empty-handed. In Tanzanian culture, this could be a reason for isolating oneself and avoiding social events. Other examples included not being able to afford higher value items such as high protein foods (meat and fish) or a razor to maintain one's appearance.

'Mzee Eliakimu', resident at Amani could be sure of receiving three meals daily, provided by the government rations. Yet, because he felt the indignity of not being able to maintain his appearance through shaving, or by bringing an "offering" to church. He bitterly compared his situation with that of older adults in Zanzibar, who receive a universal state pension.

I cannot speak about saying that I want or I would like the government to help me with something for me to have leisure, no! I can say that the government can decide to give us pensions, like the government of Zanzibar, they do not. They do not just give pensions to the elders who worked (for the government), but to all the elders who are there who don't have means, they are given money every three months. Now that money is not for leisure, that money is for buying items to help one. You have sugar

and tea, but then you drink without buns, you can't find even a razor for shaving your beard, you do not have, you do not have the money for buying the razor, you might go church and now…? (Mzee Eliakimu, 78 years, civil servant, 4th May 2017)

Poverty in urban Cape Town was discussed in relation to older adults' self-identities (Sagner, 2002). The author describes a similar difficulty that older people faced in maintaining their "adult" social identities when, despite receiving a pension, the meagre amounts did not stretch far enough. This poverty threatened their abilities to continue in their work of caring for their families and cultivating family relationships (Sagner, 2002). In this study, 'Mzee Eliakimu' despite not having family, and living with frailty still wanted to be seen and appreciated for his contributions to the community and money was, as he points out, "not for leisure" but rather, a means to be included again.

This sub-theme has also enabled, to the author's knowledge, the first comparison of frailty according to the lived-experiences of older people living in a residential home with those living in the community. The lack of ability to participate in community activities in a dignified manner because of a lack of spending money was important to the residents of Amani, but can be contrasted with the struggle for daily subsistence, which was often seen as the main factor producing and epitomising the experience of frailty in the community (*"Nini kinakufanya uwe na furaha?"*: What is it that makes you happy?). This contrast has also been borne out in a small quantitative study from Morogoro, Tanzania which compared the nutritional status of institutionalised and community-dwelling adults aged over 60 (Nyaruhucha et al., 2004). The most common form of income for the older adults living in the community was begging, suggesting that food insecurity was a problem for them, while older institutional residents were more often overweight, which authors suggest was "probably due to the fact that elderly people in institutional centres were assured of having food" (Nyaruhucha et al., 2004).

Nevertheless, this sub-theme highlights the importance of the psychological aspect of the experience of frailty, that of the distress of indignity. The next sub-theme follows on, with another of the lived-experiences of frailty, that of feeling excluded.

5.29 "Sina uhuru wa kibinadamu": I don't have the freedom of a human being

This sub-theme describes the experiences of frail older people feeling trapped or imprisoned. 'Baba Thomas' describes his experience of blindness as being "a prison", and the two elders interviewed together at Amani describe not being permitted to leave the residence to visit friends. Ageing and frailty, compounded by a lack of income led to a loss of physical freedom

and was a dehumanising experience. ‘Mzee Masana’ a retired teacher contrasted the freedoms he’d heard existed for older people at residential homes in Europe, highlighting the indignity of this. Crucially, where older people with frailty felt they lacked freedom, it was not in order to have the capability to explore or pursue their own adventures or desires, instead it was in order to maintain their dignity and for the purpose of cultivating relationships.

You cannot get used to this environment, the environment at our place, is a thing which you cannot take with you own authority, have you heard that we have that freedom of saying, “I can move here and go to relax somewhere else, I have my friend whom I left there?” you are not allowed! So these are problems. I do not have the direct freedom that a human being is supposed to have! But the way it is in Europe, I hear that they have freedom. They are visited and other people come, others have their parents there, they come to see those people… But at our place nothing like that. (Mzee Masana, 76 years, secondary school teacher, 16th February 2017)

The importance of being able to visit and spend time relaxing with others becomes clear when the cultural understanding of what it is to be a “human being” is fully understood. The African philosophy of *“Ubuntu”*, captures the notion of personhood as a relational entity (Sagner, 2002). As discussed by Sagner, the concept can be understood to mean; “people are people through people”. Put another way, we give each other our humanness. Therefore the complaint expressed in this sub-theme of, “I don’t have the freedom of a human being” expresses not having the ability to be socially and relationally validated, as others are. In evidence for this interpretation, frail older people who were immobile did not express this sentiment if they felt cared for “closely” by family, and received frequent visitors. For example ‘Bibi Hosiana’, aged 93 and bed-bound following a stroke in 2004, said she lacked nothing in life, and enjoyed *“people coming and telling stories”(5th August 2017).*

5.30 “Ninapenda serkali inisaidie”: I would like the government to help me

From describing their many unmet needs, for example for healthcare or financial support, this sub-theme expresses older people’s impassioned requests for help, and their varied ideas for what should be done in response[28]. Due to their varied experiences of financial and other

[28] A note on the expression of need in Tanzanian Swahili: It is impolite to say “Ninataka”, meaning “I want”, instead the verbs “-omba” (to beg), or “-penda” (to like), are used. In Kenya, they freely use the verb “-taka”, which can cause offence in Tanzania because it is interpreted as a demand rather than a request. Bearing this in mind, the quotation, used as the sub-theme title; “ninapenda serkali inisaidie” is likely to be expressing a strong desire, or perceived need. This quotation was chosen to represent the theme as it encapsulates this typical style of communicating which is polite, with an emphasis on humility and respect. Yet it is not, as suggested by the English translation, just a preference.

support, their ideas differed, but were coherent in the sense that better care and provision was owed to them, underpinned by the value of reciprocity.

Many expressed the view that the Tanzanian government should organise a pension, and improve healthcare and complained that the government "of today" was not providing enough for older people. This 60 year old ten-cell leader compared the single-party post-independence government, with the current multi-party system, which has disappointed him with its empty promises.

I mean those elderly even among them, land for cultivating they do not have, even to hire for an income, to get income to provide for their own life, they don't have. The small amount they get they distribute within the family. Even their children are in a difficult situation as well, they cannot help them because the land they have is small. You find an elder is staying with his wife truly in a very bad condition. If you take us as ten-cell leaders who have been selected in the period when the political party was giving help, you find we are calling on one another currently, because as you look at a person, even hospital service, there is none. They have added many political parties to help them but they are in the air[29]*. (Mzee Temba 24th July 2017)*

In complaining in this way, as was found in urban South Africa, older people achieved many different purposes at once (Sagner, 2002). Firstly, in both studies participants complained to highlight the disjunction between their expectations and current life experience (Sagner, 2002). In the same manner as older adults expected reciprocal care from their families, this expectation also extended to the Tanzanian government. This complaining discourse was also in the context of linking-up with others and was used to reclaim continuity with the past (Sagner, 2002), occurring particularly in the context of FGDs. This complaint discourse has also been described previously in Tanzania, where older adults distanced themselves from the present and used reminiscence to identify themselves with the idealised socialist past (Kamat, 2008). Lastly, complaints such as these were empowering, allowing older people to voice their strong opinions (Sagner, 2002), of what *should* constitute reciprocal care from the government. Suggestions for action included introducing a national state pension, or improving healthcare provision.

[29] "They are in the air" is an expression meaning nothing tangible has come from the political parties' promises.

However, the counter narrative within this sub-theme was one of disempowerment and loss of agency. Emphasising the concept of frailty as a "childlike" state, this 91 year old resident of Amani expressed his feeling of dependency and reliance on the government;

I cannot do anything. I depend to the government, the government is my father and mother. I can't do anything, the government should take care of me. (Mzee Joseph, 16th February 2017)

In framing himself in the social role of a "frail dependent" with the government as his parents, 'Mzee Joseph' is also echoing the sentiment expressed in the sub-theme *"Kwa sababu wazee wamefanyakazi sana Tanzania"*: Because the elders have worked so much for Tanzania. Being weakened and in need of care was evidence of the strength invested in the country, and was evidence of his identity role as a "good" and deserving Tanzanian citizen.

Apart from the government being seen as an agent of providing reciprocal care and a means of expressing connection with the past and its political ideals. Foreign "sponsors" were also mentioned as providing care and assistance. For example 'Baba Thomas' had a child who was funded by a European Christian organisation to be educated at a private school, and the residents at Amani were grateful for the perimeter wall built by the UK-based NGO. However, this form of care was expressed as happening through God's blessing or good luck, and may have led to a sense of disempowerment. The older frail person could only hope and pray for good fortune, rather than bring about change through their own actions.

So now am sitting here for seven years in a shadow, praying to God and asking for help from good Samaritans for my family and I (Baba Thomas, 63 years, retired accountant, 14th August 2017)

Putting this together, living with frailty in this context was characterised by complaint discourse, which represented action and agency (Sagner, 2002), and was compatible with the underpinning value of national reciprocity (*"Kwa sababu wazee wamefanyakazi sana Tanzania"*: Because the elders have worked so much for Tanzania). However it was also countered by a disempowering narrative of reliance on the chance benevolent care provided by foreign governments or organisations. This may have led to a reduced sense of agency as well as devaluing the meaning and importance of the government-citizen reciprocal relationship for older Tanzanians.

5.31 "Mimi ndo mama huku nyumbani": I am the mother in the house

The gendered experience of care-giving and responsibility for dependents, often extending into old age, is the focus of this sub-theme. Throughout these data, older women took responsibilities for providing care in the form of income and food for their older husbands and other household members. 'Bibi Zakia' (76) explained she had no choice but to be the main provider.

Bibi Zakia: Yeah, it's just like that, I tire but I go out to search and search and bring (something) to him (her husband)[30], if we all get tired and we all stay sitting what will we do now?!

Oppong's overview of the situation of older African women in their family roles is consistent with these data (Oppong, 2016). The author portrays older women in SSA as simultaneously, and out of necessity, holding the roles of grandmother, care-giver and provider, typically continuing past "retirement" age and in the face of material hardship and undernutrition (Oppong, 2016). On one hand this gendered role of care-giving extending into old age is not a new phenomenon, a leisurely and restful retirement is an invention of industrialised welfare states. Indeed, over half of older men and women continue to work into old age in SSA, usually in the "informal" sector (Aboderin, 2017b). Yet "work" and "care" cannot be readily separated in this setting. As has been discussed, subsistence farming "work" is a form of "care" for one's dependents, and caring through working is what adults, including women, of all ages do. The additional factors challenging older women in this study include economic difficulties, food insecurity, urban migration of adult children, and physical ill-health, all contributing to and causing frailty ("*Kwasababu ya kukosa lishe na chakula bora*": because of missing nutrition and good food.).

Much has been made in the social sciences literature of the social impact of the HIV/AIDS epidemic. Chazan asserts however, that HIV/AIDS has not fundamentally changed the care-giving experiences of grandmothers, and that HIV/AIDS is only one of many cumulative stressors faced by older women (Chazan, 2008). This certainly holds true in this sub-theme's data. Despite herself being HIV-infected, 'Mama Josephine' (married to 'Baba Thomas') was forced to "run the family" with assistance from children who also helped to supplement their income. Typically, the literature has focused on grandmothers as "Africa's heroes" (Chazan,

[30] "Searching" in this context refers to working or begging for money, and the repetition suggests that she does it little by little, repeatedly.

2008), but rarely are grandmothers and mothers portrayed, HIV-infected or not, as striving in their ordinary hardships of carrying out their domestic and agricultural work.

Our life is not a good life that we live, because my husband lost his eyes, he cannot see any more so I am the one who runs the family and I cannot do this without Jesus Christ. (Mama Josephine, 45 years, subsistence farmer, 14th August 2017)

In continuing these work activities, older women were delaying frailty by avoiding becoming dependant on others, like their dependent "childlike" husbands. They remained in their responsible (working and caring) adult identity roles, through their work in the *"shamba"* (farm) or at home, both arenas where women usually carry out the bulk of the work responsibilities (Cattell, 2002). Cattell's anthropological research on the themes of gender, age and work in western Kenya, described the daily gendered division of labour as being heavily weighted towards women. In van Eeuwijk's study of older people's care arrangements in Dar es Salaam and Rufiji District of Tanzania, care for frail older people was provided by an older person in a third of households (van Eeuwijk, 2018). In general, husbands were expected to provide financially or organise and arrange resources for the care of their wives, but providing extensive household and personal care was not seen as part of their gendered role. In practice, the conventional age disparities between older husbands and their younger wives, and the possibility of widowers re-marrying meant older women continuing longer in their working care-giving roles was the norm.

5.32 "Nini kinakufanya uwe na furaha?": What is it that makes you happy?

This sub-theme highlights some of the important values held by this generation of Tanzanians, as well as some of the challenges of conducting cross-cultural research. During the data collection process, Sen's "capabilities approach" was highlighted as a potentially useful framework for understanding frail older peoples' lived-experiences (Sen, 1985). According to the capability approach, the aim of human development efforts should be to *"expand the freedom that deprived people have to enjoy 'valuable beings and doings'"* (Alkire, 2005, p117). That is, the aim of human development should be to provide resources and choices aligned with beneficiaries' values. So attempts were made to investigate the capabilities of "being" and "doing" valued by older adults living in rural Tanzania.

This approach informed the topic guide, but operationalising the concept and interrogating deeper to investigate older peoples' values proved challenging. Initially the question, "what makes a good life in old age?" was asked, but responses were persistently "limited" to gaining basic resources, with answers such as "getting food". Following this, a different question;

"what is it that makes you happy?" was trialled. Older adults, perhaps because of the huge and constant uncertainties of their lives often took "happiness" to mean "getting money" so as to be assured of having food, and their hunger addressed at least in the short term. The phenomenon which I was coming across has been described in psychology as "scarcity mindset" (Shah et al., 2012), the cognitive consequences of poverty. This theory suggests that when facing a scarcity, attention is focused on the immediate scarcity, such as a lack of food, drawing attention away from other important, but less urgent priorities, (for example attending to one's health) and makes the area of scarcity loom large and dominate one's cognitive processes (Shah et al., 2012). This is particularly pertinent when describing frailty itself as a state of "being in scarcity". These data suggest that frail older people's experiences of frailty extended to their thinking, which was dominated by attending to their immediate and pressing resource scarcities.

When encouraged, apart from the necessities of money or food, many older people enjoyed "making stories" with others, as an important source of comfort and happiness. For older men particularly, happiness was found drinking the locally-brewed *"mbege"* beer with friends. But fundamentally, happiness was being able to "sit and eat". Cattell described *"this vision of 'sitting and eating' of basking in the sun or sitting before a fire and waiting for food to be brought" was a "commonly expressed metaphor for a successful old age"* (Cattell, 1990, p382). For example, 'Bibi Abraham', who considered herself to be frail due to being unable to walk, gave a common response, whereby "getting money" was her happiness;

JR: Do you think right now, because you fail to walk, do you think there is something if you get it, it will give you pleasure, you are happy?

Bibi Abraham: eee

JR: What is that maybe?

Bibi Abraham: There is a time when you find money, yes then you say looh! (laughing) (Age unknown, 28th July 2017)

It is worth noting that this money would be for instrumental purposes, and to meet the next pressing need, rather than for an accumulation of personal wealth. Thus, there were limitations to the usefulness of applying Sen's capabilities approach to exploring the values of frail older adults who were living with significant food and resource scarcity. Until essential needs are met and a reliable source of food/income is guaranteed, a conversation about other capabilities will be necessarily difficult. Alkire has argued that needs and capabilities may not

be mutually exclusive, and may be incorporated together (Alkire, 2006). Needs can be determined contextually, for the prevention or avoidance of a contextually specific harm, or to meet a particular end (Wiggins and Dermen, 1987). These older people often said that they were in need of food; described either as a better diet, or not having to miss meals (*"Kwa sababu ya kukosa lishe na chakula* bora": because of missing nutrition and good food). Therefore, frailty would be the specific "harm" to be avoided by not having this need met, and the capability would be having food security.

In addition to the problem of needing to prioritise essential needs, before being able to address other capabilities, another crucial limitation of this framework for examining the lived-experiences of frail older people in this particular context, is that it is based on the individual (Dean, 2009). Individual capabilities matter less in Tanzania than collective capabilities. This is borne out in these data, whereby happiness was experienced by frail older people when they felt a sense of respect and *"kushirikiana"*[11] (sharing together) in their families and communities. This 75 year old frail woman describes her happiness at having a house girl for company now that her grandchildren are at school.

Now a person completely, when I see my heart is not happy, I have been staying with grandchildren but now they have been taken to school. I call my child helper and we sit together outside, we speak and we laugh, I feel happy. (Bibi Ndumaeli, 75 years, subsistence farmer, 5th July 2017)

Field notes written on 3rd of July 2017 reveal the difficulties of exploring valued capabilities cross-culturally;

I explained to Dr Kissima that I wanted to find out about the things that people valued in their lives beyond getting food, and he replied saying "a village person cannot say that they need to see the Serengeti before they die, no"[31].

JK's comment led to a re-examining of my participants' ageing experiences through the concept of the "Third Age" as introduced in the literature review chapter (section 2.21). The "Third Age" can be seen as a chronological life-stage of reaching one's maturation and self-actualisation (Laslett, 1996) or as generational entity in "western" society (Gilleard and Higgs, 2002). This comment led to a comparison between the experiences of ageing in rural Tanzania with that of the retired European and North American tourists who visit Tanzania.

[31] The term "washamba" was used, which literally could be translated as "countryside people", but it is sometimes used in a derogatory way, often interchangeably with "peasants". This language use may imply that more middle-class educated Tanzanians themselves place less value on lower-class subsistence farming people.

These safari vehicles full of leisured, healthy consumerist "third agers", which daily pass through Kilimanjaro region where this study's rural villages lie, emphasised that this form of "Third Age" is a high-income country, generational entity (Gilleard and Higgs, 2002). In Moshi and the surrounding rural Hai District, these inequalities were brought to the fore by a globalized tourism industry. The seemingly "limited", "unimaginative" responses, given to the question "what makes a good life in old age?" highlights the fact that the "Third Age" as a concept can only usefully be applied to the particular generation of older European and North Americans who have benefited from universal social welfare coverage, high quality and accessible healthcare and retirement and were choosing as individuals to travel, experience and enjoy their lack of agedness.

The capabilities approach was limited by failing to incorporate the values of reciprocity and the capabilities of the collective. In answering "getting food", the underlying meaning was "receiving care" as deserved. In answering "making stories" the older person was expressing the importance of nurturing family relationships. Asking "what makes you (the individual) happy?" was bound to be answered differently than expected, in a society based on *"Ubuntu"* philosophy, where an individual only matters within the context of the collective, and where notions of family and nation provide more value and meaning than individualism and autonomy.

5.33 "Wajukuu ni mzigo": The grandchildren are a burden

This sub-themes, and the following; *"Familia nayo inapata shida hasa watoto"*: The family gets problems especially the children, will be discussed together as they form a counter narrative to each other, and together lead to a better understanding of older people's experiences of living with frailty within their families. 'Mama Julieth', an assistant nursing officer working at the village dispensary observed;

*"They are elderly but they have many little children which are like grandchildren, that is a burden and a big worry, other daughters are in town leaving their children until you find the children are weakened also". (*26 years, *28th July 2017)*

As a young person, she was concerned that older adults' ongoing responsibilities of care for younger family members, put a burden on them and led to a worse outlook for the whole family. The care-giving activities were expressed as "finding food" (working in the farm or through money-generating activities) and "educating" them, that is (paying for school fees). However, in these data "care" and "work" were mostly shared across often complex situations of interdependency where younger children or grandchildren also contributed to the

household by providing domestic help, physical care or by supplementing the household income through earnings from casual labour or cattle herding.

In an analysis of the different social networks of older people in rural and urban Uganda Golaz made similar conclusions (Golaz et al., 2017). Due to a lack of universal pension older people work until they cannot, gradually reducing their activities as they age and become too frail to work. In addition to having to support themselves, older adults may remain in care-providing roles. Although there were possible benefits from keeping active, shouldering the bulk of these responsibilities could take its toll, both physically and psychologically*; "the benefits of remaining active are fast absorbed by the needs of family networks that still weigh on older people"* (Golaz et al., 2017, p83). In Golaz's work many examples were given of older adults' social networks and household set-ups. Often these were carefully negotiated and precariously balanced arrangements which were mutually beneficial. Examples given include unemployed adult children and orphaned or "dropped-off" grandchildren, who provided practical care, whereas the grandparents provided lodgings and land to cultivate.

On the whole, this also seems to be the case in Tanzania. For example, the couple 'Baba Ayubu' and 'Mama Amina' aged 70 and 74, lived with two grandchildren aged 8 and 9 years. They were responsible for providing food and shelter for them and helping towards their school fees. Captured in field notes written on the 3rd of July 2017 the older couple denied feeling burdened by this adopted parental role: 'The grandchildren live with them, yet they said they are happy about this, their grandchildren are blessings not a burden. Their son doesn't contribute at all, he is always at the bar (alcohol dependent), his wife left around six years ago.' This couple relied on remittances from other adult children living in Spain and Dar es Salaam, and they claimed that they could depend on them should they need medical care in the future. Between them and their ten adult children sending remittances or bringing gifts when they visit, they were confident of being able to manage. Although their food harvest and income was dependent on the increasingly unpredictable rainy seasons, they could also rely on supplementing their income with the grandchildren's work on other farms.

Baba Ayubu: we get our income from what we cultivate, sometimes there is drought, the income decreases, sometimes it's little like this year, a little bit better we can get some maize, I think we can get it.

Mama Amina: We get our income cultivating. When it rains we get a lot of maize, we get a lots of beans, everything we get, but now during drought the children help us to get food.

The nuance within this sub-theme is important to capture. Makoni argues a point which is reinforced by these data, which is that caring for one's children or grandchildren as part of one's filial responsibilities was not a "burden", or even thought of as "care-giving" (Makoni, 2008). The author illustrates this with an African proverb, *"an elephant has never found its trunk too heavy to carry"* meaning, it is not a burden to do what is in one's nature to do (Makoni, 2008). Extrapolating further, care-giving was seen as the "natural" activity of a responsible adult, thus 'Mama Julieth' may have been making a judgement on what she saw as the irresponsible behaviour of "other daughters" who have migrated to the town.

In the context of inter-generational responsibilities, these data show that households often relied on young children for care, and to help supplement incomes. Children could even be described as resources: 'Baba Thomas's' child was taken by an uncle to central Tanzania to work in his shop, on the understanding his earnings would be paid to the household in remittances. A dispute with the uncle meant that the child was not paid and was being kept there against his family's wishes. As well as the distress of losing his oldest son, 'Baba Thomas' was frustrated at the loss of potential earnings or practical assistance for the household.

…so it is hard this life, life is hard, I think I say it could have been better if he was still at home he could have helped me here to cultivate a garden eeh (Baba Thomas, 63 years, retired accountant, 14th August 2017)

In summary, although the sentiment of grandchildren being a burden to older people was expressed, these data generally do not support this finding. Older people and family members generally, provide care and take on responsibilities to provide financially through whatever means they can, in complex, negotiated, and interdependent family relationships (Schatz and Seeley, 2015).

5.33.1 "Familia nayo inapata shida hasa watoto": The family gets problems especially the children

This sub-theme provides the counter argument to the previous sub-theme. The title came from the comment by a 69 year old health committee member, who encouraged households to keep chickens for eggs and to enrol in the Community Health Fund. He believed the pressures of having a frail older person in the family was particularly felt by the children.

And also the family which is concerned for a person like this one who has failed in life like this, the family also gets problems, especially the children, mother gets problems

finding enough to meet their needs… so the family will get really big problems. (Mzee Terewandumi, 5th July 2017)

As discussed in the previous sub-theme, these data support a more nuanced view of a shared burden of care. These data suggest that while raising children, and also "raising"[13] frail "childlike" elders, it was the adult working generation who face the biggest difficulties and responsibilities. The negotiation of who provides, and receives care in a household is decided upon pragmatically based on the most immediate needs, the availability of resources, as well as on relationships. These decisions, are underpinned by the strong value of inter-generational reciprocity (*"Kutunza wazee ni wajibu"*: taking care of the elderly is a responsibility).

The adult son of 'Babu Elirehema', a 44 year old household-head ('Baba Jumanne') chose to focus his meagre earnings and hopes on his children's education, rather than spend this money towards addressing his father's multiple healthcare problems. In looking ahead, and preparing for a better life for his children, he was not only hoping to improve their employment prospects, wealth and well-being, but also looking forward to an old age where he would be cared for. His metaphor, likening his father's life to "bad capital" perhaps suggests that his father's past life choices were not in the interests of his family and children. 'Babu Elirehema' had been married five times, but four ended in divorce or separation, while his last wife was "shown mercy[32]". The implication being that he failed to maintain close relationships with his children, or invest in them by providing them with a good education. In weighing-up his responsibilities therefore, 'Baba Jumanne' chose to prioritise his four children's futures. One can infer from this that his son felt 'Babu Elirehema' deserved his poor living conditions.

We all want good life goals but they do not get fulfilled, it is when I have said that the life of this elder remained in a bad condition, which first their life is a foundation it's like when the capital has gone bad you cannot do business. So where I am, I am like saving for a future life. I am thinking mine will not be very good but I will have built for the ones coming at the back[33]. For example like the children now, but for me I cannot set a goal and hope for that again because the time has passed, but my goal is to prepare for the last children. (Baba Jumanne, 4th July 2017)

In this instance then, it was not the children who "got problems", but the grandfather, 'Babu Elirehema', who lamented;

[32] To "be shown mercy" is a euphemism for death
[33] "coming at the back" refers to the next generation, which are often described as though each person were in a procession, oldest at the front "leading" and youngest at "the back"

My life at this time, now I see my life is very hard, really, really, it has troubles, I feel bad in the body, until now I am here, I am very sick from this part of the head until and... the eyes and ears hurt, this thing I am getting there… (Babu Elirehema, 4th July 2017)

Taking these sub-themes together, (*"Wajukuu ni mzigo"*: The grandchildren are a burden, and *"Familia nayo inapata shida hasa watoto"*: The family gets problems especially the children) the message which they share is that frailty is a family problem. Frailty puts pressures on the interdependent relationships existing across generations. It is not as simple as one generation or group within the family suffer more due to frailty, pragmatic decisions and negotiations about priorities of care occur, underpinned by the strongly held value of reciprocity. Within some families, the older frail person struggles on as a care-giver, while other families make calculations based on prior investments and allocate the shared resources accordingly. In Part Two, it will be seen that frailty was not only experienced as a family problem, but was also felt as a challenge at a village community level.

5.34 Summary

5.34.1 How is frailty understood in context?

Two formulations of frailty have been developed from the themes and sub-themes presented and are outlined with reference to some of the relevant themes and sub-themes in *Table 5-1*.

Table 5-1 A summary of the two formulations of frailty with evidence from the data presented in this chapter

	Frailty as "returning to 'childlike' dependency" (Themes and sub-themes)	Frailty as "being in scarcity" (Themes and sub-themes)
Is it expected?	It is expected as part of normal ageing in very old age towards the end of the life course. (*"Mwili si unakuwa vingine"*: the body can't become another way *"Nguvu zimepungua au zimeisha"*: the strength is reduced or used up.)	It is not expected. Rather, it is an aberrant form of ageing, a form of frailty which is seen as ageing "too early" or "too quickly". (*"Hana mahali pa kuishi"*: Without a place to live *"Kwa sababu ya kukosa lishe na chakula bora"*: because of missing nutrition and good food *"Kukosa lishe"*: Missing food)
How do people feel about it?	Accepting, although it is not a desired state because it means a loss of adult role identity, but it is understood to be an inevitable stage of the life course. It is the socially accepted time to stop working, and receive care. (*"Kutunza wazee ni wajibu"*: taking care of the elderly is a responsibility *"Nguvu zimepungua au zimeisha"*: the strength is reduced or used up)	Frustration, anger and disappointment directed mostly towards the Tanzanian government at what is seen as neglect and breaking of the reciprocal contract. Psychological existential distress caused by perceived abandonment by adult children. (*"Ninapenda serkali inisaidie"*: I would like the government to help me *"Changamoto kwa wazee ni ngumu sana"*: The challenge of the elderly is very hard *"Watoto wako safirini basi anadhoofika"*: Your children are travelling then you become frail)
How does it manifest?	Physical and cognitive slowing and weakness, tiredness in the body, and importantly, being unable to work. (*"Nguvu zimepungua au zimeisha"*: the strength is reduced or used up.	Extreme poverty, manifested as hunger, poor diet, poor housing, chronic illness. (*"Hana mahali pa kuishi"*: without a place to live *"Kukuosa lishe"*: Missing food

	Frailty as "returning to 'childlike' dependency" (Themes and sub-themes)	Frailty as "being in scarcity" (Themes and sub-themes)
	"Mwili si unakuwa vingine": the body can't become another way *"Tatizo ya kumubumu"*: The problem of memory)	*"Chakula bora"*: better food *"Magonjwa sugu"*: resistant or chronic diseases
What is it caused by?	A using-up of a finite amount of life-energy or "blood" over a life of work for others. (*"Kwa sababu wazee wamefanyakazi sana Tanzania"*: because the elders have worked so much for Tanzania *"Nguvu zimepungua au zimeisha"*: the strength is reduced or used up)	A scarcity of material support from family, missing meals, poor diet, difficulty affording and accessing healthcare and psychological distress due to a perceived lack of reciprocal "deserved" care. (*"Wazee, hawana umuhimu na vijana"*: Elders, they're not important to young people *"Hawajiwezi"*: They cannot do for themselves/they have no means of their own)
What is the response/remedy?	To be cared for "closely" meaning attentively, and in close physical proximity, by one's family, and close to one's community on the family land. Care should include the provision of healthcare, company/comfort along with a fitting funeral. (*"Kutunza wazee ni wajibu"*: taking care of the elderly is a responsibility *"Awe ajisikie faraja"*: Let him feel comforted)	More formal opportunities for care, more government-provided resources such as through a universal state pension. (*"Ninapenda serkali inisaidie"*: I would like the government to help me (Qualitative results Part Two *"Wazee wakipatiwa mahali"*: The elders should be given a place)

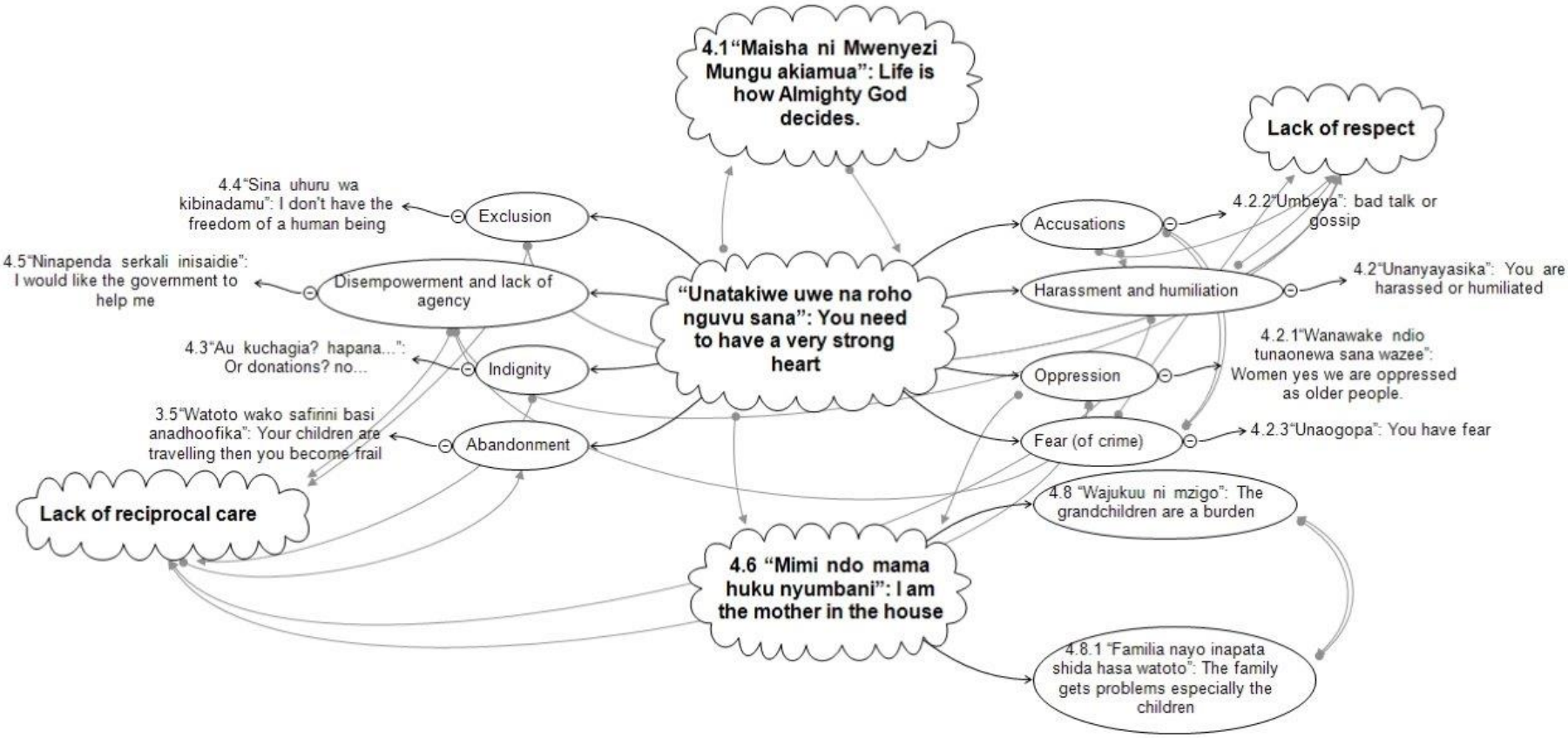
5.34.2 What is the lived-experience of frailty?

Experiences of living with frailty in Tanzania were generally experiences of hardship and struggle. These have been illustrated graphically in the mind map below (*Figure 5-6*). Overall, it took a certain fortitude and inner strength, which for many was drawn from a personal faith, in order to survive and subsist in difficult circumstances. Older people continued in their working and caring "adult" social roles, with negotiated interdependent caring relationships both between and within generations, but with older women seen in more visible caring roles.

The experiences of ageing and becoming frail were characterised by a lack of respect and a lack of the deserved reciprocal care. The lack of respect was experienced through indirect accusations or "bad talk" producing mistrust and suspicion. It was also experienced as harassment and humiliation, the disrespecting of legal rights, and fear of crime and victimisation. The absence of reciprocal care was experienced as a dehumanising exclusion, abandonment by family and the government, and a form of indignity at being unable to contribute in society. The corresponding themes and sub-themes describing each of these experiences and exploring the relationships between these sub-themes are illustrated in *Figure 5-6*.

While these experiences of becoming frail in old age were mostly negative, there were also examples of ageing "successfully", despite frailty (for example 'Bibi Hosiana', 'Bibi Eliaika' and 'Babu Materu'), who generally experienced being cared for "closely"[16] (with all the inferred meanings of the word). However, there were examples of scarcity within the predominant "childlike" frailty model of successful ageing. For example 'Bibi Eliaika' was described as becoming like a "wretched" person when she felt neglected by her children. The research question did not aim to define successful ageing according to Tanzanian sociocultural norms, however, in the exploration of frailty, it became evident that physical frailty was not mutually exclusive of ageing successfully according to the first formulation of frailty as a return to "childlike" dependency. Reflecting on the more common frailty-associated experiences, underpinned by a lack (or scarcity) of deserved respect and reciprocity it is suggested by these findings that most older people were ageing unsuccessfully, both by "western" and Tanzanian standards. It can also be concluded that the dominant, and most common formulation of frailty was that of frailty as "being in scarcity", (*Table 5-2*).

Figure 5-6 Mind-map illustrating the lived-experiences of frail older people



The findings presented in this chapter have been summarised to make a comparison between these data and Rowe and Kahn's theoretical model of "successful ageing" (Rowe and Kahn, 1999). As demonstrated in *Table 5-2*, the Tanzanian perspective of "success" in old age is fundamentally different. Crucially physical frailty does not preclude ageing successfully. Taking together the three components of Rowe and Khan's "successful ageing" theory, it is clear that these are focused on the individual. Even where social interaction is required for maintaining "engagement with life", it has been framed as the individual's responsibility to continue in "productive activities" and "relating to others" (Rowe and Kahn, 1999, p47), without considering that "engagement with life" could be considered a two-way interaction. The Tanzanian model highlights the role of family and community in their duty to *include* the older person through mutual sharing (*"kushirikiana"*[11]) and co-operation in order to enable the older person's social participation. Makoni contrasts the "western" paradigm that independence equates to a good and successful old age, with the SSA understanding that interdependence is the desired successful state (Makoni, 2008). Each of the components discussed below highlight that it is not possible to age successfully in Tanzania without the co-operation of other people. Physical frailty, it can be argued, is almost irrelevant to one's experience of advanced old age in comparison to one's experience of care. Care for frail older people will be the focus of the following chapter (Qualitative Results Part Two).

Table 5-2 Comparing Rowe and Kahn's "Successful Ageing" with Tanzanian "success" in ageing

Component	Rowe and Khan	Hai District
Health	Avoiding disease	Maintaining health in order to work (care) for as long as possible (for the benefit of others), but after a certain point physical frailty is accepted as a realistic expectation.
Capabilities	Maintaining high cognitive and physical function	Individual physical function is expected to diminish. When this happens, receiving "close" care by family signifies a successful life and old age (honoured through reciprocal and respectful care), and signifies the successful functioning of the family.
Social involvement	Engagement with life	Social involvement is a two-way interaction where successful agers are included and kept "close" to family and community life.

Chapter 6 Qualitative Results Part Two: Care and healthcare for frail older people

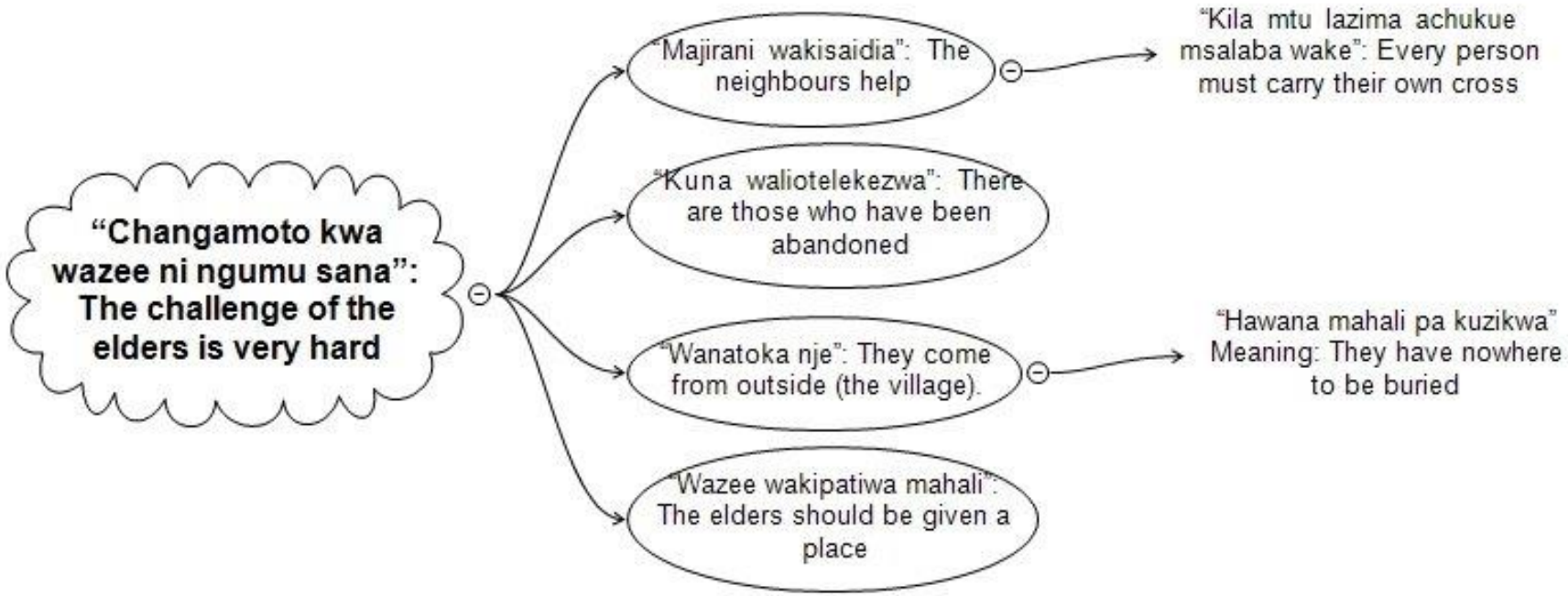
6.1 Introduction

Part One of the analysis of these qualitative data sought to understand the conceptualisation of frailty and the lived-experience of frailty. This second part seeks to answer the question; How are frail older people cared for? As has been discussed, frailty is conceptualised as a time of dependency, and of needing care. Providing healthcare for older people was an important caring activity and a lack of healthcare was understood to be a cause of frailty (*"Magonjwa sugu"*: Resistant or chronic diseases). Thus the investigation of how frail older people are cared for, also includes an investigation of how frail older people access healthcare.

Two themes will be discussed *"Changamoto kwa wazee ni ngumu sana"*: The challenge of the elders is very hard[1] and *"Tunapata dawa"*: We get medicine. These themes will be discussed with reference to the previous themes presented in Part One in order to answer the research questions. Care of frail older people will be discussed from the perspective of the theoretical framework developed by Baart when drawing on data from a volume of localised research on care provision for older people in Sub-Saharan Africa (SSA) (Baart, 2018).

6.2 Theme: Changamoto kwa wazee ni ngumu sana

Figure 6-1 Mind map of the theme "Changamoto kwa wazee ni ngumu sana" and its six sub-themes



6.3 "Changamoto kwa wazee ni ngumu sana": The challenge of the elders is very hard

The focus of this theme is on the place and practices of care for frail older people, from the perspectives of community representatives. Data was drawn from focus group discussions (FGDs) held with ten-cell leaders and village health committee (VHC) members, who are elected community members responsible for representing their village at the local government level (section 3.14.3). Comprising of six sub-themes (*Figure 6-1*), this theme demonstrates that frailty was experienced as a community problem or even a wider national social-ill[34]. This perhaps echoes the discourse found in international public health, which frames frailty as a global public health problem (Cesari et al., 2016).

Sub-themes of "Changamoto kwa wazee ni ngumu sana"

6.4 "Majirani wakisaidia": The neighbours help

This sub-theme describes instances where the neighbours[35] are described as providers of practical support to older people in the village. Often, neighbours were the only sources of support, perhaps alongside the local church or mosque. The care of frail older adults fell to neighbours both as community-members, and also as fellow "Africans". The following excerpt is from a FGD with VHC members who are responding to the 'Bibi Jones' case vignette (Appendix G), which describes an older widow living alone in London. They contrast the UK, where they are surprised to learn that older people frequently live alone, with what is perceived as "an African way of caring" for older people.

Mama Mbasha: That at your place you see it normal but here at our place we see it is very difficult because even if you do not have a child, there will be the aunt's child, a cousin. It is possible then if the children have the means they keep a worker for you. But staying alone in that situation for us in Africa that is very difficult. There will be even just a neighbour or a Good Samaritan who will give their child to stay with you. It is very difficult for a person like that one to stay inside alone, here in Africa.

(Background noises of agreement from others)

(Mama Mbasha, VHC member and subsistence farmer, 51 years, 5th July 2017)

[34] Changamoto *n* (changamoto) 1. challenge, 2. appeal 3. -toa changamoto to issue an appeal 4. To make an appeal. Using the word "changamoto" to describe the topic of frailty in the community, may also have been an appeal for help to manage the situation better, given the dual meaning of the noun.

[35] Majirani=neighbours While neighbours are usually thought of as people who live close by, in the rural villages, households or compounds tend to be quite spread-out geographically so these are people who might live within walking distance rather than "next door".

Despite the evident pride in their community's generosity and value placed in providing "close" attentive care for their older people, care provided by neighbours was acknowledged to be more ad-hoc. A neighbour might provide meals, or help with chores such as fetching water, but could not be expected to provide more intimate care, or care which could be depended upon on a regular basis. Similarly, Golaz describes neighbours providing care in rural Uganda, but explains that the quality and consistency of care was unreliable in such cases (Golaz et al., 2017). Despite having the desire to assist frail and poor neighbours, there was a general agreement that due to financial difficulties this could be challenging. This form of "ad-hoc" charitable assistance was not only less reliable, but was usually only provided in the short-term, so was not the idealised form of "close" care which older people deserve (*"Kutunza wazee ni wajibu"*: taking care of the elderly is a responsibility).

We arrange a Christian community to go and care for them though it is not one hundred percent that they get that care. So the elders are getting a lot of trouble, so it is until only when the community go and give financial care and situational care, even by giving them medicine. But it is short term, not for all time. So I would advise that the community should be educated and continue to serve the elders so they do not get serious consequences. (Mzee Ulomi, 68 years, subsistence farmer, experienced VHC member)

Notably, the previous quotation illustrates that healthcare was perceived to be a form of care, providing justification for investigating access to healthcare in order to answer the study question which is the focus of this chapter. Grenier et al. (2017) define "precarity" in older age as an old age characterised by situations of "uncertainty and insecurity". They discuss the concept of "precarity" in later life as intersecting with experiences or situations of disadvantage. The authors label these situations or experiences as, "locations of disadvantage", and argue that they exacerbate the needs, risks, and inequalities of old age (Grenier et al., 2017). Examples given by these authors include foreign-born older adults, women, and ageing with disability. In the context of this study however, it could be considered that all frail older adults are living with "precarity", due to their lack of financial security or access to healthcare. Within this precarious experience of old-age, those who are reliant on neighbours for their practical day-to-day care could be described as being at a particular "location of disadvantage" given that they lack the "close" care of a family network, and are reliant on the intermittent generosity and charity of neighbours and other community members. Grenier et al. (2017) discuss the fact that in the context of economic recession, policies of austerity, and cuts to public services (in Canada and England), the

precarity of late life has been exacerbated. In Tanzania, in the absence of a well-developed or functioning social care and healthcare system, the precarity of old age has been affected less by cuts to public spending as compared with HICs. Rather, the precarities of frail old age have been affected by many other interacting social and economic changes, for example high levels of unemployment and rural-to-urban migration in the younger generation (Apt, 2011). Both of these factors may have contributed to declines in family support for older people, and led to an increased reliance on unreliable and informal avenues of care from neighbours.

Among this population were those with increased "locations of disadvantage" due to not having a close family network: specifically frail older people who were from "outside" or who have been "abandoned". The upcoming sub-themes *"Wanatoka nje"*: They come from outside (the village), and *"Kuna waliotelekezwa"*: There are those who have been abandoned, describe these two particularly precarious groups from the perspectives of their community members.

6.4.1 "Kila mtu lazima achukue msalaba wake": Every person must carry their own cross

This sub-theme provides the counter-narrative to the previous. Rather than care for frail elders being a matter of socialist solidarity as of the *"Ujamaa"* period (Komba, 1995), or a consequence of a traditional "African" neighbourliness. This sub-theme expresses the idea that traditional social cohesion is being eroded (Cattell, 2008).

'Babu Elirehema', an 80 year old widower who lived in the same compound as his son "Baba Jumanne", a 44 year old motorbike taxi driver and subsistence farmer. 'Baba Jumanne' was the only breadwinner for the family since his wife left. His main expense was paying his children's "school fees", (an expense that would also include transport to school, uniform, and books). 'Babu Elirehema' complained to us of many symptoms, which had not received any medical attention. Nevertheless JK noted that the son 'Baba Jumanne', was "striving" (see sub-theme *"Najitahidi"*: I strive) while failing to meet his father's healthcare needs. JK's expectation was that a family with the means to help should be *"co-operating in a family way"*, in Swahili *"kushirikiana"* (sharing together), and helping him in his financial struggles. Therefore, JK asked whether there were any other forms of support available to him and whether the community or family had the means to help. The community and his family, 'Baba Jumanne' explained have become more "selfish" in their attitudes. Everyone is struggling with their own burdens and similar situations in a climate of economic hardship. Therefore the community solidarity seen in *"Majirani wakisaidia"*: The neighbours help, may form only an idealised script which was discussed in the more public FGD forum.

In the following excerpt JK probes as to why 'Baba Jumanne' feels the community have not been forthcoming in providing help to him and his family:

For sure that one I will not be able to understand…I will not be able to know why, or maybe I cannot ask, why you have not done this and that? Because the answer which they will give you is that "everyone must carry their own cross". (Baba Jumanne, 4th July 2017)

This quotation could be suggesting that 'Baba Jumanne' feels his own financial struggles are not unique, and that economic hardship is a problem affecting the majority of families, and thus the reducing capacity of families to provide care for of the majority of older people. This would fit with the "material constraints" explanation for declining family support for older people (Aboderin, 2004b, Gorman and Heslop, 2002). This theory argues that material decline in the support provided to older people is not due to a reduced *willingness* on the part of the younger generation, rather it is due to material and economic limitations, which makes providing care more difficult. Yet, this explanation has been critiqued for not taking into account factors such as motives and attitudes towards providing care (Aboderin, 2004b).

'Baba Jumanne' in this study describes people's selfishness as a reason for the lack of support from wider family and community networks. This discourse was also found in an ethnographic study of older Tanzanians living in Mbande, a village on the southern outskirts of Dar es Salaam. The older people interviewed expressed nostalgia for socialist times, and also felt that in present times friends and neighbours were *"becoming increasingly selfish"* (Kamat, 2008). This, the author suggests, may reflect a clash between the socialist ideals of Nyerere's presidency, and a younger generation who have been raised with the influences of a free-market economy, and according to capitalist values of hard work, competition and entrepreneurship (Kamat, 2008).

6.5 "Kuna waliotelekezwa": There are those who have been abandoned

Here, community members describe situations where older adults have been neglected by their families or children, or those who do not, for whatever reason, have children or close family members. While the "inter-generational contract" is a strong value discussed in *"Kutunza wazee ni wajibu"* : taking care of the elderly is a responsibility, in this sub-theme, this duty of care has been broken through the abandonment of older people.

In rural Kenya McIntosh describes the attrition of the extended family, however the author concludes that interdependency and inter-generational connections are still prominent (McIntosh, 2017). Evidence for these maintained, but changed connections may be seen, it

was argued, in the common practice of adult children sending remittances to their older parents through mobile phone banking, particularly common in East Africa. A practice which was found in this thesis too, in addition to many older people stating that in an emergency they would be able to rely on their adult children for assistance, often saying "I will call them" or "they will come". Being able to mobilise adult children to provide financial support and healthcare in an emergency was a form of social resilience described by Obrist in a qualitative study of frail older people in Rufiji District and Dar es Salaam, Tanzania (Obrist, 2016). Therefore, even when care might not be apparent in a "close" fashion, (section 5.10), care through resources, may still be provided in this more distant form.

When community members mentioned these exceptional cases of abandonment, it was with shame and judgement, given the strongly held value of inter-generational reciprocity (Van der Geest, 2002a). The following excerpt describes a dramatic story of an "abandoned" person living with frailty, from the perspectives of the village ten-cell leaders. They imply that had the older person not been abandoned, the accident would have been prevented, and shame the frail person's relatives by putting themselves in the role of relatives, in the fact they contributed money to pay his hospital fees:

Mzee Kimaro: There are many people with problems, you even feel compassion for them. Above the limit! The day before yesterday there was a person in our neighbourhood, he had a problem of losing consciousness (epilepsy). When he was in his own house at night he was touched by the illness (had an epileptic seizure) while he was warming by fire. He fell into the fire and, he was on his own in the house, he was rolling in the fire, until the fire was put out on his body. He is now admitted at the district hospital, his condition is bad and he has one hand, his whole abdomen is badly burnt, with no skin left, because of his epilepsy disease. He has a bad condition but he needs to, with that one hand to look for food[36]. But now he is in bed because he got burnt, this is the second time. So we have people like these whose conditions are bad. He is an elderly man with no male children, his children are still young.

JR: And who does he live with at home?

Mzee Kimaro: He was living alone in his house, he felt cold, it was really severe, and he said I will light a fire tonight, he saw it was good to warm himself by the fire, the fire was burning well, then the disease arrived, right there he fell into the fire, rolling

[36] In this context, looking for food means working, Mzee Kimaro is highlighting the lack of care, by emphasising that this older person is being forced to work beyond his capabilities.

this way and that way, it helped put out the fire quickly, but his clothes were also burnt. Right now he's being helped by relatives the way he is. As relatives, the day before, we contributed some little money and took it to him, he is at the district hospital up to now.(54 years, church curate, 14th July 2017)

6.6 "Wanatoka nje": They come from outside (the village)

The challenge of providing a place of care is the overarching concern of the following three sub-themes."*Wanatoka nje":* They come from outside, raises the challenge posed by older people growing frail away from their places of origin. These outsiders are people at risk of "increased locations of precarity" in old age, as described previously. While being from "outside" was a form of being displaced in life, in *"Hawana mahali pa kuzikwa"*: They have nowhere to be buried, the discussion was around being displaced in death. Lastly, *"Wazee wakipatiwa mahali"*: The elders should be given a place, is a plea for these displaced older people to be given a place where they can be cared for "closely".

"They come from outside" refers to the particular problem caused by the migration of working-aged adults from other parts of Tanzania, who have grown old away from their homes. These people from "outside" may have originally come to take up work as labourers in commercial farms/plantations or as house-keepers for wealthier families, and subsequently settled in that location. This may be more common in Hai District given that relative to other areas in Tanzania it is an affluent area. Recent Ministry of Health data show that 2.8% of the population of Kilimanjaro fall into the lowest wealth quintile (Ministry of Health Community Development Gender Elderly and Children, 2016); the lowest rate of severe poverty in Tanzania, other than Dar es Salaam, the commercial capital. Given that these workers have no land or wealth of their own, their poor status may have precluded them from marriage. Estranged from their home villages, and with no family in the village where they have settled and worked, they remain outsiders. Cattell's study of old age in western Kenya, described the same phenomenon of the *"landless labour migrants"* as one of the many economic and social trends which makes the situation of care provided by the traditional extended family, less relevant (Cattell, 1990, p377). Ironically, this type of migration, for work and survival leads to the loss of strong family ties, and threatens security and survival in old age.

'Mzee Massawe', was born in Malawi and came to Tanzania as a worker before independence. He worked on sisal plantations and as a construction worker building the old road from Moshi to Arusha. The following transcript extract illustrates how unusual and counter to cultural norms this lifestyle was, and is still considered to be.

JR: Now, Babu did you have the ability to marry?

Mzee Massawe: For sure to say the truth, myself, for bad luck I was moving around.

JR: Eeeeh?

Mzee Massawe: I was moving around.

JR: You were moving around, what does it mean?! (surprised)

Mzee Massawe: (while laughing) Just a vagrant[37]. (95 years, 11th August 2017)

In a study comparing the practices of care for frail older people in Ghana, Crete and the Netherlands, four main types of migration relating to old age were described (Van Der Geest et al., 2004). These four types of migration included people who migrated for economic reasons in their productive adulthood, and who have grown old away from their places of origin. Secondly, were older people who migrate when (or because) of their old age. Third were workers migrating for employment in the care sector, providing care to older people. Lastly, there was the out-migration of young people, from rural areas resulting in older people being left behind without children to look after them (Van Der Geest et al., 2004).

The first type of migration was described by this sub-theme. Those from "outside" were generally still Tanzanian, but from different regions, and due to the diversity of language, custom and belief between regions and tribes, it could be considered equivalent to being a foreign immigrant. In fact, these older people may suffer more estrangement from their home villages than was described by older foreign immigrants to the Netherlands (Van Der Geest et al., 2004), because of their inability to travel in order to visit, and their lack of technology for communication. This results in a particularly vulnerable situation, but as 'Mama Veronika' describes, it is also a problem for the village as a whole. As a 61 year old subsistence farmer who has been a ten-cell leader for 15 years was troubled by the presence of these displaced older people in the village.

Especially the elders from different places like (another village)… they should be given more priority because they are the ones making us suffer a lot here in the village. They do not have children, when you ask them where are they from they will say (another district), they do not know which part of (that district). They are already getting old when they are here. (Mama Veronika, 13th May 2017)

[37] uhuni=noun vagrant or prostitute. This was originally translated as "hooligan" by JR, which perhaps conveys the antisocial nature of his lifestyle.

A 57 year old hamlet leader and subsistence farmer with 23 years of experience in his leadership role found it overwhelming to try to solve the problems caused by older adults ageing and becoming frail away from their places of origin and traditional family networks. He highlighted the absence of formal avenues of support from the government, voluntary or private sectors.

You find some are not from here, they moved to this place, it's a problem, it gives us challenges to sit and think what we should do to help them. You find that in helping them we must involve maybe the hamlet leadership, maybe healthcare workers but still there are more challenges from the elders than we can cope with. Thanks. (Mzee Lyimo, 13th May 2017)

6.6.1 "Hawana mahali pa kuzikwa": They have nowhere to be buried

This theme refers to a particular concern raised by ten-cell leaders and health committee members during FGDs, when the topic of aging "outsiders" was raised. In Tanzanian custom a male should be buried on their father's and other male ancestors land, while a married woman is usually buried on her husband's land. This is an important social norm which acknowledges belonging to one's family by birth or by marriage (Whyte, 2005). The expression "they have nowhere to be buried", used by these community members highlights their discomfort with this unusual situation of not belonging, by land, within the village. It may also reflect the common belief that if someone is buried far from their ancestral or family home, their soul will not rest (Whyte, 2005). Thus frailty and death were linked through traditional beliefs and customs. Burying a body in the wrong place is believed to be a source of bad luck which could hold serious consequences for the village, for example leading to bad harvests or a child's death. In addition to these concerns, there would also be financial implications (the funeral costs would need to be borne by the village somehow), and many of the FGD participants, as community leaders would shoulder the responsibility for making these arrangements, which would traditionally be made by the deceased's oldest living relatives.

In my opinion these elders were like workers, when their age has gone, they remain with those families which they were working for. They are the ones caring for them but they are not cared for properly, it has just been care to pass the days, when they die, others get trouble because have been buried in unofficial places, so we ask if it is possible, these elders should be organised and be listed in a way to look for a place to

go to be helped, so they can go to be helped. (Mama Urasa, 38 years, VHC member, 10th June 2017)

Funerals in Tanzania are usually whole-village affairs costing a significant amount. The emphasis on the importance of a fitting burial has been described as a last and crucial "act of care" carried out for an older person (Van der Geest, 2002a). The burial is a public display of the esteem and honour that the older person holds within a family or community, and in Tanzania around half of that cost is borne by the community (Case et al., 2013). The following quotation (from VHC member 'Mama Silayo') illustrates the dishonour of not providing a proper funeral and place for burial. It would be as though the deceased had not received any care at all.

Here at the village, at this village challenges in giving care are there. It is the help from the community seeing that "I have stayed with them for a long time I should help them with some small thing", but when the condition has worsened, maybe they have died, they just bury them in a place without any help at all, so then it is as if he has not gotten any help. (Mama Silayo, 47 years, farmer, 10th June 2017)

During data analysis and the development of these themes an illustrative case was developed, for 'Mzee Massawe', a person from "outside", who was reliant on the assistance of neighbours, and was ultimately buried in uncustomary circumstances on hospital land in another village. This illustrative case has been included in Appendix Q, in order to demonstrate how these themes interact through the experiences of one individual living with frailty.

6.7 "Wazee wakipatiwa mahali": The elders should be given a place

Community representatives' repeatedly called for institutions to be built to care for older adults without family-based care. This was one of the many ideas contributed in response to the "*changamoto"* (challenge/appeal)[34] that was felt by the community. However, it was seen as an appropriate response only for those without a family network. A 53 year old farmer, 'Mama Nuru' who provided care for her ageing mother-in-law summarised the situation as she saw it in her village;

The challenges which are facing the elders are many. There are those who have been abandoned. You find an old person is alone, they do not have any support. They do not have children, or they are very far, they do not care about their elders. Therefore these elders they need to be cared for with food, treatment and other needs. So it is really important if there is an organisation or really if there is an institution, it should

help these elders who do not have means and should arrange a place, where the elders should be placed, like a residence to be cared for together, it would be good. (Mama Nuru, 13th May 2017)

In describing "the place" which would provide a situation, it was described as a place of togetherness. Rather than feeling abandoned, the elders should feel surrounded and close to others. This imagined place should therefore be a place where elders can receive the type of idealised "close" care which older people deserve, and which the younger generation "strive" to provide (as discussed in *"Awe ajisikie faraja"*: Let him feel comforted).

Another reading of this sentiment, is that it was out of protection for the community. Cowgill discussed the economic burden of older adults in collectivist communities, describing how food sharing can be an adaptive means of overcoming shortages due to unpredictable weather events such as drought (Cowgill, 1986a). In situations of famine and extreme shortage where the individual has *"become a severe burden or handicap to an already hard-pressed community"* the author describes older adults selecting themselves for sacrifice, and becoming seen as *"expendable"* (Cowgill, 1986a, p104). When interpreting these data it should be remembered that at the start of data collection in February 2017, there was a food shortage in this region, after disappointing short-rains led to a poor harvest in December 2016. It is on this background that community members suggest that responsibility for care should fall to the government or other organisations, rather than putting a further strain on their own limited resources.

Nevertheless, there was widespread condemnation of the suggestion that older people *with* families should be cared for in institutions. For example, 'Mzee Kimaro' described it as a degrading treatment.

Thanks, myself (Mzee Kimaro) I have a different opinion, and I don't think it is good to build a special house for the elders and leave them there like animals! I don't see it working. I suggest they stay in the same places they live, I would not like to see the houses being built because they already have places to live… So personally, my advice would be if it is possible this service should be found in the hospitals for free, yes I would prefer this more. (Mzee Kimaro, 54 years, curate and school chairman, 14th July 2017)

The general agreement was that institutionalisation should be the final resort in providing care for older people. The "last resort" nature of this solution was highlighted by 'Mama Werande', stating, only those who don't have houses should be given a place to receive care.

That is, the displacement and indignity of being moved to an institution would only be acceptable if that person was already displaced and was facing the frailty of "being in scarcity" ("*Hana mahali pa kuishi"*: without a place to live).

Instead of taking them to a centre, they can be helped in their own place. For example you may find another one maybe who doesn't have a house. As the government has the ability, it should help to build houses for them, also they should look at those who have problems of food, shelter and clothes, also treatments, it would be even better than moving the ones who have their houses already and taking them to other houses. But for those who do not have houses it will be good if they are taken there, because they will be in the care of the government because they have nobody to look after them. (Mama Werande, 67 years, 5th July 2017)

The staff working at Amani Residential Home (Amani) provide a fascinating insight into attitudes regarding institutionalisation in this setting. Staff members describe the residents' lives in Amani as "very good", because they are able to provide the idealised "close" care and all their essential needs are being met. Yet, there was strong resistance to the idea of allowing one's own parent to live in such an institution.

In our centre the elderly are living a very good life, because first, completely, we the workers are close to them, when they come across any sort of problem we are altogether with them. Also, the life is good because, they eat food well, they eat three meals daily, they're bathed. So in reality they are living a life similar or even better than other regular people, because in the street, life is tough for the elderly person. (Mama Magreth, 47, care assistant, 27th May 2017)

Hired care was seen as an acceptable alternative to providing care yourself (if means and circumstances allow), as this would permit the older person to remain embedded in their community and thus, in their correct "place". Importantly, this would allow them the deserved care of a burial in the correct place too.

I myself would completely not accept for my parents, I would absolutely not accept for them to be brought here. I would stay with them absolutely. Then, if I am married and with my husband and my husband doesn't want me to go there, then I would hire a person to care for my parents at home, and would care for them in this way until God

loves them[38]*, that's it. (chuckles) (Mama Zainabu, 27 years, cook at Amani, 27th May 2017)*

It is possible that this consensus rejection of institutionalised care for older people was influenced by the FGD setting, where individuals would be reluctant to break a cultural taboo such as this. However, participants did contradict each other occasionally, and also expressed the same in individual interviews. The main benefit of residential care was seen as its provision of a community for older people, reflecting Tanzanian cultural ideals of care. Conversely, the often expressed worry about institutionalised care was that older people would become abandoned there.

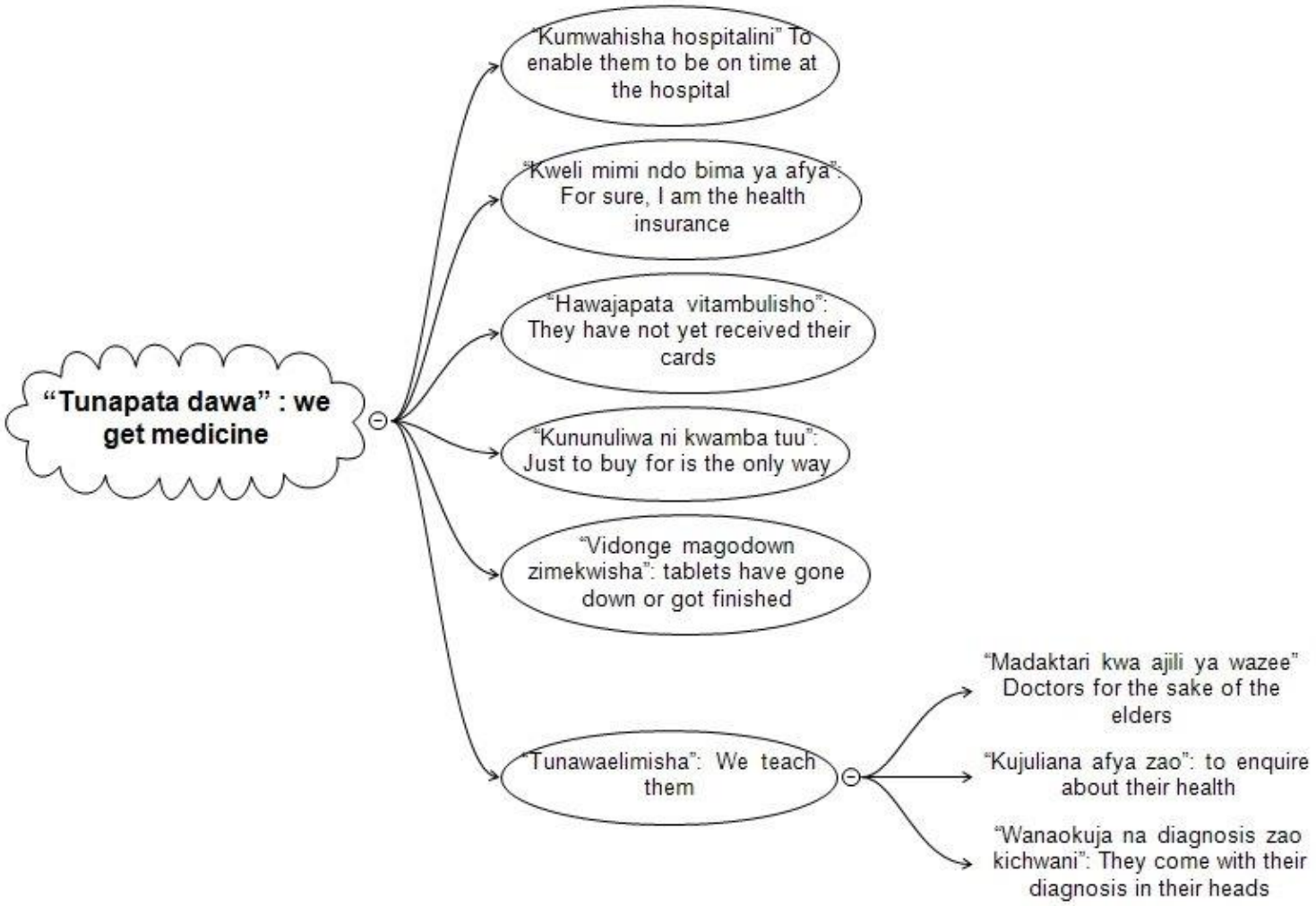
In this manner these data support the government stance on care for older people. The Tanzanian National Ageing Policy states succinctly (Ministry of Labour Youth Development and Sports, 2003):

The ability of the oldest old to manage themselves is either minimal or not existing. Due to this fact the society has the responsibility of providing them with care and support. However the family will remain the basic institution of care and support for older people. Institutional care of older people will be the last resort.

[38] "To be loved by God" is a common euphemism for death.

6.8 Theme “Tunapata dawa”

Figure 6-2 Mind-map illustrating the nine sub-themes of "Tunapata dawa"



6.9 "Tunapata dawa": We get medicine

Enabling an older person to receive healthcare was conceived of as a form of care, particularly for older people living with frailty. Discussions about access to healthcare services and treatment for older adults was an important topic of concern for participants, and forms the content of this theme. This area of investigation was led by study participants rather than by the original topic guide. After the first few FGDs in which ten-cell leaders raised the topic as an issue of importance, questions were added to the topic guide. Listening to participants' grievances, and allowing space for them to express their frustrations became an important part of building trust during the interview process. Likewise, representing this theme authentically has become a matter of personal and researcher probity.

Enabling access to healthcare was an important activity of care for older people, which became increasingly important with the increasing financial and physical dependency of frailty. Additionally, a lack of access to healthcare was seen as a causative and contributing factor to frailty due to living with chronic diseases and unmanaged symptoms (see *"Magonjwa sugu"*: Resistant or chronic diseases). Thus a scarcity of healthcare resources and services contributed to the conceptualisation of frailty as "being in scarcity". The Theme includes nine sub-themes, illustrated in *Figure 6-2*.

Focusing on access to healthcare, it is important to describe the healthcare services present locally. For most of the study participants there was a hospital accessible within two hours by foot or by bus. Otherwise, there were rural health clinics or dispensaries that were usually closer. These facilities are variably government-run, faith-based, or private facilities. This patchwork of healthcare provision developed following the collapse of Nyerere's free universal healthcare in the 1990s (1.4.2), but a focus on provision of healthcare for older people has largely been neglected. Encouragingly, the most recent Tanzanian National Health Policy 2017 includes a section on "geriatric services" for the first time (The United Republic of Tanzania Ministry of Health Community Development Gender Elderly and Children, 2017). It highlights what is sees as three main problems for older people in accessing healthcare;

The elderly now constitutes 6 percent of the Tanzanian population. This group remained disadvantaged in the previous Health Policies. Most probably because in terms of numbers they were not so visible. Now however their numbers have increased substantially. There are special challenges this group is facing. First and foremost is lack of human resources for health who are trained specifically to understand the health problems of the elderly. Secondly, their health problems are age specific and so

deserve care guided by specific inputs and facilities. Thirdly, they have no income to pay for care.

These results to a large extent concur with the government's summary of problems, yet these findings will be used to further investigate the barriers to accessing healthcare with a particular focus on older people living with frailty. In these data older people, their families and community members discuss the challenges of negotiating an unclear and bureaucratic government system, and a pleuralistic private system, in order to access healthcare which is often inadequate for their needs. Participants were often angered and frustrated by their difficulties in accessing appropriate, timely and affordable healthcare, as described through the following sub-themes.

Sub-themes of "Tunapata dawa"

6.10 "Kumwahisha hospitalini": To enable them to be on time at the hospital[39]

The problem of delays in access to healthcare will be discussed with reference to the "Three Delays" theoretical model (Thaddeus and Maine, 1994). This was a theoretical framework developed to help explain factors which contribute to maternal mortality in low-income country settings. The three forms of delay were first, a delay in deciding to seek healthcare, followed by a delay in arriving at a health facility, and lastly a delay in receiving appropriate healthcare, all of which were found to increase the risk of death in obstetric emergencies (Thaddeus and Maine, 1994). All three types of delay were mentioned within this sub-theme, which referred to the barriers older people with frailty face in accessing healthcare in a timely manner.

The first delay was the delay in deciding to seek healthcare. This VHC member 'Mzee Tarimo' gives diabetes as an example of a chronic disease which could emerge insidiously, without an older person being aware. In the absence of affordable primary care, this participant claims, older people tended to avoid seeking healthcare proactively.

You can find you are diabetic but you don't know it. It is because of not checking what? Their health. So I would advise them just to be checking their health that is why

[39] Note the passive form of language here. Older people were mostly referred to as "being taken" or "shifted" by family members. Due to their frailty, and/or acute illness, older patients largely lack agency and are moved around by the younger, paying family members. This highlights the point made in sub-theme *"Hawajiwezi":* They cannot do for themselves/ they have no means of their own, where older people, once frail belong to their families, in the same way as children and the sick do. Their individual agency is forgone, and autonomy minimised for the sake of the welfare of the household as a collective.

at the beginning I said many of them fail to go to the hospital as they do not have health insurance. (Mzee Tarimo, 58 years 10th June 2017)

Delay two accounts for the delay in getting to a healthcare facility, once the decision to go has been made. This staff member at Amani complained that it could take a long time to arrange transport for a resident with frailty and reduced mobility. The residential home, although it was situated in the outskirts of Moshi town, was too far to walk to reach the government hospital. This delay is typical of rural SSA, where people live long distances from hospital facilities, where the availability and cost of transportation are limiting factors and where road conditions, particularly during the rainy season can delay a patient's arrival to hospital (Thaddeus and Maine, 1994).

Yes it is difficult, it is very difficult, and it is difficult because there are not enough facilities. For instance when these elders are sick and are supposed to be taken to the hospital, you find that I do not have means of transportation to take them unless I ask people, different institutes to give me a means of transportation, and this takes a long time. So the old person continues to get sick still without any care until I succeed in getting a car. This is a challenge, it's a problem because the elder cannot receive the care at the same time as they are having the problem.(Social officer in charge, 16th February 2017)

Delay three describes the delay in receiving good quality healthcare in a timely manner. This FGD was held in a participant's compound, where participants were able to be freely critical of their local government hospital and dispensary. This ten-cell leader, describes "getting afraid" that his older relative may not survive due to the slow, inadequate care at the government hospital:

Matters of the hospital, right now the hospitals have few drugs, really, if a person is very ill you don't get treatment until you pay money, if you look at government hospitals nowadays, you can be there wondering, until the patient's condition worsens, until it is not good. So we try to rush to the non-government hospitals, because the government hospital delays care, to the extent that you get afraid, or you see yourself you came for nothing, so the government hospital nowadays it is really a problem, for sure. But for a person with a fever which is a little bit low, you can take them because they will be treated. (Mzee Mushi, 50 years, subsistence farmer and choir member 14th July 2017)

Older people with frailty only accessed healthcare through their relatives. They became the passive recipients of care through whichever means the family decided was appropriate. For housebound older people, their relatives sought healthcare advice or medicines on their behalf. For example, 'Mama Theodora' the 40 year old daughter-in-law and main care-giver of 'Bibi Hosiana', a 94 year old, immobilised following a stroke, describes the situation thus:

Mama Theodora: For example if she has a fever I go to the pharmacy. I explain to them, they give me medications, I bring it to her. If it is headache I buy Panadol (paracetamol) I give her and the head gets better.

JR: If you face grandmother becoming very sick, even if you give her medication, they don't help, what do you do there for example?

Mama Theodora: There was a time I was going there to the mission hospital. I explained to sister, she gave me medications, I brought them to her and they helped her.

JR: But you have never taken her and brought her to hospital at all?

Mama Theodora: No we have never (5th August 2017)

Schatz et al. applied the three delays model to explore barriers in accessing healthcare for rural-dwelling older Ugandans, and found that concerns about ageist attitudes held by healthcare professionals was an important factor that influenced the decision to seek healthcare (Schatz et al., 2017). Participants expressed concerns that they would not be taken seriously and would face discrimination because of their age. Additionally, certain symptoms such as painful joints were not thought to be a valid reason for seeking healthcare, as this complaint was attributed to old age (Schatz et al., 2017). Echoing the Ugandan context, delays in deciding to seek healthcare were due to impaired mobility or financial limitations, delays in reaching care were because of limited transportation options, and the delayed receipt of appropriate healthcare was because of poorly equipped facilities and an inability to pay for services. There were no explicit mentions of people being discriminated against by healthcare workers on the basis of age, but implicit discrimination based on an inability to pay was often mentioned.

One critique of this model, when applied to frail older people is that it fails to consider the long-term management of multiple chronic conditions. Chronic non-communicable diseases (NCDs) management does not only rely on being able to access timely care, but on continuity of care, alongside patient education, self-management, and preventative measures (Agyepong

et al., 2017, Lloyd-Sherlock et al., 2012). These data corroborate the Ugandan study in that all three delays were evident, but also highlight several important weaknesses. Despite some knowledge and discussion about the benefits of early health checks, healthcare was largely sought for symptomatic episodes of acute illness e.g. fever. Even hypertension which is largely asymptomatic, was often described as causing episodic symptoms such as headache and dizziness, and understood to be cured after a week's course of antihypertensives, once symptoms resolved. Therefore, a significant weakness in applying this theoretical framework to the long term care of older people with frailty, is that the management of frailty requires a paradigm shift away from acute and episodic care, towards delivering community-based primary care and improved health education, particularly for the management of chronic NCDs (WHO, 2015, WHO, 2017a).

This study adds to Schatz's findings in that frail older people faced an even greater risk of delay one; deciding to seek healthcare. Frail older people lacked the social and financial agency to seek healthcare. In their "childlike" dependent roles, they were required to rely on the household-head to make decisions regarding accessing and paying for healthcare. When acutely unwell, older people could ask their children for assistance, but were largely reliant on these younger family members to decide to seek healthcare, to arrange a form of transport, and to manage the household finances in order to pay for services at a hospital or clinic. Older people living with frailty, therefore faced the additional delay caused by this process, especially if younger family members lived elsewhere. An additional weakness of applying this "three delays model" to the most severely frail older people, is that due to their physical disability, and "childlike" social role, these older people were largely excluded from hospital care altogether.

6.11 "Kweli mimi ndo bima ya afya": For sure, I am the health insurance

The focus of this sub-theme was the financial barriers to accessing health insurance for the majority of households reliant on subsistence farming. The quotation forming the sub-theme title comes from an interview with 'Bibi Felista' (93) and 'Mama Agnes' (47), a mother and daughter who couldn't afford health insurance. 'Mama Agnes' frankly described the situation as she saw it;

(laughing). For sure, I am the health insurance for mother because I am with her, I live with her, I know how she is staying, what she has eaten, how she gets medicine, treatments, true I am the health insurance. Yes I care for mother. (Mama Agnes, 5th July 2017)

The majority of healthcare costs are paid out-of-pocket (OOP) by the service user in Tanzania (Counts and Skordis-Worrall, 2016, Brinda et al., 2014). Formal sector employees are secured by mandatory health insurance, for public employees (such as teachers, nurses and civil servants) this is the National Health Insurance Fund (NHIF) (Counts and Skordis-Worrall, 2016). The NHIF permits access to a wide range of services and treatments, and older adults may be included on an adult child's insurance policy if they are formally employed in government institutions (Mtei et al., 2012). For informal sector employees, such as subsistence farmers, and market-sellers, the Community Health Fund (CHF) is designed to be more affordable and to assist with essential healthcare coverage (Mtei et al., 2014). Potentially covering up to 6 individuals for an annual premium of 30,000 Tsh[40] in Hai District, the CHF provides care at one local health centre or dispensary within the district, but not hospital care, or services outside of the district (Macha, 2015). CHF coverage is low, at about 7.1% of the total population (Macha et al., 2014), despite the fact that informal sector workers and their dependents, comprise over 70% of the population. This poor uptake has been attributed to a perceived poor quality of service at local public dispensaries (Mtei et al., 2012). According to this sub-theme participants found the annual CHF premium unaffordable to them, as "lower class people". The following quotation was a comment made by a VHC member who had received training to encourage people to enrol in the CHF scheme, and who volunteered checking drugs at the village dispensary;

For sure the health (insurance) costs are very high such that we cannot afford again. Those who can afford it are the people who are working for the government who are sure of being paid the big insurance, but for farmers and lower class people for sure we ask the government to look at us otherwise a lot of deaths will occur due to healthcare cost being high. (Mzee Rajabu, 47 years, 3rd July 2017)

The finding, that CHF annual premiums were not affordable for those that they targeted was corroborated by a study examining the determinants of CHF membership in Tanzania (Macha et al., 2014). The authors found that the middle three wealth quintiles, but not the poorest quintile were most likely to enrol, while larger households, and those with children or older adults were also most likely to enrol due to an expectation of higher healthcare costs (Macha et al., 2014).

[40] 30,000 Tanzanian Shilling is roughly equivalent to £10.00 using the currency conversion of 1 TZS = 0.0003 GBP valid June 2018.

6.12 "Hawajapata vitambulisho": They have not yet received their cards

The topic of exemption from healthcare costs was discussed within this sub-theme. In the 1990s, when user fees were introduced in Tanzania, so were a system of exemptions and waivers for vulnerable groups: These groups are pregnant women, children under 5 years, adults aged ≥60 years, HIV/AIDS, and TB/Leprosy patients (Frumence et al., 2017). Due to a decentralised healthcare system, each health district is responsible for implementing national policies such as these, leading to variation between regions (Maluka, 2013). In the following quotation 'Mzee Mrema' speaks on behalf of his peers, describing the frustration felt at the disjunction between what they have heard in the media, and their experiences;

In my own thinking, I think frailty in old age needs positive care in the provision of healthcare, example, old people in (this village) got identity cards for them to receive healthcare but it has been difficult until today. There is not any elderly person who has ever benefitted from this service, it's the major complaint of all older people here in general…the way we complain that elders do not receive any services while we are told the service is there! It becomes like a dream! (Mzee Mrema, 64 years, village chairman, 14th July 2017)

The government policy of exemption from healthcare payments for the over 60s is dependent on having an identity card as proof of eligibility. Ten-cell leaders and VHC members were often involved in running registration sessions where older adults were invited to the village office to have their name and age recorded, and photograph taken. However, long delays in receiving the cards, confusion about the eligibility criteria and a variability between villages, led to angry complaints:

They were from the district, they came to our village, the elders here in the village, they wrote their names, they have just taken the papers and whatever, we had faith that the elders would get helped. But it was not an institute, it was the government, it was the government, but we have not seen the feedback. We have not seen the elders getting the rights which they told us about here at our village! Although they listed all the names, I do not know how it has been? Therefore I see, I request, because they are old they should not wait until tomorrow! An elder person, when they need help they should be helped at once! I would beg for this to be seen as an issue of humanity! (Mzee Meena, 67 years, Tailor and ten-cell leader 13th May 2017)

There were a few exceptional cases of older people living in very poor circumstances who described getting free treatment in their local dispensary after being given a letter by their

village chairman. For example ‘Bibi Helena’ was in a minority of frail, poor and socially excluded individuals receiving free healthcare;

We go here to our government’s place, there we don’t pay, we were given a letter, and our government won’t make us give money even to climb into the bus, we ourselves don’t give them money yes when we have our letter with us. (Bibi Helena, 90s, traditional birth attendant, 21st July 2017)

From the perspective of healthcare workers trying to implement the policy, they were faced with the problem of having to prove an older person’s age, which was much more challenging than identifying children under five years of age. This dispensary worker explains her perspective.

Thank you truly it’s a big challenge, because for example if children we are able to identify. Aah you find a baby starting from 0 to 5 years, this one can be treated for free, and they will show you their Clinic Card, so you have a place where you can record it. But now this elder is coming as he is, telling you I have ‘so and so’ years then you record, when you send the report they tell us, ‘you said this one was for exemption how come? Where is the card number?!’ (Mama Julieth, 26 year old assistant nursing officer, 28th July 2017)

Overall, the situation caused significant frustration with the government described as “singing a song”. The majority of older Tanzanians, when speaking freely, expressed their cynicism at the empty promises of politicians.

I agree with the government but it should not be mere words because in our village we say the government is like it’s singing a song! Because for a long time we have heard of pensions but we have not seen anything like that! So it is better they improve these pensions and healthcare services really well, so that we can get what we need completely, so it is not a song as we supposed it was just a song. (Mzee Swai, Hamlet chairman, 66 years, 14th July 2017)

6.13 “Kununuliwa ni kwamba tuu”: Just to buy for is the only way

This sub-theme deals with experiences of OOP payments, particularly for hospital services. The negotiation of that payment and its impact were important for frail older people, their households and communities.

In this example, ‘Mzee Rajabu’ describes the risk of having to sell land to pay for healthcare. The small plot of land which would be left over after paying the hospital bills, would be both

literally and figuratively a place of death[41]. Literally, because it would be a fitting size for a grave, and figuratively, as it would be too small to cultivate enough food for the household, and thus may hasten death.

…because what costs us or causes us to suffer is the health costs. The health costs are very high in such a way that, to everyone, even if they have an insurance it is not a solution, the health costs when you take an elder or someone with a severe disease to the hospital you must sell farmland otherwise you will not be able to pay for the treatment. So if you sell part of the farm once, then for the second time, the family will only remain with a small patch which you can only depend on as a grave. (Mzee Rajabu, 46 years, VHC member, subsistence farmer, 3rd July 2017)

This is a dramatic example of what is termed Catastrophic Healthcare Expenditure (CHE), usually defined as OOP household spending on healthcare which exceeds 40% of a household's income after spending on food (Counts and Skordis-Worrall, 2016). Two papers have sought to characterise household factors which may increase the likelihood of CHE in Tanzania. Brinda et al. found the overall proportion of households with CHE was 18%, (calculated from N=3,265) (Brinda et al., 2014). According to their multivariate linear regression model, factors associated with OOP healthcare expenditure for adults ≥60 years were visual impairment, functional disability, lack of formal education and traditional healer visits (Brinda et al., 2014). Visual impairment and functional disability both being important problems which contribute to physical frailty, and lack of a formal education a useful proxy marker for socio-economic status. Older people may use traditional healers because of holding traditional health beliefs, but also due to traditional healers being more easily accessible in rural areas (Brinda et al., 2014).

When comparing households affected by chronic illness with households not affected by chronic illness in Tanzania (defined as any illness lasting ≥ 6 months), an increased OOP expenditure of 22% was found (Counts and Skordis-Worrall, 2016). The number of older men in a household was also a positive predictor for healthcare expenditure. According to a scoping review of the determinants of CHE in SSA, having a household member aged over 65 increased the risk of household CHE, and this spending was more likely to be high (Njagi et al., 2018). These findings substantiate the qualitative results of this study, yet this sub-theme

[41] According to Chagga tradition, you should be buried on your own land. When visiting a Chagga household in Kilimanjaro region it is common to come across the graves of deceased family members within the compound.

also adds to the current published literature by illuminating the possible impact of CHE on older people living with frailty.

In one example ‘Mzee Eliakimu’ a 78 year old, single, retired civil servant recounted the events leading up to being admitted to Amani in 2007. After falling and sustaining a fractured neck of femur, he delayed going to hospital due to a lack of financial means.

I did not have any relative nor house, I did not have any help. So I had an accident, I fell inside a hole and I broke my hip. I stayed for two weeks without getting treatment. (Mzee Eliakimu, 4th May 2017)

Eventually, a fortnight later, he was transported to the hospital. Despite the fall and fracture being an acute trauma-related condition, this developed into a chronic problem which would require mobility aids, physiotherapy, occupational therapy and rehabilitation in order to be discharged back to the community. These services were not available to him.

So I owed a lot of money…I owed money, but there was no one to pay. I was not able to walk at all, I was walking with… even these sticks like these ones I could not walk with. I was in a wheelchair. (Mzee Eliakimu)

Hip replacement surgery, the treatment of choice in high-income settings, was not available at the local tertiary teaching hospital. ‘Mzee Eliakimu’ found himself in debt and unable to pay his hospital bill. He was also physically frail and immobile, with nobody to provide care for him, so he could not be discharged, and remained an inpatient for five years. Meanwhile social workers tried to contact a previous employer to recover the payments which were owed.

They had to research with the social welfare, and they found that this person does not have a place to go, he does not have relatives, he does not have a community. (Mzee Eliakimu)

Finally, having no means of living independently he was given accommodation at Amani a government-financed residential home. With no prospects of being rehabilitated or discharged back into the community ‘Mzee Eliakimu’ expects this will be his institutionalised home for life.

This sub-theme demonstrates that a rare but important outcome of frailty in this setting may be institutionalisation. Chronic ill-health and frailty was exacerbated by and co-existed with poverty and CHE. The result, in unusual circumstances where the frail older person survived

long enough, was admission to an institution as a form of last resort. This constituted a displacement from the older person's community, without the ability to meet with friends and was experienced as a form of deprivation of dignity and freedom, (discussed in the sub-theme *"Sina uhuru wa kibinadamu"*: I don't have the freedom of a human being).

As described in Part One, older people in Tanzania who are living with frailty return to a state of "childlike" dependency. The frail older person, lacks agency in this context (as a child or patient, they belong to their family), and are "bought for", hence the sub-theme title[42]. The following ten-cell leader summarises the situation well. Older people require either means of their own, or someone they can rely on to be their health insurance, and to take them to receive healthcare and to pay their hospital fees.

Frailty is as a result of lots of things, for example in my opinion, if you look at our nation the elderly have no health insurance. At the time that they become sick they can get health services with that identification, yet still this is a problem. So when they get those thoughts or become sick if they lack help or a person to help them by taking them and paying the hospital fees, that contributes to frailty too. So a big source is that, if they were able (financially) then thoughts and frailty would be much reduced inside them. (Mama Lema 55 years, providing care for her parents, 13th June 2017)

Yet, as this ten-cell leader describes, in the event of needing hospital care, even selling cattle won't cover the costs incurred. This is a significant comparison culturally, especially for Masaai who measure their wealth by the size of their herd, and where the "bride price[43]" may be paid in cattle.

It's a very difficult place here in the government (hospital), it squeezes us just in treatments, we can handle very small needs. Because, for example, if you go to the (referral hospital) there without like three hundred thousand, you cannot get any health services, and there is no cow which is sold at three hundred thousand in our village! Now we are asking the government to provide for us good chances of being treated if we are to go. (Mzee Ndenfoo, 59, subsistence farmer, 24th July 2017)

6.14 "Vidonge magodown zimekwisha": Tablets have gone down or got finished

Throughout the interviews were complaints that medicine stocks were low, particularly in government facilities, (such as at local dispensaries, which would be covered by the CHF

[42] "*Kununuliwa*" is the passive form of the verb "*-nunua*" "to buy", thus medicines, which constitute a large part of healthcare costs particularly for chronic NCDs, are usually bought on behalf of older people, by their adult relatives.

[43] The "bride price" payment in Tanzania is traditionally made by the groom's family to the bride's family.

benefit). There were oblique accusation of corruption, suggesting that perhaps drugs were being sold to private pharmacies, and criticism of the poor continuity of medications available through donor-sponsored systems.

The following quotations exemplify the frustration felt by many. ‘Baba Thomas’ a retired accountant described the availability of drugs for opportunistic infections in HIV/AIDS becoming less available over time.

It’s very hard to say a country is developed if the health sector can’t even provide medicine, when you are supposed to take your hospital prescription to buy your own medicine there in the pharmacy! (Baba Thomas, 63 years, 14th August 2017)

As a person living with HIV infection, according to government policy he should be exempt from HIV medication costs (Maluka, 2013). Yet, in his comment about “cunning people” is a subtle accusation of corruption. ‘Baba Thomas’’s case has been described in more detail in Appendix Q.

But since 2010 every medicine is not there, and I do not know if the sponsors bring the medicine or not, you don’t see, and in this country of ours there are many cunning people. (Baba Thomas)

The following quotation from a 54 year old ten-cell leader ‘Mzee Kimaro’ demonstrates the outrage at the situation he faces, in trying to access medicines for his older parents.

But there they prescribe the medication for you, the doctor has no problem, he will write for you all the medication required. Then go, this medication we don’t have, and this one we don’t have, go and buy. And they say free service for the elderly?! There is not this service, it’s just a name!! (Mzee Kimaro, 14th July 2017)

6.15 “Tunawaelimisha”: We teach them

The volunteer work done by VHC members in Hai District was described in this sub-theme. VHC members volunteer in these positions and become involved in educating the community and spreading public health messages. They are also able to represent their village on health-related issues at the district level through their communications with the village council and village chairman (Frumence et al., 2017). For example, many VHC members describe going from house to house in their local areas to inspect latrines and water access, and to encourage households to grow vegetables in the garden. The range of activities which VHC members carried out, working towards improving health in their respective villages was diverse.

Below, a lab attendant at a village dispensary talked about the benefits of health education in order to prevent frailty for future generations, and described the VHC's voluntary work as a form of solidarity and "holding hands" with more vulnerable groups in the community. This village-level activism is reminiscent of Nyerere's *"Ujamaa"* rural development ideology, which argued in favour of communities co-operating, led by engaged rural people, for the development of their own livelihoods and wellbeing (Komba, 1995).

I think something that can be helped with maybe is health education… the village and maybe different institutions should help them, they should hold their hands, and also I see the most important thing which would help this, as I see it, is health education to teach these people that in a meeting they should told about it (frailty), especially so that these contemporaries should not come to face such a situation again. (Mama Ndosi, 40 years, 5th July 2017)

In addition to aspiring to lead and educate their communities in a larger way, the VHC members gave practical assistance, visiting older people in their homes and using their influence to advocate for individuals to receive waiver letters in order to be able to access hospital care where needed. As described in the case of 'Bibi Helena', this was an ad-hoc process in response to urgent and extreme need, rather than the proper implementation of the exemption policy for all ≥60 years.

6.15.1 "Madaktari kwa ajili ya wazee": Doctors for the sake of the elders

'Baba Munuo' a 70 year old, subsistence farmer and small business owner, provided a unique perspective: He was caring for his mother who had advanced dementia, and had worked closely with the research team, assisting with enrolment of older people to the study. He had also been a VHC member since 1999 and as a part of this work he had attended seminars on sanitation, child and maternal health, and HIV-prevention held by the district health team. This combination of personal experience and an overall knowledge of the welfare of older people in his village gave him a special outlook. Toward the end of his interview, after being given an opportunity to ask questions 'Baba Munuo' made a heartfelt recommendation that there should be doctors who specialise in caring for older people. He saw that older people may have special needs, particularly in their abilities to communicate (due to sensory or cognitive impairments) and from his position as an elder, he wanted to advise the research team. Despite the fact that this was mentioned only once, coming from his unique perspective of VHC member and care-giver it has warranted its own sub-theme. It is also particularly pertinent, given that the National Health Policy also recognised a lack of specialised

healthcare workers as one of the main barriers to providing geriatric services (The United Republic of Tanzania Ministry of Health Community Development Gender Elderly and Children, 2017).

Now, I have no question, but I have a request, because these elderly are like children and I know they can't express themselves in the same way that they would like to explain. Now I think there is a need for doctors who are for the purposes of the elderly, they have studied the elderly, the elders… they give services to the elders according to their education. Eeeh yes that is my recommendation. (Baba Munuo, 13th June 2017)

6.15.2 "Kujuliana afya zao": To enquire about their health

Primary care and preventative care were emphasised across many FGDs, where VHC members advocated for early testing for chronic diseases as a means of preventing frailty and multimorbidity in old-age. In several FGDs it was suggested that older adults could be prevented from developing severe frailty by getting tested and treated early, for conditions such as hypertension and diabetes.

The next quotation comes from a VHC member with experience of counselling her parents on diet and medications. She expressed the idea that despite the inevitable reduction in strength with age, what was needed was a health system geared towards improving the prevention and management of multimorbidity:

Elders to us Tanzanians, we have not built for ourselves a system of testing, but when a person gets to fifty years and above is the time of developing diseases often because the strength has decreased. But when there is a system of checking health, to know "I have which problems?" Because there are tests for diabetes, high blood pressure, weight and height. If we had a system like this then old age would not be a reason for diseases, meaning we will know which illness we have early. (Mama Urasa, 38 years, security guard, 10th June 2017)

These data highlight a gap between the reality of services available to older people and international NCDs policies (Prince et al., 2015). VHC members, who were educated and motivated on issues of health are aligned with these policies however. But with regards NCDs the National Health Policy concedes:

Early detection through regular medical examinations promotion efforts have started but have been limited (The United Republic of Tanzania Ministry of Health Community Development Gender Elderly and Children, 2017).

6.15.3 "Wanaokuja na diagnosis zao kichwani": They come with their diagnosis in their heads

One health committee FGD recognised a problem of older adults making impractical demands of the government dispensary. Often unrealistic expectations of the capabilities of "modern" or "western" medicine, combined with low levels of health education produced concern that people could come to harm, and spend unnecessarily ("give up their body and their money"), at private health facilities. However, this sentiment also suggests that there was an increasing demand for private healthcare services, where at least payments were seen to guarantee services and medicines, in contrast with government facilities where services and drugs were inconsistent. The 27 year old, clinical officer at the dispensary gave the sub-theme its title, describing those who come with these demands as more likely to complain.

Those who bring problems are those who come with their diagnoses in their heads and the medication which they want. (Mzee Mmari, 13th July 2017)

A retired clinical officer, with experience of working at the government dispensary since 1979 seemed bewildered by what he saw as people being easily impressed by the appearance of colourful medications, invasive procedures and inappropriate intravenous fluids and drugs given at private facilities, which were expensive, but not necessarily providing better treatment.

Eeeeh!, And everyday medication for a private hospital, they do not have white medication, even paracetamol is coloured, If they see coloured tablets, red, blue, green and so on, together with a drip then they say "here I have been treated well!" So this is a challenge, what I see is we need health education to be given so that they understand there are other places where you will give up your body and your money. (Mzee Munisi, 61 years, 13th July 2017)

From the perspective of an 82 year old subsistence farmer, despite feeling frail and having a wife with disabilities, OOP payments at private healthcare facilities seemed the most certain course of action, and resulted in less wasted time. In this situation an individual simply pays for what they want, rather than having to negotiate the "struggle" and "suffering" of accessing treatment at a government or faith-based hospital.

Sir, the insurance I went there, I have not wanted the insurance, I cannot tell lies, I have not wanted the insurance. But if you go there you go with the people who have insurance, you are told 'here, there is no medicine, go and buy medicine there in the shop, here there is no medicine'! They leave you there, the one with money goes to be treated! It is not that I am accusing them, I am not given medicine. I do not struggle to go to them, I used to go to one doctor…I used to go to that doctor to get treatment instead of suffering by going to (a government or faith-based) hospital to be treated. I pay money and get treated then I return to my home. (Babu Obadia, 5th July 2017)

These data provide evidence that a perceived low quality of care, particularly at government facilities was driving an increase in OOP payments, with frail older people choosing to opt-out of insurance and exemption schemes completely. In the absence of high quality, fair and reliable services, older people resorted to a simpler consumer-provider model, where treatment and services were at least more assured in an emergency.

6.16 Discussion

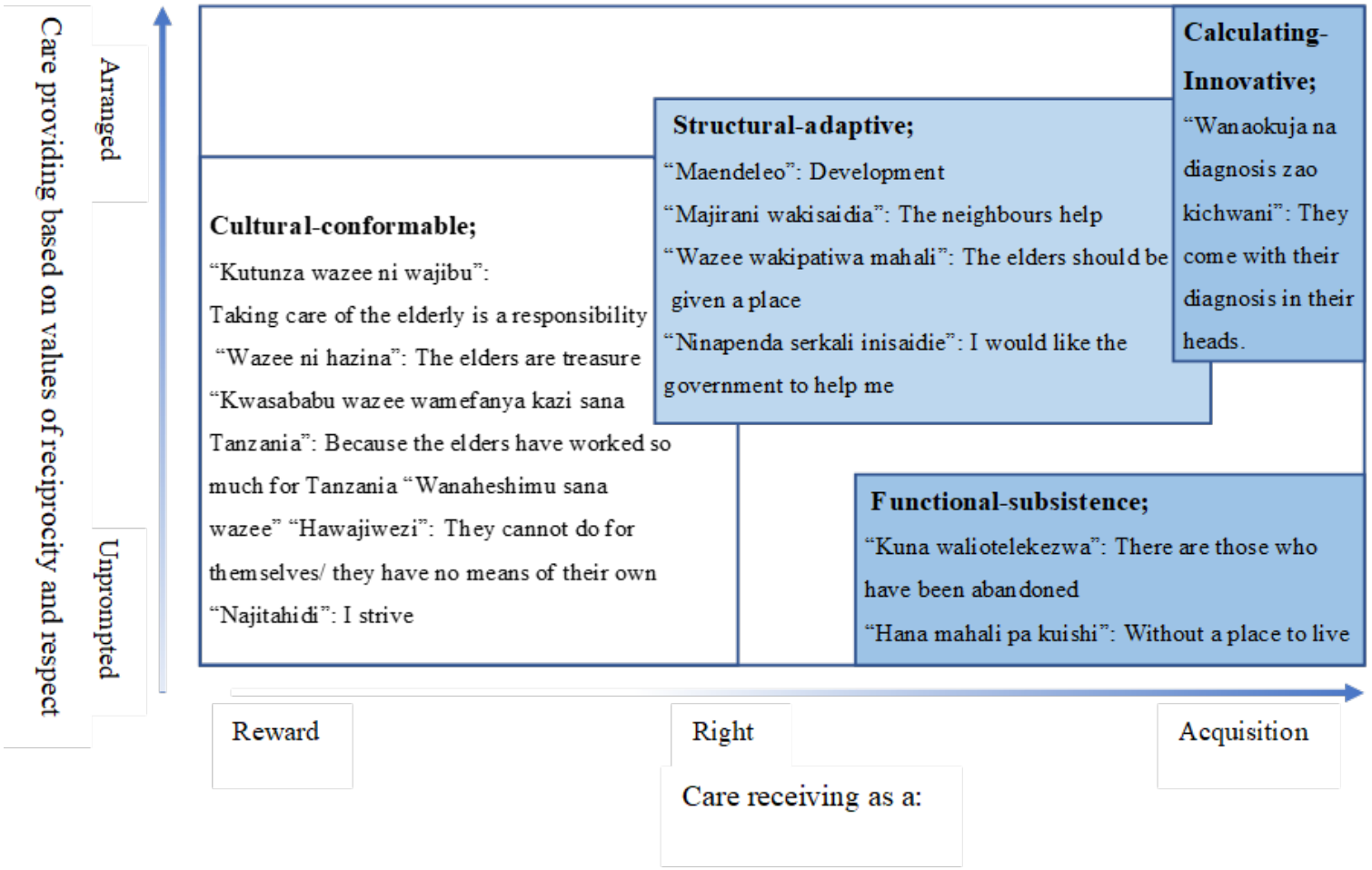
This section will seek to draw together the findings presented in Parts One and Two in order to answer the research question pertaining to this chapter; How are frail older people cared for? As previously explained, enabling a frail older person to access healthcare was seen as an important care-giving activity, therefore this chapter also describes how frail older people access healthcare in this context. As has been described, healthcare in Tanzania is difficult to access, particularly for older frail individuals and requires a negotiation of bureaucracy and/or financial resources. Particularly for frail individuals, who have taken on the social role of "childlike" dependency, they become dependent on the family to enable them to receive healthcare. This is corroborated by Peter van Eeuwijk's work in Tanzania, where it was found that *"buying medicine"* and *"accompanying to hospital or to the healer"* were activities of care related to frailty and illness (van Eeuwijk, 2018, p81).

6.16.1 The place and practice of care for frail older people

In order to answer the question, how are frail older people cared for, the themes and sub-themes will be discussed with reference to the discourses of care as outlined by Baart (2018), (introduced in section 2.25.4). *Figure 6-3* illustrates the relationships between the four discourses of care, and their relationship towards the receipt and provision of care on the spectrum between care as an unprompted reward, to arranged or acquired care. *Figure 6-3* has been adapted from Andries Baart's original with reference to this study's findings. In particular, care provision was based on the underlying values of respect and reciprocity, so rather than care as a "gift" as per the original (Baart, 2018), care was conceived of as a

“reward” in response to a lifetime of work and of raising one’s family. Appendix R outlines the four discourses, and the relevant sub-themes and discusses what this thesis adds.

Figure 6-3 An illustrative representation of the four discourses of care



Adapted from the work of Andries Baart (2018)

6.16.2 The "Cultural-Conformable" Discourse

This was the dominant discourse is described throughout *"Kutunza wazee ni wajibu"*: Taking care of the elderly is a responsibility, and its sub-themes. There was an expressed duty of care for elders according to tradition, and even an "African way of caring" described (Van der Geest, 2018). The ideology was expressed through the proverb, *"Wazee ni hazina"* (The elders are treasure). In repeating the phrase participants were reiterating, an idealised value which *"ought to prevail"* (Baart, 2018, p196). According to this conservative discourse, older people should not be "abandoned", a form of neglect and disrespect by the younger generation, rather they should be given "close" attentive care. As discussed in Part One, "close" care formed the idealised notion of care for older people, the qualities of which included receiving care provided by close family, close to the older person's community (on family land ideally), and with close attention at all times (*"Awe ajisikie faraja"*: Let him feel comforted). This form of care was rewarded by adult children who acknowledged the debt of care owed to their parents, thus this form of care was provided reciprocally, across generations.

While this form of reciprocity across generations applies across Africa, (Pype, 2018, Schatz et al., 2018, Van der Geest, 2002a, Johnson, 2008) this study adds to this discourse by the fact that this traditional form of caring was shown to extend to the state or government, due to the influence of socialism. Expectations were that "the government" should be as responsive and caring as one's relatives, and that the traditional value of reciprocity which underpins family-based care, should also be extend to a caring government looking to reward its citizens for a lifetime of service (*"Kwa sababu wazee wamefanya kazi sana Tanzania*": Because the elders have worked so much for Tanzania, and *"Ninapenda serkali inisaidia":* I would like the government to help me). Additionally, this study's findings add to the discourse through the fact that traditional values of respect and reciprocity are largely being upheld, in spite of "modernisation".

"Modernisation theory" has been used in an attempt to explain the decline in material support and care for older people as societies urbanise, industrialise and develop a market economy (Aboderin, 2004b). These macro-level societal changes were theorised to lead to attitudinal changes such as increased secularisation and individualism (Cowgill, 1986a). However, this study provides evidence that traditional values underpin the motivations for providing care, and extended into the other discourses. Despite "modern" configurations of care, reciprocity and respect were the underlying motivations for adult children sending remittances through mobile banking, or providing paid-for home-based care, and staff at Amani provided care to

residents in acknowledgement of their working lives for the Tanzanian Nation. Thus, even in a "modern", formal, institutionalised system of care, traditional values of reciprocity and respect were present.

6.16.3 The "Structural-Adaptive" Discourse

The "structural-adaptive" discourse was particularly strong throughout these data. The first president of Tanzania argued for rural development, led by communities as part of his *"Ujamaa"* villagisation policy (Komba, 1995). Particularly for the older generation, the idea of community empowerment for development has been embedded through the ideology of Nyerere's socialism. One sub-theme which conveyed this political ideology, described one of the most important "elder" roles as leadership for village development (*"Maendeleo"*). Equitable and rural development being one of the key projects of *"Ujamaa"* socialism (Green, 1995). The volunteer members of the VHCs, expressed a "trained solidarity", where many had attended seminars on public health topics and were enthused to co-operate to improve health in their local communities. VHC members described the ways in which they educated the community and advocated for the health of older people, for example by communicating with the village leadership on behalf of frail older people so that they might receive a waiver letter to access free healthcare (*"Tunawaelemisha"*: We teach them).

As previously discussed, the value of reciprocity was extended to the Tanzanian government which explains some of the frustration and anger towards the government for its poor provision of healthcare and financial support for older people. This frustration was similarly described by Kamat who investigated the cultural understandings of healthcare from the perspectives of older adults in Mbande, a village outside Dar es Salaam (Kamat, 2008). This investigation found that older people harboured a longing for the socialist time of Nyerere, where the government had provided *"households and individuals with free healthcare, subsidised food and social security"* (Kamat, 2008, p360). Thus, formal opportunities and systems of care provided by the government were seen, not as a move away from "the cultural-conformable" discourse of care, but significantly overlapping (*Figure 6-3*). The older participants of this study, understood that the Tanzanian government, in addition to the family, was in a reciprocal relationship with its older citizens, and after a life of service and "good citizenship" they were disappointed and frustrated at what was perceived as the government's neglect and abandonment. Conversely, for those who felt they were receiving the government's support, particularly at Amani, the care given and received was in accordance with the principle of reciprocity between the state and its citizen. In an investigation of care at a Kinshasa retirement home, older people resident there had lost their

identities and been excluded from the *"primary space of identity attribution: the family"* (Pype, 2018, p64). While this was to a large extent also the case in Tanzania, explaining much of the resistance to residential care for those with existing family structures, there was evidence that the influence of socialism and Tanzanian nationalism has made providing and receiving care in the institutional setting more culturally congruent. It is also possible that as more formal systems of care for frail older people develop, whether that be at institutions or through professional home-based care, that an emphasis on reciprocity as an underpinning value, would make these forms of care more culturally acceptable.

6.16.4 The "Calculating-Innovative" Discourse

The third, "calculating-innovative" discourse was represented the least within these findings. According to the "calculating-innovative" discourse, the older person receiving care is an autonomous individual with financial capital, and is a consumer of care. According to *"Wanaokuja na diagnosis zao kichwani"*: They come with their diagnosis in their heads, paying for private healthcare was seen as preferable to wasting time, facing discrimination, and having to pay for medicines at government hospitals. Explicitly, the low quality of healthcare experienced by older adults at government facilities forced them to opt to pay privately. Discussion in the sub-theme *"Wazee wakipatiwa mahali"*: The elders should be given a place, also accepted that in certain instances, a paid care-giver providing home-based care, would be acceptable. While it might seem that the transactional nature of this care-giving arrangement conforms to the "calculating-innovative" discourse, in many ways it manages to uphold traditional ideals.

These data found the experience of ageing and becoming frail in this context, involved a loss of one's financial capabilities to contribute as would be expected of adults (*"Au kuchagia? Hapana…"*: Or donations? No…, and *"Hawajiwezi"*: They cannot do for themselves/ they have no means of their own). Having the social and financial agency to choose and pay for health or social care was not within the means, or possibility, of many of these older participants. Frailty led to a loss of adulthood, and a "childlike" state of dependency where it was expected that all decisions and payments be made by the younger generation. Indeed for most, being an independent consumer of care would not have been seen as desirable, given that desired care in frail old age was inter-generational reciprocal or interdependent care (Aboderin and Hoffman, 2015, Whyte, 2017). Making decisions and paying for one's own care might indicate having been abandoned by one's family, hence, the acceptability of home-based care, paid-for by and on behalf of an adult child. That is to say, the care has been

commercialised, but it is accepted in this instance because the *meaning* of the paid care is still a recognition of the debt of care owed by the adult child.

6.16.5 The "Functional-Subsistence" Discourse

The "functional-subsistence" discourse was prominent throughout these results. Individuals such as 'Mzee Massawe' and 'Bibi Helena', were extreme examples of frailty through "being in scarcity" who had found themselves alone and surviving day to day on their own dwindling *"physical capital and streetwise inventiveness"* (Baart, 2018, p197). Many more of my participants, survived in this manner relying on neighbours, religious groups, or the government for intermittent, unreliable and inadequate care. Older frail participants lived in these precarious states even within "traditional" family networks, as with 'Bibi Zakia' and 'Babu Shuma', who resorted to begging for food in the neighbourhood, or 'Mama Josephine' and 'Baba Thomas' who relied on their school-aged children to provide the household income. This struggle to subsist can be seen throughout *"Unatakiwe uwe na roho nguvu sana"*: You need to have a very strong heart, where older people described needing a strength of heart or spirit, to live with the frailty of "being in scarcity". Cattell similarly described a case study of an older widow who survived according to the functional-subsistence discourse, and consistent with demonstrating the cognitive consequences of frailty as "being in scarcity" and was quoted saying *"we old people only think about food"* as she walked around the neighbourhood begging (Cattell, 1990, p383).

The findings presented in Part One and Two relating to the "functional-subsistence" discourse are in keeping with Gorman and Heslop's study of multidimensional poverty in old age (Gorman and Heslop, 2002). Multidimensional poverty, describes poverty affecting multiple domains of life, and was exacerbated or caused by particular old-age disadvantages. Similarly, the absence of income security, inadequate family or social care as well as poor access to healthcare were all described as problems of old age in low and middle-income countries (Gorman and Heslop, 2002). What this thesis adds in particular, is an understanding of the experience of living in this state of scarcity, where economic migrants (or "outsiders") and widows were most vulnerable to the negative experiences described in *"Unatakiwe uwe na roho nguvu sana"*: You need to have a very strong heart.

6.17 Summary

These two themes have been presented in order to answer the research question; how are frail older people cared for? The first theme *"Changamoto kwa wazee ni ngumu sana"*: The challenge of the elders is very hard, reveals that providing care for frail older people was experienced as a challenge at the village community level. The community provided ad-hoc

and short-term neighbourly care for those without adult children to rely on. However, due to the material constraints faced by all, this form of care was unreliable. Those frail individuals providing a particular challenge to the community were economic migrants from "outside", and those who have been "abandoned" or found themselves without a family network. For these individuals without the mainstay family-based care, the village leaders and community members as "neighbours" attempt to provide care, yet the sub-theme *"Wazee wakipatiwa mahali"*: The elders should be given a place, reveals the opinion within the community that there is a need for more formal opportunities and resources for care, including the provision of a specific "place" to care for those who are displaced within the community.

The provision of healthcare was seen as a caring act for older people with frailty. According to *"Tunapata dawa"*: We get medicine, older people lacked the agency to access healthcare themselves, only to mobilise attentive adult children to enable it. This form of care provision for acute episodes of illness was hampered by delays in deciding to seek healthcare, delays or barriers reaching a facility, and delays receiving appropriate care, commonly due to low stocks of appropriate medicines. There were bureaucratic and financial barriers to accessing healthcare, which particularly affected older people with frailty, due to their higher levels of financial and physical dependency. One of the rare but important outcomes associated with frailty was that frailty could result in CHE and institutional admission. VHC members particularly saw the potential benefit which could come from better health education, specialised services and prevention or early detection of chronic NCDs.

These four discourses of care will be returned to in the discussion chapter, (section 8.28) when debating the implications of these findings for access to healthcare and long-term institutional care for older people with frailty living in SSA.

Chapter 7 The biomedical outcomes associated with frailty at follow-up

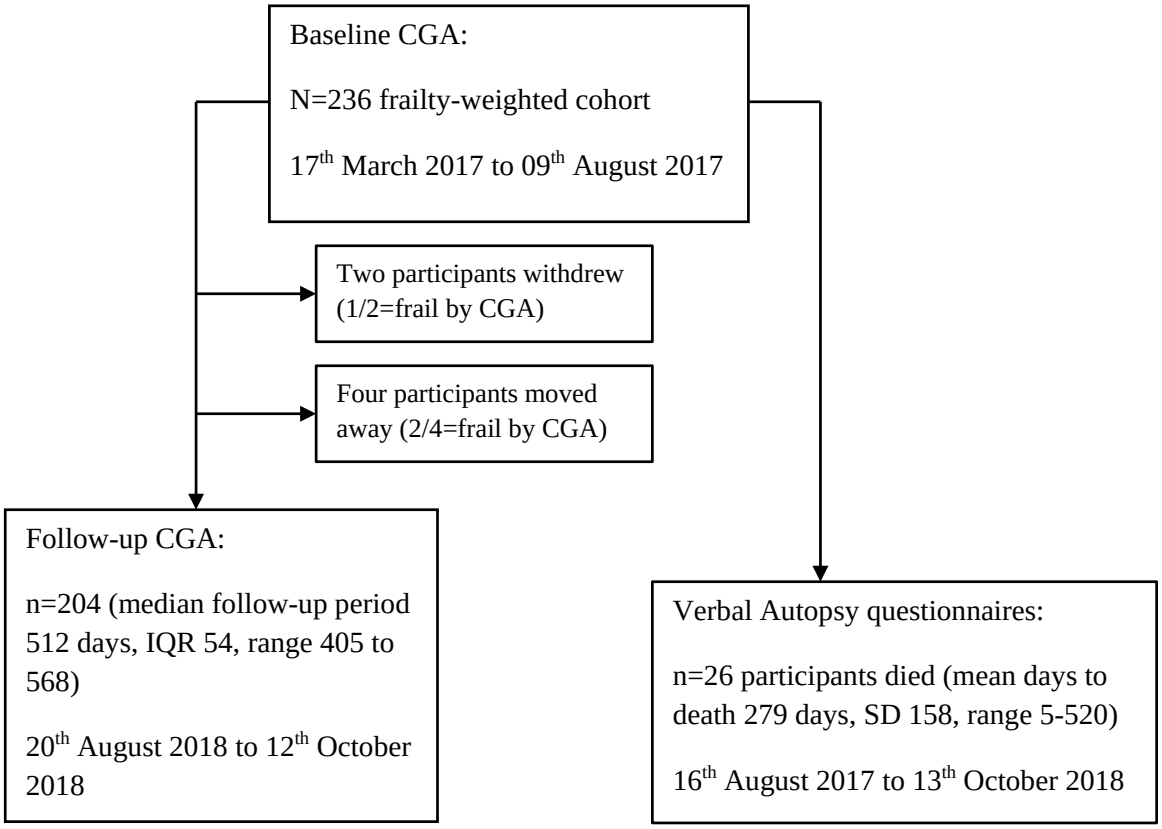
7.1 Introduction

In high-income country (HIC) settings the outcome measures which have been associated with of frailty include hospitalisation, admission to long-term care institutions, falls and ultimately death (Clegg et al., 2013). In sub-Saharan Africa (SSA), mortality and dependency of the activities of daily living (ADLs) have both been shown to be associated with frailty (Gray et al., 2017, Payne et al., 2017) but beyond these studies there has been limited exploration of outcomes associated with frailty. This study sought to confirm these associations, and explore other possible outcomes associated with frailty in this setting. These additional outcomes of frailty (present in HIC literature) were worsening disability, hospital admission, and falls. The present study is one of only a few longitudinal studies of frailty in rural SSA, therefore this component of the investigation also sought to investigate frailty-associated mortality, as well as the underlying cause of death (COD) for those who died during the follow-up period. This was with the aim of confirming the predictive validity of the biomedical models of frailty employed.

7.2 Overview of follow-up

The follow-up activities and timeline have been illustrated in *Figure 7-1*. By the end of follow-up 210/236 participants (88.9%) were still alive, of whom 204 (86.4%) were re-assessed. Of those not re-assessed at follow-up, 26 (11.0%) had died, four (1.7%) had moved away, and two (0.8%) had withdrawn from the study. The median follow-up period was 512 days Inter-quartile range (IQR) 54, (range 405 to 568). For the 26 deaths, the mean number of days to death was 279, Standard deviation (SD) 158, (range 5 to 520). All deaths were followed-up with a verbal autopsy questionnaire (VA), conducted between the time of the baseline Comprehensive Geriatric Assessment (CGA) and end of the follow-up CGA assessment period. The village enumerators contacted the families or neighbours of the four participants who had moved away from Hai District in order to confirm their location. None of the six participants lost to follow-up were reported to have died before the end of the follow-up period according to neighbours or relatives of those participants.

Figure 7-1 Flow chart outlining the follow-up of the frailty-weighted cohort



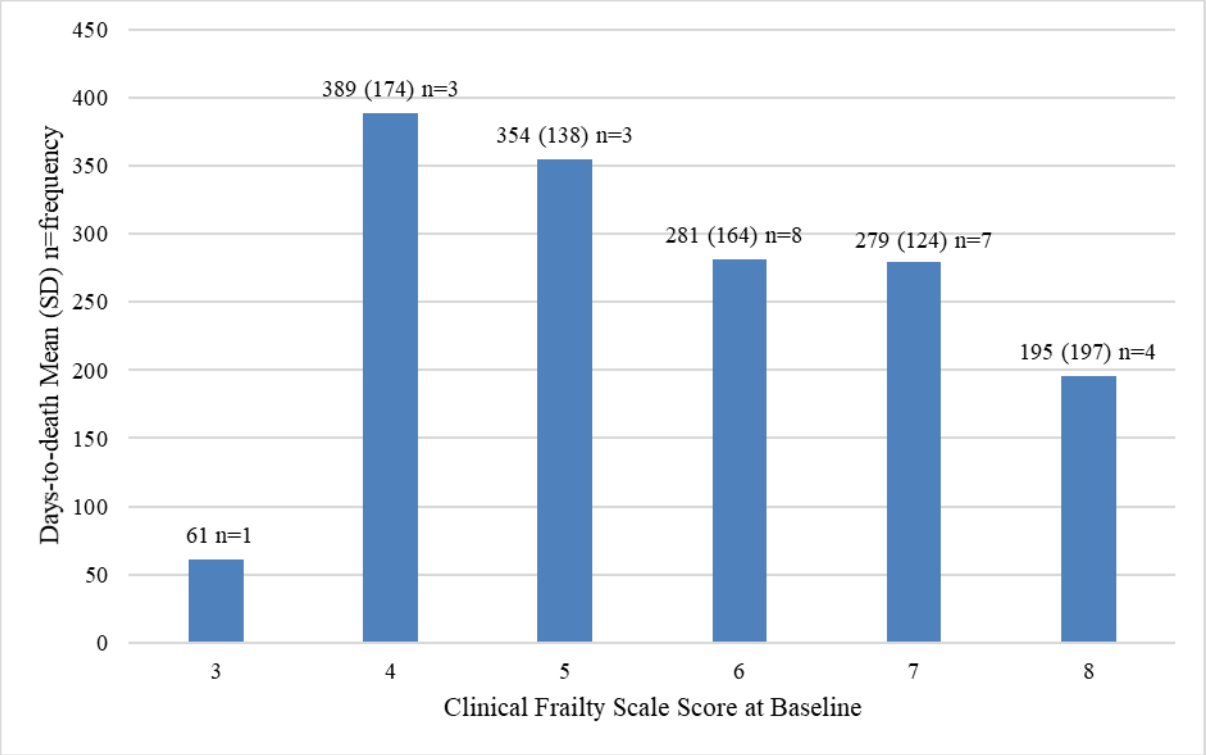
7.3 Frailty-associated mortality

The following section will examine the mortality rate in the studied population, calculated from the deaths observed in this cohort. The ability of each of the frailty measurements to predict risk of death will be compared. Lastly, descriptive data from the VA questionnaire will be presented.

7.3.1 Mortality rate

Twenty six deaths occurred during the follow-up period, within the frailty-weighted cohort of 236. *Figure 7-2* demonstrates that except for the participant with a Clinical Frailty Scale (CFS) score of 3, as frailty severity increased, the mean number of days to death reduced. The mortality rate in community-dwelling adults aged ≥60 years in Hai District was 1 in 10,000 person-days, calculated by adjusting the number of days of follow-up and number of deaths by the Brief Frailty Instrument for Tanzania screen (B-FIT) weightings.

Figure 7-2 The mean days to death plotted against CFS scores at baseline CGA



7.3.2 Hazard Ratio for death by each measure of frailty

Cox Regression Survival analysis was used to calculate the risk of death, while taking into account the time to death or follow-up among the cohort. Unadjusted Cox Regression shows a hazard ratio (HR) of 10.28 (95% CI 3.53 to 29.90) for frailty by CGA compared with non-frail older adults. When controlling for age, sex and education, the effect of frailty by CGA was attenuated, but remained a significant predictor for death, with a HR of 4.62 (95% CI 1.42 to 15.04). *Table 7-1* demonstrates that when comparing the different frailty assessment methods, the Frailty Index (FI) with a cut-off of 0.38 was the most predictive of death, with a statistically significant adjusted HR of 4.97 (95% CI 1.53 to 16.10). Indeed, the FI (0.38 cut-off), CGA, Frailty Phenotype (FP), and B-FIT, were all significantly predictive of mortality over this follow-up period. While the B-FIT screening tool produced the lowest HR for prediction of death it remained significant after adjustment for age, sex and education status.

Table 7-1 Comparing the predictive abilities of each measure of frailty for death

Frailty assessment method	Unadjusted Cox Regression HR	95% CI (p value)	Adjusted Cox Regression HR*	95% CI (p value)
Predictive abilities of the CGA and B-FIT for n=236				
CGA	10.28	3.53 to 29.90 (p<0.001)	4.62	1.42 to 15.04 (p=0.011)
B-FIT	4.63	2.12 to 10.10 (p<0.001)	2.38	1.03 to 5.47 (p=0.040)
Predictive abilities of the FI and FP for n=234**				
FI (cut-off 0.25)	13.22	1.79 to 97.64 (p=0.011)	4.98	0.62 to 39.74 (p=0.129)
FI (cut-off 0.38)	11.22	3.86 to 32.62 (p<0.001)	4.97	1.53 to 16.10 (p=0.007)
FP	6.97	3.03 to 16.08 (p<0.001)	3.36	1.37 to 8.22 (p=0.008)

*Controlling for age group, sex and education

** The FI and FP were not calculable for two cases excluded from these analyses. One frail case was excluded due to large amounts of missing data. Another case was excluded from FI and FP analysis due to withdrawal from the study after CGA (*Figure 4-2*).

7.3.3 Cause of death in frail and non-frail older adults by Verbal Autopsy

During the follow-up period 26 deaths were observed from the frailty-weighted cohort (*Figure 7-1*). In all but one case, where the VA was completed by the village chairman, VA questionnaires were completed by a close relative who had lived with the deceased in the time leading to death. The demographic and healthcare information of the deceased are presented in *Table 7-2*.

Due to low numbers in the non-frail group (n=4), no statistical associations have been calculated. Notably, three from four of the non-frail who died were deemed “vulnerable” according to the CFS score at baseline assessment. The further participant who was assessed as “managing well” died by suicide. A higher number of frail individuals sought care at private hospital facilities and received invasive treatments such as intravenous fluids and antibiotics. Consequently a higher proportion of families of those who were frail reported household financial difficulties as a result of healthcare costs in the final illness. Those who received treatment during the final illness, but not the treatments listed among the invasive procedures and treatments below, presumably received oral medications (*Table 7-2*).

Interestingly, traditional medicine was used in the final illness by only one participant, this finding may point to a different approach to terminal illness or acute severe illness in older people, or it is possible that VA informants withheld this information from external researchers who may have been seen as representing “western” biomedicine.

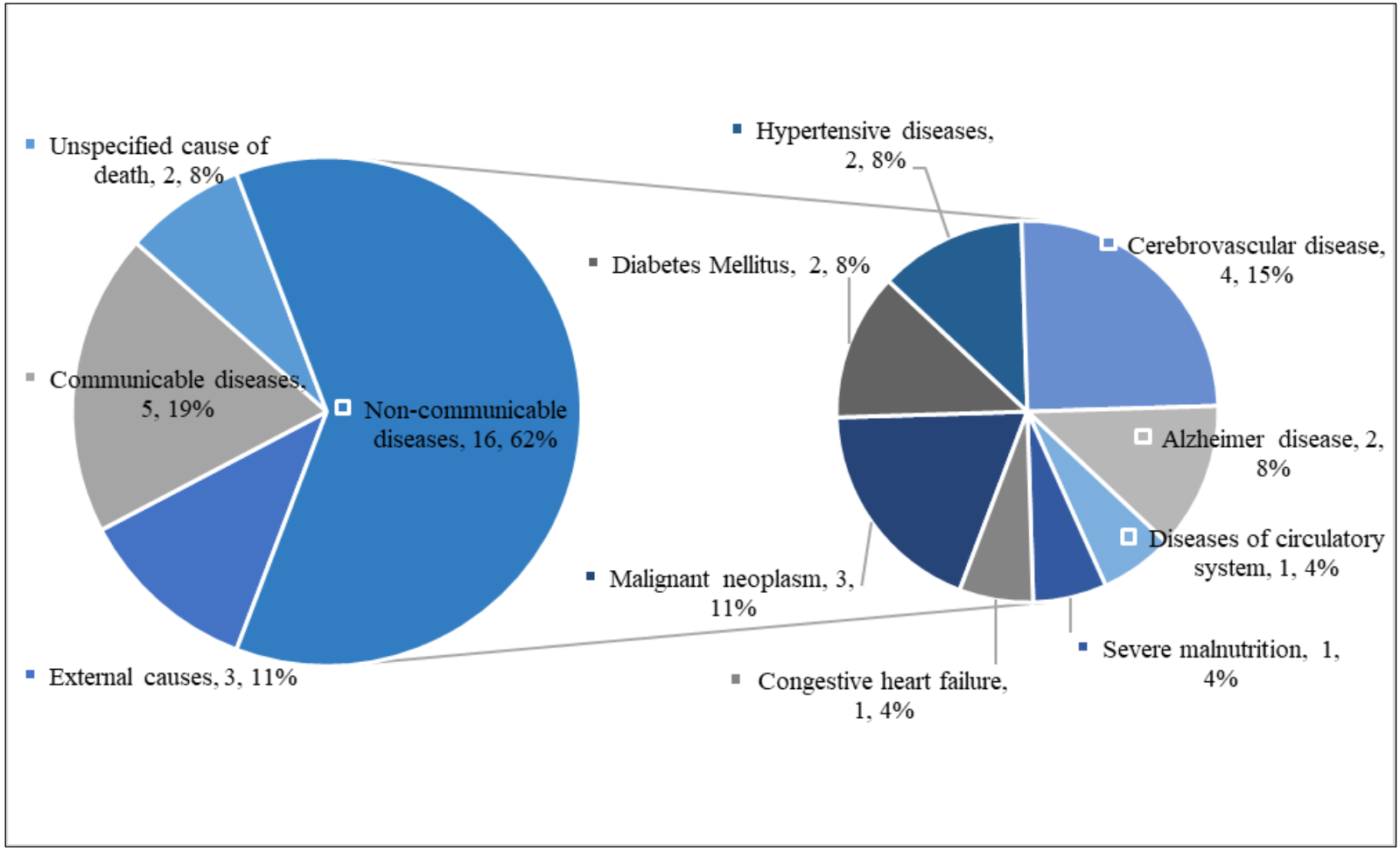
Table 7-2 VA demographic and healthcare data by CGA frailty status

	Frail n=22	Non-frail n=4
Age Mean (SD, range)	86.3 (10.3, 62-110)	84 (10.4, 75-99)
Female sex	13 (59%)	2 (50%)
Able to read/write	12	1
Marital status	Widowed=14 Single=2 Married=6	Widowed=3 Single=1
CFS score distribution	Mildly frail=3 Moderately frail=8 Severely frail=7 Very severely frail=4	Managing well=1 Vulnerable=3
Place of death	Hospital=10 On the way to hospital=2 Home=10	Hospital=1 Home=3
Was care sought outside the home during the final illness?	Yes=15 Government hospital=6 Private hospital=8 Government clinic=1	Yes=4 Government hospital=3 Private hospital=1

Was treatment received for the final illness?	Yes=19 IV fluids=13 Blood transfusion=4 IV antibiotics=16 NGT=4 ARV=1 Operation=5 Discharged “very ill”=6	Yes=4 IV fluids=1
Does it take > 2 hours to get to the nearest hospital or health facility from the deceased's household?	Yes=5	Yes=0
In the final days before death, was traditional medicine used?	Yes=1	Yes=0
Over the course of illness, did the total costs of care and treatment prohibit other household payments?	Yes=16	Yes=1

IV fluids= Intravenous fluids, NGT= Nasogastric tube, ARV= Antiretroviral medication

Figure 7-3 VA COD titles, by categories of communicable, non-communicable and external causes of death



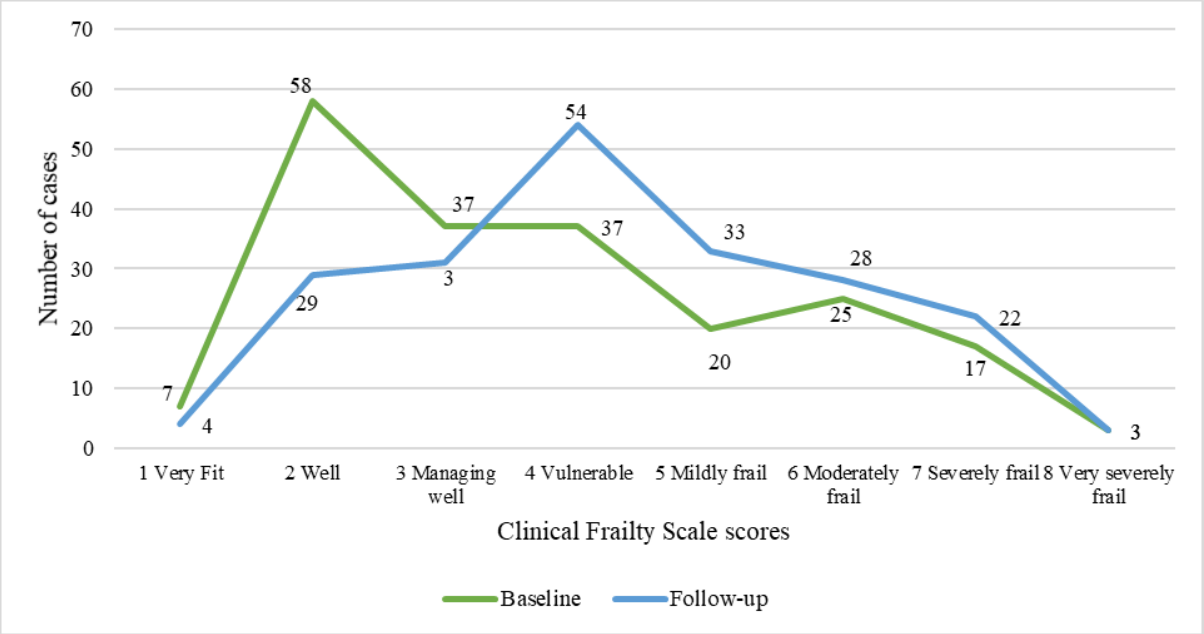
Appendix S provides further detail of the VA COD codes and titles, and their corresponding ICD-10 codes and titles, listed in order of the participant's CFS category. Non-communicable diseases (NCDs) accounted for 16 deaths (*Figure 7-3*), while communicable diseases contributed to five deaths. Cerebrovascular disease was the most commonly coded VA COD, which in three from four cases led to death through aspiration pneumonitis (Appendix S). There were three deaths from external causes; an assault, a suicide, and a road traffic accident. It was not possible to assign a COD from the available VA data for two deaths, which were assigned the code "Unspecified COD". The expert consensus panel, blinded to the results of the CGA and prior CFS status also produced a medical certificate of COD from VA data (Appendix T). There are several notable differences between the VA codes, ICD-10 codes, and the assigned medical certificate of COD. Firstly, frailty was felt to have contributed to the death (and was mentioned in part II of the death certificate) for ten cases, one of whom could not be assigned a COD. Secondly, the VA COD codes did not permit the coding of two cases of sepsis due to urinary tract infection, and one case of sepsis from an infected foot ulcer, so less specific COD codes were chosen ("infectious diseases, unspecified" or "other specified causes of death").

7.4 Outcomes associated with frailty

Death is only one of the adverse outcomes known to be associated with frailty, and the concept of frailty offers more than a method for assessing the risk of or predicting death. The follow-up assessment, which updated participants' CGAs, sought to identify other potential adverse outcomes which have been identified in HIC settings; these were falls, hospital admission, and disability according to the World Health Organization Disability Assessment Schedule, (WHODAS 2.0 full version). Episodes of acute illness not managed in hospital were also recorded in order to capture episodes of illness in those who faced financial or other barriers to accessing hospital care. Institutional admission was not investigated by these methods as it is extremely rare.

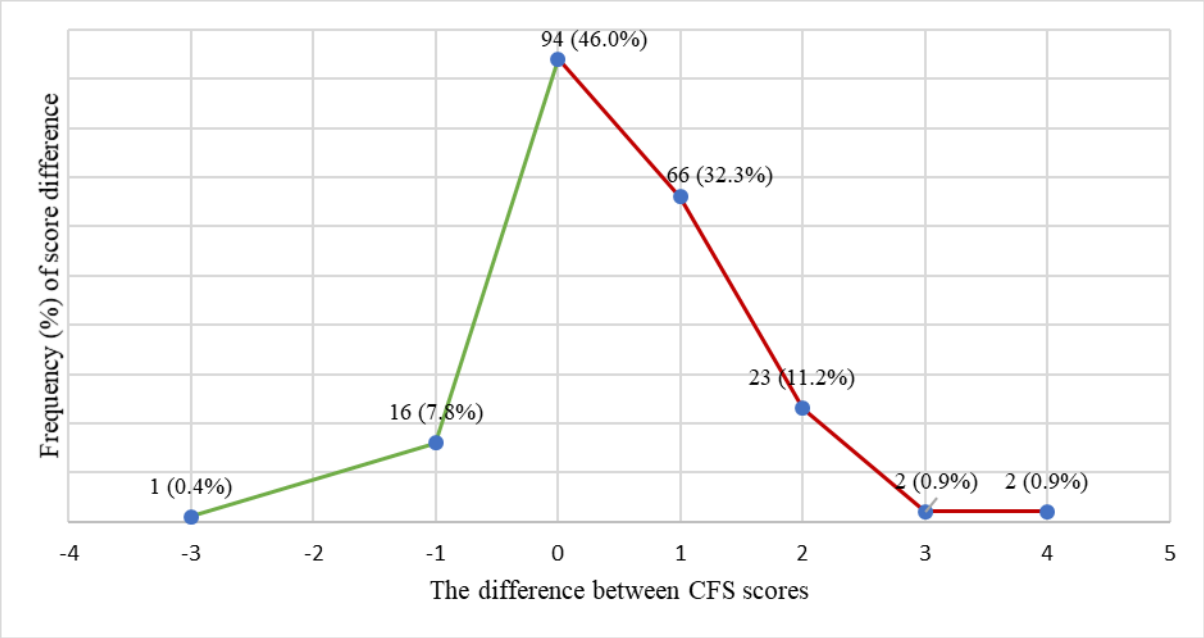
Baseline CGAs were conducted between the 17th of March 2017 and 9th of August 2017 inclusively, while follow-up assessments were conducted between the 20th of August 2018 and 12th of October 2018 (*Figure 7-1*). The CFS was graded at both assessments and scores were arrived at by consensus with a Tanzanian research colleague. *Figure 7-4* shows the sum of CFS scores in each category across the two assessment periods for the 204 participants assessed at baseline and follow-up. The CFS scores at follow-up were given with knowledge of the previous CFS and CGA.

Figure 7-4 Distribution of CFS scores across time points for survivors



The median score at baseline was 3.50 IQR (2.0-5.0) and at follow-up was 4.0 (3.0-6.0) with a Wilcoxon signed ranks test showing a significant difference between the two time points (Z=-7.190, p<0.001). When comparing the two CFS scores, given at a mean of 16.5 months apart, the CFS score, which takes into account an overall impression of an older person's general functioning, energy levels and mobility, was static for 94 participants (46%). The CFS scores deteriorated by 2 points in 93 individuals (45.5%), of whom 23 were newly categorised as frail as a result. A notable minority of 16 (7.8%) improved by one CFS point between their baseline and follow-up, of whom five were newly categorised as non-frail from being frail (*Figure 7-4*). These findings are consistent with frailty as a dynamic and potentially reversible state (Kojima et al., 2019). *Figure 7-5* illustrates the frequency and percentage of change in CFS scores between assessments.

Figure 7-5 The change in CFS Scores between baseline and follow-up assessments



With regards to adverse outcomes associated with frailty, there was a significant association between frailty and hospital admission, while episodes of acute illness without hospital admission were common but not significantly associated with frailty. Falls were not significantly more common in the frail group, which may be accounted for by multiple factors, including reduced mobility (*Table 7-3*). Interestingly, additional analysis demonstrated no association between cognitive impairment (IDEA cognitive screening tool ≤7) and falling (X^2 (2)=0.09, p=0.753).

Table 7-3 The association between frailty (by CGA) and adverse outcomes in survivors

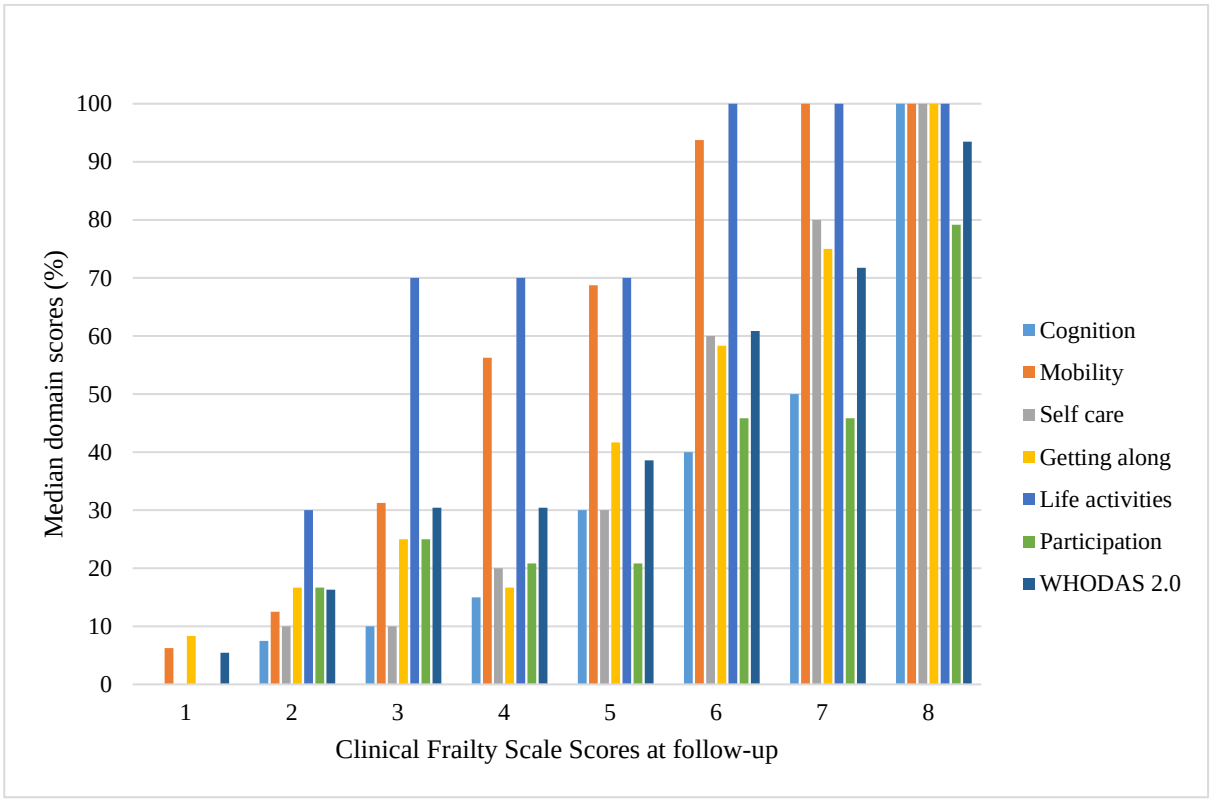
Outcomes	Frail (N=86)	Non-frail (N=118)	Significance
Hospital admission (%)	26 (30.2)	11 (9.3)	X^2 (2)=14.64 p<0.001
Illness episode (%)	51 (59.3)	69 (58.4)	X^2 (2)=0.14 p=0.906
Falls (%)	26 (30.2)	26 (22.0)	X^2 (2)=1.76 p=0.185
WHODAS 2.0 IRT complex coding (32 item) Median (IQR)	54.3 (39.67-71.73)	19.5 (7.33-32.60)	U=11.62.5, z=-8.600, p<0.001
Domain 1 Cognition Median (IQR)	37.5 (15.0-65.0)	5.0 (0.0-20.0)	U=1920.00, z=-6.757, p<0.001

Outcomes	Frail (N=86)	Non-frail (N=118)	Significance
Domain 2 Mobility Median (IQR)	87.5 (62.5-100.0)	25.0 (6.25-50.0)	U=1173.00, z=-8.608, p<0.001
Domain 3 Self-care Median (IQR)	50.0 (20.0-80.0)	10.0 (0.0-20.0)	U=1042.5, z=-9.068, p<0.001
Domain 4 Getting along Median (IQR)	58.3 (33.3-75.0)	16.6 (8.3-25.0)	U=1291.5, z=-7.141, p<0.001
Domain 5 Life activities Median (IQR)	100.0 (77.5-100.0)	40.0 (0.0-70.0)	U=1781.0, z=-7.141, p<0.001
Domain 6 Participation Median (IQR)	37.5 (16.6-58.3)	16.6 (4.1-30.2)	U=2868.5, z=-4.286, p<0.001

7.4.2 The Disability Assessment Schedule

Below, *Figure 7-6* shows the median scores for the WHODAS 2.0 and each of its domains plotted against the CFS scores at follow-up assessment. The domains assessed by the WHODAS 2.0 encompass many of the areas of life affected by frailty, for example carrying out ADLs (such as washing oneself and dressing) and daily work (e.g. household tasks). Notably, median disability scores were raised earliest in the "mobility" and "life activities" domains, which produced the highest disability scores within the non-frail categories. Interestingly, the "participation" domain, which represents an evaluation of one's ability to join in with community activities remained comparatively low, even as frailty severity increased. High disability scores in the "cognition" and "self-care" domains occurred later, in the severely frail and very severely frail categories.

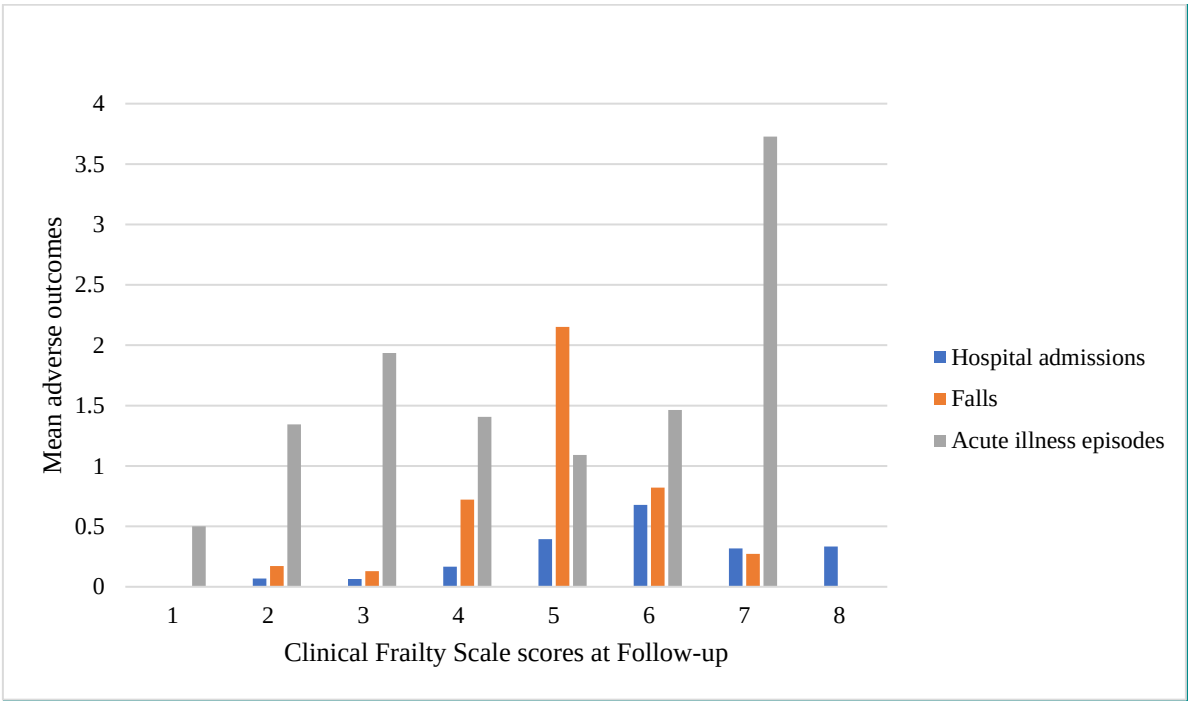
Figure 7-6 Median WHODAS 2.0 domain scores plotted against CFS scores at follow-up



7.4.4 Adverse outcomes by Clinical Frailty Scale scores

The following cluster bar chart illustrates the distribution of adverse outcomes (hospital admission, falls, acute illness episodes) across the distribution of CFS scores at follow-up (*Figure 7-7*). The pattern of distribution for each of these outcomes, (from very fit=1, to very severely frail=8) will be presented here and discussed further at the end of this chapter, given that interpretation of these findings are helped by contextual information.

Figure 7-7 The mean adverse outcomes plotted against CFS scores at follow-up



7.4.5 Falls

An interesting trend was observed, whereby the mean number of falls peaked in the mildly frail (CFS=5), and decreased thereafter. Moderate, to very severely frail older adults may fall less frequently because they are less mobile, and yet, no falls out of bed, or from a chair were documented.

At follow-up, the assessing doctor took, a brief history of the reported falls. These have been categorised by likely underlying cause. From 52 individuals who reported falling, 28 (53.8%) fell once over the preceding 12 months, 11 (21.1%) reported two falls, and 13 (25%) had ≥3 falls. Most falls were clearly explainable, usually due to slipping or tripping on wet or uneven ground. Two participants had falls which were associated with road traffic accidents, and two reported falling out of their wheelchairs. Five individuals described falls which were likely to be due to an underlying acute medical illness, for example a stroke or hypoglycaemic episode. A further 14 participants described preceding symptoms, for example of dizziness, before

falling. These histories suggest either postural hypotension or vasovagal episodes as underlying reasons for falling. Two participants fell where the main reason was visual impairment, and one fell due to suspected alcohol intoxication. Twenty four (46.1%) participants reported sustaining an injury from falling, but only four of those injuries resulted in a fracture.

7.4.6 Hospital admissions and illness episodes

The mean number of hospital admissions (defined as admission with an overnight stay) was highest in moderately frail participants and decreased with frailty severity, while the mean number of acute illness episodes was high across all CFS scores, but peaked in the severely frail (*Figure 7-7*). The number of participants reporting an episode of acute illness was high overall n=120 (58.8%), however n=51 (42.5%) were frail by CGA, a non-significant association, (Pearson Chi-square .014, p=0.906). An overnight stay in hospital in the previous year was a less common outcome overall, n=37 (18.1%) but was more common among frail participants. Individuals deemed frail by CGA accounted for n=26 (70.3%) of hospital admissions, (Pearson Chi-square 14.64, p<0.0001). Further interpretation of these patterns will be returned to in the discussion section of this chapter (Section 7.5.3).

7.4.7 Comparisons of measures at baseline and follow-up

The WHODAS 2.0 short form has been validated for cross-cultural sensitivity to change with time (WHO, 2010a), and in our frailty-weighted cohort at follow-up, there was a significant worsening in summary disability scores (*Table 7-4*).

The B-FIT screening tool, which has not yet been validated for sensitivity to change over time, demonstrated an unexpected improvement in results at follow-up compared with baseline. In order to explore this finding further, the two components of the tool were analysed separately: the Barthel Index (BI) and IDEA (Identification and Intervention for Dementia in Elderly Africans) cognitive screening tools (section 3.8.2). This revealed a significant worsening in the IDEA cognitive screening tool over time, as would be expected. The BI score increased (i.e. improved) slightly and significantly over the two time points. The increased weighting of the BI as part of the B-FIT, as described by Gray et al. (2017), is likely to have caused this unexpected finding, which will be discussed further in section 7.5.4. There was a small non-significant increase in the mean number of falls reported at baseline and follow-up. The CFS scores significantly increased across the time-points.

Table 7-4 Comparisons between baseline and follow-up assessments

	Baseline assessment	Follow-up assessment	Significance of Wilcoxon Signed Ranks test
WHODAS 2.0 short form median (IQR) n=203*	25.0% (6.25-50.0)	29.1% (10.42-52.08)	Z=-1.910, p=0.056
B-FIT scores median (IQR)	2.00 (0.00-3.00)	0.00 (0.00-2.75)	Z=-3.983, p<0.001
BI scores (from 20)	18.0 (16.0-20.0)	19.0 (17.0-20.0)	Z=-2.281, p=0.023
IDEA cognitive screen (from 12)	10.0 (7.0-11.75)	9.0 (6.0-11.0)	Z=-3.113, p=0.002
Number of falls in preceding 12 months mean (SD)	0.39 (0.98)	0.73 (3.75)	Z-1.073, p=0.283
CFS scores median (IQR)	3.50 (2.0-5.0)	4.0 (3.0-6.0)	Z=-7.190, p<0.001

*One case was excluded from this analysis due to having not answered the WHODAS 2.0 12-item questionnaire at baseline. Their WHODAS 2.0 12-item score at follow-up assessment was 70.8%

7.4.9 Risk of adverse outcome by frailty status

Frailty (by CGA) led to a small but non-significant increased risk of falls. Frailty increased the odds of an overnight hospital admission OR 2.69, however this effect became non-significant when controlling for demographic factors. There was no increased risk of an acute illness episode occurring within survivors when comparing frail with non-frail groups (*Table 7-5*). Analysis does not take into account the time to each adverse outcome, and therefore relates to the risk of an adverse outcome occurring within the maximum follow-up period.

Table 7-5 Adverse outcomes associated with frailty by CGA

Adverse outcome	Crude OR	95% CI (p value)	Adjusted OR*	95% CI (p value)
Falls	1.44	0.74 to 2.77 (p=0.277)	1.38	0.62 to 3.08 (p=0.422)
Hospital admission	2.69	1.30 to 5.57 (p=0.008)	2.37	0.95 to 5.91 (p=0.063)
Acute illness episode	0.92	0.51 to 1.68 (p=0.802)	0.81	0.40 to 1.65 (p=0.573)

*Adjusted for age, sex, education status and frailty by CGA at baseline assessment

7.5 Discussion

7.5.1 Summary of the biomedical outcomes of frailty at follow-up

This study can conclude that frailty is a significant independent predictor of death in older adults in rural SSA. These findings have demonstrated that all of the measures of frailty employed were significantly predictive of death and ranged from a HR of 2.38 (95% CI 1.03 to 5.47, p=0.040) for the B-FIT, to a HR of 4.97 (95% CI 1.53 to 16.10, p=0.007) for the FI (0.38 cut-off). Twenty six deaths occurred during the follow-up period, of whom 22 were frail. The VA COD revealed that NCDs accounted for the majority of deaths n=16 (62%), and demonstrated that those with frailty more often sought hospital care, and faced household financial difficulty as a result. Cerebrovascular disease was the most common underlying COD (accounting for four deaths). None of the other adverse outcomes investigated were significantly associated with frailty after adjustment however measures of disability and functioning generally showed a deterioration between baseline and follow-up assessment. Each of the outcome measures investigated will now be discussed in relation to their methodological strengths and limitations.

7.5.2 Disability as an outcome of increasing frailty

Disability was measured using the WHODAS 2.0, and median scores were presented against the CFS scores (*Figure 7-6*). Problems walking and with daily household work occurred

early, perhaps reflecting the high physical demands of daily household tasks in the study's setting. Additionally, the "participation" domain remained the lowest scoring domain with even those deemed severely frail feeling able to participate in their communities despite considerable levels of disability and impaired mobility. This is surprising, given that frailty was strongly associated with being unable to attend church or social meetings; OR 21.98, (95% CI 7.22 to 66.88, p <0.0001) and OR 21.79, (95% CI 7.17 to 66.19, p <0.0001) respectively (*Table 4-3*). There are several possibilities for this apparent discrepancy, the WHODAS 2.0, is a measure of self-assessed functional limitations, and perhaps if frail older people were interviewed with a care-giver or family member present, this might have altered their self-assessed responses so as not to appear critical of their care. Alternatively, a possible explanation may be that older people felt included, despite being unable to attend religious or social meetings because they were visited at home. "Participation" is often measured as part of the concept of social frailty (section 2.10.3). Therefore, further work could investigate the mechanisms by which older people maintain their sense of participation, however qualitative data, (particularly sub-theme, *"Awe ajisikie faraja"*: Let him feel comforted), suggest that this finding may relate to the type of care provided to older people.

7.5.3 Frailty, hospital admissions and acute illness episodes

Figure 7-7 illustrates that episodes of acute illness were common across the spectrum of CFS categories. The highest mean number of illness episodes was found in the severely frail group, however, the mean number of hospital admissions did not increase as would be expected. This pattern implies a possible gap between the healthcare needs of moderate to very severely frail individuals, and their ability access to healthcare. A possible reason for this disparity, may be due to frailty being associated with a four-fold increased odds of having difficulty using transport (*Table 4-3*), a problem which would be particularly pertinent if living rurally. Additionally, financial barriers caused by the poor implementation of the exemption policy, low health insurance coverage, and the high costs of hospital admission, may be a particular barrier for frail older people and their households whose financial situation may already be affected by the three-fold increased odds of having to reduce or stop paid employment in order to provide care (*Table 4-3*). Another possible interpretation is that older people with frailty developed more frequent episodes of minor illness (not requiring hospital care), and these illness episodes were appropriately managed in the community. Furthermore, these findings could be due to chance, due to the low numbers in each CFS score category.

Another important methodological limitation which affects the interpretation of these outcomes is that "acute illness episodes" were not defined objectively. Rather, the follow-up

assessors took a brief history of the “acute illness episodes”, which had occurred over the previous 12 months. These episodes of illness which did not lead to hospital admission were recorded based on the assessor’s judgement. Yet, a symptom or criterion-based method for defining an “acute illness episode” would have improved standardisation of this outcome and perhaps increased the likelihood of finding a significant association with frailty. However, had a narrower definition of “acute illness episode” been used, this may have led to an undesirable exclusion of minor but more common illness episodes, such as urinary tract infections, which may occur across the spectrum of “very fit” to “very severely frail”, but with varying levels of clinical deterioration (*Figure 2-1*). Further work could be done to define case definitions for an “acute illness episode”, or perhaps alternative objective markers for acute illness could be employed, for example pharmacy or chemist visits, which would help to reduce this subjectivity. It is also worth noting that the assessors did not routinely investigate the use of traditional medicines, a concerning omission given that the aim of investigating this outcome was in order to be as inclusive as possible of those who may be limited in their access of hospital services due to financial or physical barriers.

7.5.4 Limitations of the comparison between measures at baseline and follow-up

These findings demonstrated a significant worsening in disability between assessments (*Table 7-4*). However, a larger change might have been expected (as illustrated by the change in CFS scores, *Figure 7-4*). Demonstrating the true change in disability across time points may have been limited by aggregation of the disability domains, which vary considerably, or by the differing contexts of the WHODAS 2.0 questionnaire administration at each time point. At baseline the 12-item questionnaire was administered as part of a larger survey, which took a mean of 1 hour 38 minutes, thus participant fatigue may have affected responses. At follow-up, the full WHODAS 2.0 was administered, rather than the 12-item tool, therefore although the same questions were administered at two different time-points, the context of their administration may have limited the ability to compare and the effect size shown.

The CFS, essentially provides a global score of general health and functioning, encompassing the domains of the WHODAS 2.0. However the significant change found across assessments is likely to have been influenced by the fact that assessors were unblinded to the baseline CGA and CFS scores at follow-up. Knowing the individual’s baseline assessment may have led to a benchmarking effect, whereby the physician assessors based their judgements on previous CFS scores, and gave slightly worse CFS scores based on their expected findings. Thus a form of confirmation bias is likely to have been produced (*Figure 7-4*).

There were several important limitations to using the B-FIT screening tool, in order to investigate changes in frailty across the two time points. Firstly, the B-FIT has not yet been validated for sensitivity to change over time (Gray et al., 2017), and an unexpected improvement in these results were found at follow-up, compared with the baseline. When the components of the B-FIT were analysed separately, (the BI and IDEA cognitive screening tools), the BI score increased (i.e. improved) slightly and significantly over the two time points. The improvement in the BI is unlikely to be due to actual improvements in participant functioning, especially in view of the significantly worsening CFS and WHODAS 2.0 scores (*Table 7-4*). A possible explanation is that the BI is doubly weighted, in its contribution to the B-FIT score, accounting for a maximum of 4 from the possible 6 points (Gray et al., 2017). Small but systematic inter-rater variability in the assessing individuals' evaluations of ADL performance is likely to have produced a measurable difference in BI scores, and thus in B-FIT scores between assessments. Unfortunately, it is not possible to test this hypothesis given that assessor data were not collected at baseline and follow-up assessments.

7.5.5 Limitations of the investigation of falls

There was a small non-significant increase in the mean number of falls between baseline and follow-up reports of falls in the preceding 12 months. However the highest mean number of falls was found in mildly frail individuals, and this number decreased with increasing frailty severity. While falls are an important adverse outcome associated with frailty in Europe and North America (Tom et al., 2013), these results suggest that falls may not be as important an adverse outcome in rural Tanzania, particularly for higher levels of frailty and poorer mobility. A similar pattern of inverse correlation between falls and frailty severity was observed in the Rockwood study from which the CFS was devised, and authors also attributed it to the risk of falls reducing with worsening mobility (Rockwood et al., 2005). Despite this concurrence with previous research, these data are likely to be limited by recall bias. Rather than recording falls prospectively, individuals were asked to recall the number and details of falls occurring within the past 12 months. Additionally, incomplete information was recorded for each fall, with histories provided by individual rather than by each fall. This has limited a detailed analysis of the characteristics of falls across the frailty spectrum. Further elaboration on the strength, limitations and interpretation of these results are continued in section 8.4 of the forthcoming chapter.

Chapter 8 Discussion

8.1 Introduction

This is the first study which has used mixed methods to investigate frailty in rural sub-Saharan Africa (SSA). Here, the findings from each component of the study will be drawn together dialectically. That is, areas of convergence and conflict between both sets of data will be examined in order to arrive at a deeper understanding of the topic. The chapter begins with a summary of the important findings from each of the quantitative and qualitative components of the study, with reference to the original research questions. Discussion points will then be raised, particularly focusing on areas of agreement and where there are tensions between qualitative and quantitative findings. Lastly, the implications of these results and avenues for future research will be detailed.

8.2 Summary of quantitative results

The quantitative aspect of the study employed multiple frailty models to explore their operationalisation cross-culturally, with the aim of answering the question "can biomedical models of frailty be applied to measure and characterise frailty, and its outcomes, in this setting?". This study has shown that each of the common models of frailty found in the biomedical literature can be successfully operationalised in order to estimate the prevalence and characteristics of frailty in older people living rurally in SSA. The use of multiple methods to measure frailty, has afforded the prospect of comparing the strengths and limitations of each when applied in this context. The degree of success in applying these models was measured in comparison with previous research (section 4.9). The prevalence estimates followed expected patterns, for example the Frailty Index (FI) produced higher prevalence estimates than the more narrowly defined Frailty Phenotype (FP). Frailty prevalence estimates were consistently higher in women, in older age groups, and differed according to educational status, across all measures. Frailty was also predictive of death, producing hazard ratios (HRs) in the same range as previously published work, and measures of disability and functional status worsened in the frailty-weighted cohort over the follow-up period.

8.3 Biomedical models of frailty

The following sections will examine the operational challenges, and key strengths and limitations of each model of frailty as applied in this study setting.

8.3.1 Comprehensive Geriatric Assessment

The real strengths of the CGA are that it successfully combined UK-based geriatrics expertise, combined with local medical expertise. It has therefore produced an assessment of

the older person in their environmental and social context that takes into account local norms. This measurement of frailty was also multidisciplinary, incorporating the opinions of allied health professionals (AHP) with considerable experience in assessing frail older people in the UK (Lewis et al., 2018b). The CGA is broad and multidimensional in scope, including domains such as cognitive impairment and mood, which means that the CGA is in alignment with current expert opinion on frailty. Notably, there is considerable overlap between the CGA and the domains of assessment agreed upon by Delphi method (Rodriguez-Manas et al., 2013). The CGA as applied in this study also helped to characterise the common problems faced by older people through the formulation of problem lists.

While the CGA was used in this study as an assessment and sampling tool, the CGA is a process, or a tool intended to guide the delivery of excellent quality geriatric care (Ellis et al., 2011), and in this sense it was not fully utilised. A growing body of evidence has shown its utility for improving the outcomes of care for frail older patients admitted to hospital, for example increasing the likelihood of survival and living in one's own home after discharge (Ellis et al., 2011, Stuck et al., 1993). There is also increasing interest in its potential for use in the community setting, in high-income countries (HICs) with the aim of preventing hospital admissions, and need for institutional care (Beswick et al., 2008). Indeed, this will be the topic of enquiry of a Cochrane systematic review, motivated by the potential for reducing the healthcare costs of potentially preventable hospital admissions (Briggs et al., 2017). Given the evidence that the CGA is a powerful clinical tool which may lead to improvements in the functional independence of older people with frailty, the CGA may lend itself best to interventional frailty studies.

However, in view of the absence of any local services dedicated to the health of older people (e.g. community-based physiotherapy), it would not have been possible to implement any interventions requiring specialist AHP input as part of the CGA in the study's setting. Additionally, the project's funding would not have allowed for nutritional or medical interventions. In fact, many of the problems highlighted by CGA related to broader systemic problems, such as a lack of access to quality healthcare, which would not have been possible to influence sustainably. Even with additional funding, or UK-AHP assistance, implementing healthcare interventions based on the CGA, might be considered unethical, if only as part of a short-term intervention for a study, and without any effort to build-up local community geriatric care capacity. The lack of local geriatrics expertise was used to justify the UK-based researchers involvement in the study, yet it also raises a considerable ethical conundrum (Dotchin et al., 2013). The problems listed, and likely clinical diagnoses made, led to

recommendations that may have been poorly aligned with older people's priorities, or out of their control to influence or change.

During the CGA, the UK assessor and Tanzanian colleague, rated each participant according to the Clinical Frailty Scale (CFS) (Appendix A) (Rockwood et al., 2005). The benefit of this method was that it acknowledged frailty as being on a continuum scale (from "very fit" to "very severely frail"), as opposed to a binary diagnosis (frail or not-frail), and was a means of quickly summarising the CGA. However, its application required some adaptation due to cultural differences. Firstly, the images on the CFS were often not applicable in rural Tanzania where access to a walking frame or wheelchair were limited, and where even the fittest older people did not usually exercise as a leisure activity (for example, the "very fit" image on the CFS depicts a man jogging). Secondly, the descriptions required adaptation for the lack of access to appropriate, quality healthcare; "Managing well" was less contextually applicable given that even among the fittest older people, chronic medical conditions were not usually "well controlled". This is evidenced by the CGA problem lists (*Table 4-4*), which describe multiple symptoms and untreated medical conditions due to inadequate primary healthcare. A further important illustration of how the CFS was not ideally suited to the study setting, is that nobody in the cohort met the criteria for CFS score 9, "Terminally ill" (for those with a life expectancy of less than six months who are not otherwise evidently frail). This would usually be applicable in diagnoses of advanced malignancies, but due to a lack of access to diagnostic testing or early screening, none of these participants were capable of being categorised as such. Cross-cultural adaptations would be required in order to more usefully apply this quick, visual screening tool in this setting. For example, the "very fit" image could be changed to a person chopping firewood, or another common strenuous physical activity.

8.3.2 The Frailty Phenotype

A particular advantage of the FP in rural SSA, is that it is a short screening tool which could be administered with minimal training by a non-expert. This practice has been termed task-shifting, whereby non-specialists or non-physician healthcare professionals take on tasks which would previously have been conducted by specialists or doctors (Joshi et al., 2014). The only technology required would be a dynamometer, requiring little in the way of maintenance and ongoing running costs, especially in view of the fact that task-shifting may provide cost savings overall (Seidman and Atun, 2017). Therefore, compared with the CGA, the FP is perhaps a more practical measurement of frailty. Task-shifting has already been shown to improve the management of non-communicable diseases (NCDs) such as

hypertension and depression in low and middle income countries (LMICs), (Joshi et al., 2014) therefore it seems likely that such an approach could be applied in order to help screen and risk-stratify older people for frailty interventions and management.

Yet this study has highlighted many important limitations to applying the FP cross-culturally (Lewis et al., 2018a). Particularly, the most frail were unable to carry-out the assessments, leading to an underestimation of the true prevalence of frailty. This was also the case in a study conducted in rural South Africa, where those with missing data due to being unable to conduct assessments had higher HRs for risk of death compared with those deemed frail by assessment (Payne et al., 2017). The implication is that an inability to complete the FP assessments has a worse prognosis than completing them poorly. Excluding cases due to missing data has also led to an under-estimation of frailty prevalence in HICs (Theou et al., 2015). This could be more important in a rural SSA setting, given that those with poor mobility and other physical disabilities are less likely to be able to reach health facilities in order to be screened, and yet are likely to have poorer outcomes.

There were many cultural aspects that made the operationalisation of the FP challenging. Firstly, assessments of physical activity needed to take into account gendered norms of work. The research team had to consider examples of light, moderate and strenuous physical activities in keeping with gendered norms in order to interpret participants' self-assessed physical activity levels. For example, women were expected to handwash clothes, while men were expected to graze cattle, yet both were considered moderate physical activities. Secondly, a cultural association between HIV-infection (and its associated stigma), and weight loss may have led to an under-reporting of unintentional weight loss, therefore this question took considerable sensitivity. It was also very difficult for participants to accurately estimate their weight loss, given that it was rare to own a bathroom weighing scales. Estimating weight loss by the fit of clothing was also difficult, as clothes bought second-hand in the market were often poorly fitting, or were loose and tied with a traditional "Kanga" cloth around the waist. A third factor was the challenge in conveying the concept of "exhaustion" cross-culturally. Unfortunately, due to the simultaneous convergent study design, it was not possible to adapt the exhaustion statements for cultural relevance based on qualitative data. For example, instead of using the Centre for Epidemiological Studies Depression scale (CES-D) statements "I felt that everything I did was an effort" or "I could not get going" (Orme et al., 1986), statements such as "I feel my strength is used-up" or "the body is tired" could have been substituted, informed by the qualitative theme (*"Nguvu zimepungua au zimeisha"*: The strength is reduced or used up). This would potentially have improved participants'

understanding of this component, whereas the CES-D questions are likely to have been open to misinterpretation. For example, the statement “I could not get going” might have been understood literally as not having access to motorised transport.

8.3.3 The Frailty Index

Frailty according to the FI produced similar prevalence estimates, and similar HRs for the prediction of death as the CGA. This is due to both assessments taking a similar broad multidimensional approach to frailty, and due to the CGA being used as the diagnostic standard for development of a “high accuracy” cut-off point. This equivalence is particularly interesting, given that the FI could be reproduced by trained fieldworkers without any clinical experience. The FI is a practical tool in HIC settings. For example, in the UK routinely-collected data from primary care electronic health records have been used to produce the electronic FI (Clegg et al., 2016). Yet, no such health records exist in low-resource settings such as rural Tanzania, meaning that this method for measuring frailty is currently impractical outside of the context of a research project.

While the lack of health records may reduce the practical application of the FI in this setting, the lack of access to quality healthcare may also have led to a bias among respondents towards under-reporting of chronic medical conditions. Without access to healthcare, older people in this study are unlikely to have received diagnoses, thus producing an artificially reduced prevalence of multimorbidity. This was a criticism raised by Gray et al. in a systematic review of frailty screening in LMICs, where the majority of studies relied on participant self-report (Gray WK, 2016). This phenomenon has been shown to lead to systematic under-representation of NCDs in LMICs, as well as falsely positive socio-economic gradients (Vellakkal et al., 2015). The FI produced in this study is likely to have been subject to this under-reporting bias, given that self-reported diagnosis by a health professional accounted for 7 from 37 deficits. Alternative approaches to avoid this problem, include the use of symptom-based or criterion-based measures of conditions, or an increased reliance on objective testing, for example of blood pressure (Vellakkal et al., 2015). While certain measurements were conducted objectively, including more would have added a considerable time-burden to each assessment. Thus, time, and also budget constraints, (given the number of variables required to produce a stable FI), are factors limiting its use, even within the context of a research project.

In answer to the question “can the biomedical models of frailty be applied to measure and characterise frailty in this setting?”, it can be concluded that it is possible, at least to some extent, to apply these frailty measurements in rural Tanzania, yet with many challenges to

their operationalisation. Each frailty measurement has unique characteristics, strengths, and limitations, which should be taken into account when designing future research, or in the development of future services.

8.4 Outcomes of frailty

The results of the investigation into the outcomes associated with frailty will now be summarised, and the challenges of this aspect of the study discussed.

Frailty was shown to be strongly associated with an increased risk of death over the follow-up period (section 7.3). When comparing assessments of disability, the World Health Organization Disability Assessment Schedule (WHODAS 2.0) and CFS scores worsened significantly. This suggests that functional capabilities worsened both subjectively (according to self-report) and objectively (according to physician assessment). Frailty has previously been shown to be associated with dependency, according to the B-FIT screening tool study in Hai District, where dependency was defined as requiring assistance with ≥1 of the activities of daily living (ADLs) according to the Barthel Index (Gray et al., 2017). A multi-site study of frailty, which included sites in Latin America, India and China, also found that frailty was predictive of mortality and dependency (defined as needing care 'some', or 'much' of the time), after controlling for comorbidity and baseline disability (At et al., 2015). These changes in WHODAS 2.0 and CFS scores over time were in keeping with expected outcomes, but direct comparisons with previous studies are difficult, due to the different methods used.

8.4.1 Acute illness episodes and hospital admission

Frailty, has been defined by an inability to maintain physiological homeostasis in response to stressor events, such as infections (Clegg et al., 2013). In rural Tanzania, it was expected that a positive association between frailty and the number of hospital admissions would be found. However it was also hypothesised that this might not be the case if physical and financial barriers to accessing secondary care precluded hospital admission for older frail people. The follow-up assessment included the physician assessor taking a brief history of the number of episodes of acute illness over the preceding 12 months. An "episode of acute illness" was not defined by criteria, but was based on the interpretation of the physician conducting the interview. Examples of episodes of acute illness were given, for example pneumonia. However, it is important to note that this outcome would also have been influenced by study participants' conceptualisations of "illness". Malaria is relatively uncommon in Kilimanjaro region (due to being at higher altitude, with cooler temperatures at night) nevertheless, illnesses associated with fever are often attributed to malaria (Crump et al., 2013). Indeed, the

concept of illness was often understood to mean "fever"[44], thus increasing the likelihood of reporting infections over other episodes of ill health.

Older people with frailty have a higher risk of hospital admission in both HICs and upper-middle income country settings (Zhu et al., 2016, Rockwood et al., 2004, Fried et al., 2001, Bandeen-Roche et al., 2006). This has been identified as a problem, given that hospital admission for frail older people is associated with an increased risk of delirium (Eeles et al., 2012), and worse prospects for rehabilitation (Hubbard et al., 2011). These outcome data found that, although there was a significant association when unadjusted, the adjusted odds of hospital admission was non-significant. The mean number of acute illness episodes increased with increasing frailty, while the number of hospital admissions did not increase in parallel. Qualitative results assist in the interpretation of these patterns, which are likely to be due to a combination of factors including the finding that frail older people lacked financial and decision-making agency to seek healthcare themselves, and secondary healthcare was unaffordable, requiring households to sell livestock or land (*"Tunapata dawa"*: we get medicine). The majority of households that sought hospital treatment in their relative's final illness, reported financial difficulties as a result according to the Verbal Autopsy (VA) questionnaire (*Table 7-2*).

8.4.2 Falls

There was no significant difference in the mean number of falls in the preceding 12 months when comparing baseline with follow-up assessments. Similarly, binary logistic regression analysis for adverse outcomes associated with frailty, found no significant increased risk of falls. It is difficult to compare the reported number of falls with other studies, due to the effect of frailty-weighting on the cohort followed-up. The lack of association is surprising, given that previous studies from SSA found that older adults with conditions commonly associated with frailty were at an increased risk of falls (Stewart Williams et al., 2015, Bekibele and Gureje, 2010, Allain et al., 2014). There are several methodological issues which may have influenced these results: Asking older people to recall the number of falls they had experienced over the preceding 12 months is likely to have produced inaccurate responses due to the effects of recall bias. Yet, methods which are usually relied upon, for example falls diaries would exclude those who were unable to read or write, either due to low educational attainment or visual impairment. Prospective follow-up by telephone may have been possible, but mobile phone ownership could exclude participants of lower socio-economic status. These

[44] An example of this was 'Babu Materu', a 93 year old who distinguished between his frailty, and illnesses such as malaria, which he referred to as "normal illness" and "sicknesses of the day".

are challenges which were also encountered in a study of falls in Cape Town (Kalula et al., 2017). The theme *"Kutunza wazee ni wajibu"*: taking care of the elderly is a responsibility, suggests that the reason for low numbers of falls in the moderate to very severely frail participants may be cultural, and relating to the fact that older people are rarely left unsupervised. For example, frail older people were often accompanied to the toilet by a child or helper and in the case of 'Baba Thomas', who described an instance of not being helped to the toilet by children who disrespected and ignored him, he soiled himself rather than attempt to get up un-aided (*"Unanyayasika"*: You are harassed or humiliated).

8.5 Summary of qualitative results

The qualitative component of this study sought to answer the following questions: How is frailty understood? What is the lived-experience of frailty? And lastly, how are frail older people cared for in this context? These results provide rich answers to each of these questions. Two formulations of frailty were developed, first, conceptualising frailty as a return to "childlike" dependency, and secondly as a state of "being in scarcity". The lived-experience of frailty, was described as one of struggle and hardship, requiring the perseverance of "a strong heart" to live with experiences of disrespect and lacking reciprocal care (*"Unatakiwe uwe na roho nguvu sana"*: you need to have a very strong heart).

8.6 Frailty as a return to "childlike" dependency

The answers to the two questions of how frailty is understood, and how frail older people are cared for, have been demonstrated to overlap significantly. Frailty was conceptualised through care; defined as being dependent on responsible adults for care.

The theme, *"Kutunza wazee ni wajibu"*: taking care of the elderly is a responsibility, and its sub-theme *"hawajiwezi"*: they cannot do for themselves/they have no means of their own, frames older people with frailty as being in need of care, which is the younger generation's duty to provide. In this understanding of frailty, care is required when frail individuals are no longer capable of caring for others (rather than themselves). The metaphor of becoming "childlike" was often used by participants to describe the physical and cognitive decline which was seen in frailty. For example, 'Babu Shuma' described crawling like a child due to his physical weakness, and 'Mzee Asanterabi' described dementia producing the mind of a small child.

Role identity theory was used to help theorise this conceptualisation of frailty as a social "role" which older adults perform (Burke and Reitzes, 1981). Additionally, the role identity of frail older person as a "childlike" dependent, was defined through its counter role; "adult" (Burke and Tully, 1977). The performance of frail "childlike" dependent was an expected life

transition, and although it was not desired, it was seen as much more undesirable to be forced to work beyond one's capacities. The *"childlike possible self"* was resisted by older adults in Freeman's investigation of care and identity in Malawi (Freeman, 2018, p128), where continuing to work, and emphasising one's past productivity were thought to represent strategies in order to maintain the adult role identity, in accordance with "identity control" theory (Burke, 2006). However, this thesis supports the conclusion that to give up adult responsibilities and work, and receive care was a socially accepted norm, and a form of successful ageing. Cattell observed a similar description of the "very old person" in western Kenya who *"'can only sit and eat' meaning they will be brought food and otherwise taken care of even though he or she has not contributed to growing the food…To be fed by others is to be like a child."* (Cattell, 2002, p170). Similarly, in Tanzania, frailty was not only a return to a "childlike" diminished strength in mind and body, but was also a return to being cared for, as a child is cared for by the family.

This description of frailty could be interpreted as a diminutive or disrespectful description of old age, however, it was not used in an infantilising or insulting manner in these data. "Childlike" frailty was not *desired,* given that it indicated a loss of one's adult identity role of working and caring for others (Cattell, 2002). However, attitudes towards this form of frailty were neutral, accepting "childlike" frailty as a natural consequence of having spent one's energies in adult activities. The neutral attitude toward the concept can be illustrated through the use of the verb *"kulea"*, (to raise), which was used with reference to caring for both older people with frailty, and children. This is a powerful indication that older people who returned to dependency were not resented for losing their "independence", just as children are not expected to be more "independent" and self-caring. The neutrality towards the concept was also conveyed in the belief that frailty in advanced age, was beyond an individual's choice and control. For example, 'Babu Obadia', aged 82, credited God with enabling him to work, rather than it being through his own efforts. Perhaps in part because of widespread religious belief, the individual was never "blamed" for becoming frail.

In this context, being dependent on family for care did not hold the same negative associations that it does in "western" cultural settings. Care was received gratefully, and without the shame or embarrassment which might be associated with losing one's "independence" and "autonomy", as is often the case in "western" cultures (Becker, 1994). In receiving care, an individual was valued for their life's work in providing for the family, rather than shamed for their lack of current physical or cognitive abilities. Receiving care was accepted within the context of a "successful life" of work and provision for others (Van der

Geest, 2002a). There was very little evidence in these data to support the idea that older people feel they are a burden in this role, conversely, the responsibility and "burden" of providing care lay with the younger family members ("*Najitahidi"*: I strive).

8.6.1 "Childlike" frailty in relation to the "Third" and "Fourth Ages"

It is helpful to discuss this conceptualisation of frailty with reference to the concepts of the "Third" and "Fourth Ages". Laslett popularised the idea of life after retirement as a time of self-actualisation; a time of health, wealth and attainment (Laslett, 1996). Crucially, a "Third Age" can only exist when working-aged adults in the "Second Age" expect confidently to enter into their "Third Age". That is, there should be the expectation of a long and relatively healthy life, in order to pursue the personal growth and freedom which characterises the phenomenon (Laslett, 1996). In addition to being able to expect a long and healthy life, some of the other characteristics required for a country to achieve Laslett's "Third Age" include a high proportion of older people to form a community and culture of the "Third Age", a social welfare system, and finally a standard of wealth which would allow a comfortable standard of living for the majority (Laslett, 1996). In Tanzania, none of these characteristics are present: Life expectancy at birth in 2015 was 65 for women and 62 for males, an improvement from 57 years for both sexes in 2005 (Kassebaum et al., 2016). However, *healthy* life-expectancy at birth lags behind, at 57 years for women and 55 years for males (Kassebaum et al., 2016). The proportion of adults aged over 60 years in Tanzania overall is low, at 4.6% (United Nations Department of Economic and Social Affairs Population Division, 2019), (although for Hai District the proportion of older adults may reach up to 10%) (Hunter et al., 2012), and there is no non-contributory pension, except on the island of Zanzibar (HelpAge International, 2016). Multidimensional poverty rates are high, indicating a poor general standard of living for the majority (UNDP, 2018).

A parallel third age in this rural Tanzanian context is that of an older person fulfilling the roles of "elder"; respected as an integral and valued part of the community ("*Mzee upo katikati kuamua na kuwapatanisha"*: The elder is in the middle to decide and reconcile). In contrast with the "Third Age" described by Laslett, this is not a time characterised by retirement, but by leadership, with the aspiration of improving the welfare of the community. By comparison, the writings of Gilleard and Higgs describe the "Third Age" as both a generational and a cultural phenomenon which embraces leisure and consumerism and rejects agedness (section 2.21) (Gilleard, 2000, Gilleard and Higgs, 2002). In contrast, the third age in Tanzanian cultural terms refers to becoming a highly regarded "elder", emphasising ones agedness by taking on responsibilities of decision-making and discernment on behalf of the

family or community (*"Maendeleo"*: development). The "western" "Third Age" and the equivalent Tanzanian third age diverge again in their goals. In rural Tanzania, these are the economic development and social harmony of one's household and community. While the goals of the generation of "Third Agers" is simply the freedom to consume and enjoy leisure time (Gilleard and Higgs, 2002), or according to Laslett, the pursuit of one's *individual* goals of self-actualisation (Laslett, 1996). This generation of older Tanzanians may have been influenced by the formative experiences of living through Tanzanian independence in 1961, and Nyerere's long presidency. This shared socio-historical context is likely to have shaped their perspectives on the goals of ageing, given that they have taken on the fight against rural poverty (Brown and Brown, 1995), as the project of their elder "third age".

The "Fourth Age", according to Laslett was the inevitable time of decline and decrepitude, occurring after the "Third Age" (Laslett, 1996). However, one could argue that this doesn't mirror Tanzanian experience. This process of "decline and decrepitude" doesn't happen after a period of good health in retirement, but starts to occur during working life, making the manual tasks of subsistence farming gradually more difficult and painful. Healthy life expectancy in Tanzania *at* age 65 is 11 years for women, and 10 years for men, compared with 16 and 14 years respectively in the UK (Kassebaum et al., 2016). This decade of health in old age is likely to be spent working, as has been shown, the functioning body is a tool for work.

The fourth age has also been conceptualised as the terrifying prospect of ageing without social agency, individuality, and autonomy (Higgs and Gilleard, 2014). However, this shared "social imaginary" of the fourth age does not exist in the same form in Tanzania (Higgs and Gilleard, 2014). In evidence of this, when asked "Do you consider yourself to be living with frailty?" around half of older people agreed in our survey, giving a prevalence of self-reported frailty of 45.4% (95% CI 38.2 to 52.5) (*Figure 4-16*). Older people in "western" HIC settings generally resist the term (Grenier, 2005, Warmoth et al., 2015, Becker, 1994, Puts et al., 2009, Kaufman, 1994). In this context however, the concept of frailty has not become abject and feared, because ageing has not been medicalised and disability has not become concentrated in long term care institutions, and as Gilleard and Higgs described; *"The brighter the lights of the third age, the darker the shadows they cast over this underbelly of aging — the fourth age"* (Gilleard and Higgs, 2013). Where older people with frailty remain unmedicalised, they remain as family members not objectified patients. Where they remain cared for within their families, they are not subject to the same social exclusion caused by being "placed in care" (Higgs and Gilleard, 2014). In Tanzania the attempt at risk-management which frailty

represents has yet to be implemented, and the term does not (yet) exist as a third-person label (outside of this thesis). Frailty, therefore has not been experienced as an objectifying label making older people "other"[45] (Higgs and Gilleard, 2014), rather it has been experienced as an inevitable loss of the finite strengths and capabilities of adulthood. While frailty itself is not desired as a social role, the fact that the term has not been medicalised, owned by professionals and used to ration services or categorise risk, perhaps frees older people to claim their frailties as they are experienced.

Additionally, there is no fear of "being placed in care" in Tanzania, as institutional care is extremely rare. According to Gilleard and Higgs, "being placed in care" is a terrifying prospect in "western" cultures, as it signifies a loss of individuality and autonomy, both values which are given high status (2014). Frailty within the fourth age also represents a loss individual choice. Indeed, even "what may appear as choices – in terms of food, clothing, or activity – are the attributions of choice created by others' actions" (Gilleard and Higgs, 2010). The frail person's individuality no longer matters, and can no longer be expressed through their consumer choices, rather their assessed risk of harm becomes the overriding concern. The objectifying of the frail individual as an object at risk, leads to a loss of autonomy for the sake of managing that risk (Becker, 1994).

Yet, in this study's context, care for a "childlike" frail person was provided in recognition and honour of their lifetime of contribution to the family and community. Care was embedded in a meaningful place, the household and family land. In situations where the younger generation will inherit this land, this signifies a success on the part of the older person, who will receive care in recognition that they have secured the household's future. The land is also connected with past generations, as it is the burial place of preceding generations[46]. One similarity between the fourth age of Gilleard and Higgs, and ageing in the Tanzanian context is the associated loss of agency (2010). The older person, similar to a child or unwell patient, loses social agency. Decision-making responsibility falls to the next most senior household member. Put another way, for the child, the patient, and the frail older person, they belong to the family, and decisions are made on their behalf by the head of the household. This was also found in a qualitative investigation of healthcare professionals' attitudes toward palliative care in a tertiary hospital in Tanzania, where information about the patient's terminal diagnosis

[45] "Othering", is taken to be the process which serves to mark-out and name individuals and groups for their perceived differences HIGGS, P. & GILLEARD, C. 2014. Frailty, abjection and the 'othering' of the fourth age. *Health Sociology Review,* 23**,** 10-19.

[46] The sub-theme *"Hawana mahali pa kuzikwa"*: They have nowhere to be buried highlights the importance of place of burial and its connection to ancestral beliefs.

was felt to belong primarily to the patient's family (Lewis et al., 2017). However, this results in a fourth age which is not characterised by a frightening depersonalisation and loss of identity, but rather a returning to the status of a cared-for dependant, who is given identity and belonging through their remaining embedded in family and place.

The frightening and troubling aspect of frailty according to this "childlike" formulation, was the fear of abandonment and of not receiving "close"[47] attentive care, as deserved. This may parallel the "western" fear of "being placed in care" (Higgs and Gilleard, 2014). Certainly, this was a substantial fear for frail older people who were unable to work to subsist, and in the absence of government social protection. Particularly, as the younger generation increasingly migrated to urban centres and struggled to earn enough to support themselves and their own children. Given that the social role of the frail older person was to gratefully receive care, this abandonment produced a form of existential distress as well as a lack of practical support (*"Watoto wako safirini basi anadhoofika"*: Your children are travelling then you become frail, and *"Kuna waliotelekezwa"*: There are those who have been abandoned).

8.7 Frailty as scarcity

The next conceptualisation of frailty was as an aberrant form of ageing, which happened "too early" or "too quickly"; this was frailty as "being in scarcity". This abnormal form of ageing was described as becoming weakened through a scarcity of resources such as food: (*"Kwasababu ya kukosa lishe na chakula bora"*: because of missing nutrition and good food), through a scarcity of care, (*"Watoto wako safirini basi anadhoofika"*: your children are travelling then you become frail), or through a scarcity of healthcare (*"Magonjwa sugu"*: resistant or chronic diseases). In this conceptualisation of frailty, becoming frail was not perceived to be part of the process of ageing, but was caused by lacking the necessities required to live (and age) well and with dignity. This form of scarcity was all-encompassing, and even produced the cognitive product of having too little; "scarcity mindset" (*"Nini kinakufanya uwe na furaha?"*: What is it that makes you happy?).

At first glance it may seem as though Rowe and Khan's discourse of "successful ageing" would be highly appropriate to apply to the analysis of these data, given that the listed causes for frailty, appear to be largely modifiable (Rowe and Kahn, 1999). Participants cited many so-called "lifestyle" factors (for example, harmful alcohol consumption), which could be improved in order to reduce or prevent becoming "old early". But, in these sub-themes, participants were not advocating for better food and exercise as a means of promoting

[47] The sub-theme *"Awe ajisikie faraja"*: Let him feel comforted describes the qualities of desired care in old age, which can be summed up through the multiple meanings attributed to "close" care, or *"kwa karibu"*.

"successful ageing" according to "western" discourse. It should be interpreted as participants highlighting their needs for resources, services, or care, with "premature" frailty as the harmful consequence of living without having these needs met.

Such analysis highlights another significant criticism of the "successful ageing" discourse applied in this context. According to Rowe and Kahn, ageing successfully consists of three components to be controlled by the individual; avoiding disease, maintaining high cognitive and physical functioning, and sustaining engagement in life (Rowe and Kahn, 1999). However, across the theme *"Kwa sababu ya kukosa lishe na chakula bora"*: because of missing nutrition and good food, participants raised issues over which they lacked control. Due to the disadvantages of being poor, rural-dwelling, and often uneducated, the choice and control to avoid "usual ageing" was simply not available to them. The "western" doctrine of self-care in order to remain healthy and independent has little cultural resonance based on data from this study. According to "successful ageing" discourse, independence is virtually synonymous with well-being (Lamb et al., 2017). But the idea of being wholly independent is not valued in Tanzanian society, particularly for older Tanzanians, influenced by Nyerere's ideology of *"Ujamaa"* and familiarity with "rural co-operative living" (Brown and Brown, 1995). Were the disadvantages removed, and individuals had the capability to prevent or modify their frailty through diet, exercise, and healthcare, the aim of such an endeavour would not be in order to maintain independence and youthful vitality, as seen in "western" cultures, but would likely be in order to continue working for longer, for the benefit of one's family and community.

8.8 The lived-experience of frailty

The theme *"Unatakiwe uwe na roho nguvu sana"*: You need to have a very strong heart, encapsulates the lived-experience of frailty in rural Tanzania. The experience was one of needing perseverance and psychological or spiritual fortitude, in order to cope. The experiences described within this sub-theme were invariably the experiences of living with the frailty of "being in scarcity". These experiences were broadly due to either a lack of reciprocal care, or a lack of respect (*Figure 5-6*). Frailty was experienced as disrespect, harassment and marginalisation (*"Unanyayasika"*: You are harassed or humiliated), either due to the directly disrespectful behaviours of others, or due to their exclusion from community activities due to physical or financial barriers. Older women were particularly at risk of gender-based discrimination, and witchcraft accusations, and yet, were often the heads of households, shouldering the bulk of household work and responsibilities despite becoming aged. Frail older people and their family members also saw themselves as being more

vulnerable to crime (*"Unaogopa"*: You have fear). Underpinning these different forms of suffering was the underlying sense that there was a loss of the reciprocal care and respect which was owed from the younger generation.

"Desired interdependency" has been theorised to be the optimal way to age in SSA (McIntosh, 2017). McIntosh argues that African societies have long benefited from an understanding of the *"give and take of care over time"* for the overall benefit of the collective. In an analysis of elderhood in Kenya it was argued that to be successfully old in rural Kenya, was to be *"ensconced among extended kin"*, whereas being completely self-reliant in this context would feel *"more like abandonment and disrespect"* (McIntosh, 2017, p189). The dependency is "desired" by both care-receiver and care-giver who appreciate the mutual benefit seen over generations. Reciprocity and respect were also described as the underpinning values of care for older people in Ghana (Van der Geest, 2002a). However, there seemed to be an attrition of authentic respect, as older people's valued knowledge was replaced by "modern" education (Van der Geest, 2011, Van der Geest, 2018).

8.8.1 The lived-experience of frailty in relation to modernisation theory

This concern around the diminishing regard and care provided for older people across the sub-continent has often been framed by Cowgill and Holmes's "Aging and Modernisation" theory (Cowgill, 1974). The theory has often been applied in academic discussions of ageing in SSA (McIntosh, 2017, Sangree, 1992, Apt, 2011), given that it seems fitting to apply to many contexts where "traditional" agricultural communities are rapidly undergoing changes associated with modernisation. If the experiences of living with frailty were typified by a lack of reciprocal care and respect, the question is to what extent can these changes be attributed to these broader societal changes observed in SSA. The theory saw a correlation between "modern" societies and an increasing proportion of older people with a lowered status, observing that *"the status of the aged is high in primitive societies and is lower and more ambiguous in modern societies"* (Cowgill, 1986b, p189).

The three particular aspects of the "modernisation" process which, are thought to lead to a lower social status for older people, were all raised as problems by older people in this study; the use of modern technology, urbanisation and lastly, education (Cowgill, 1986). First, study participants discussed the challenges of a difficult economic climate, and understood that as a result, care was not necessarily guaranteed. *"Kila mtu lazima achukue msalaba wake"*: Every person must carry their own cross, described this new climate of uncertainty, where fewer resources made neighbourliness and care within the extended family less reliable. This is in keeping with the theory of "material constraints", which has often been presented alongside

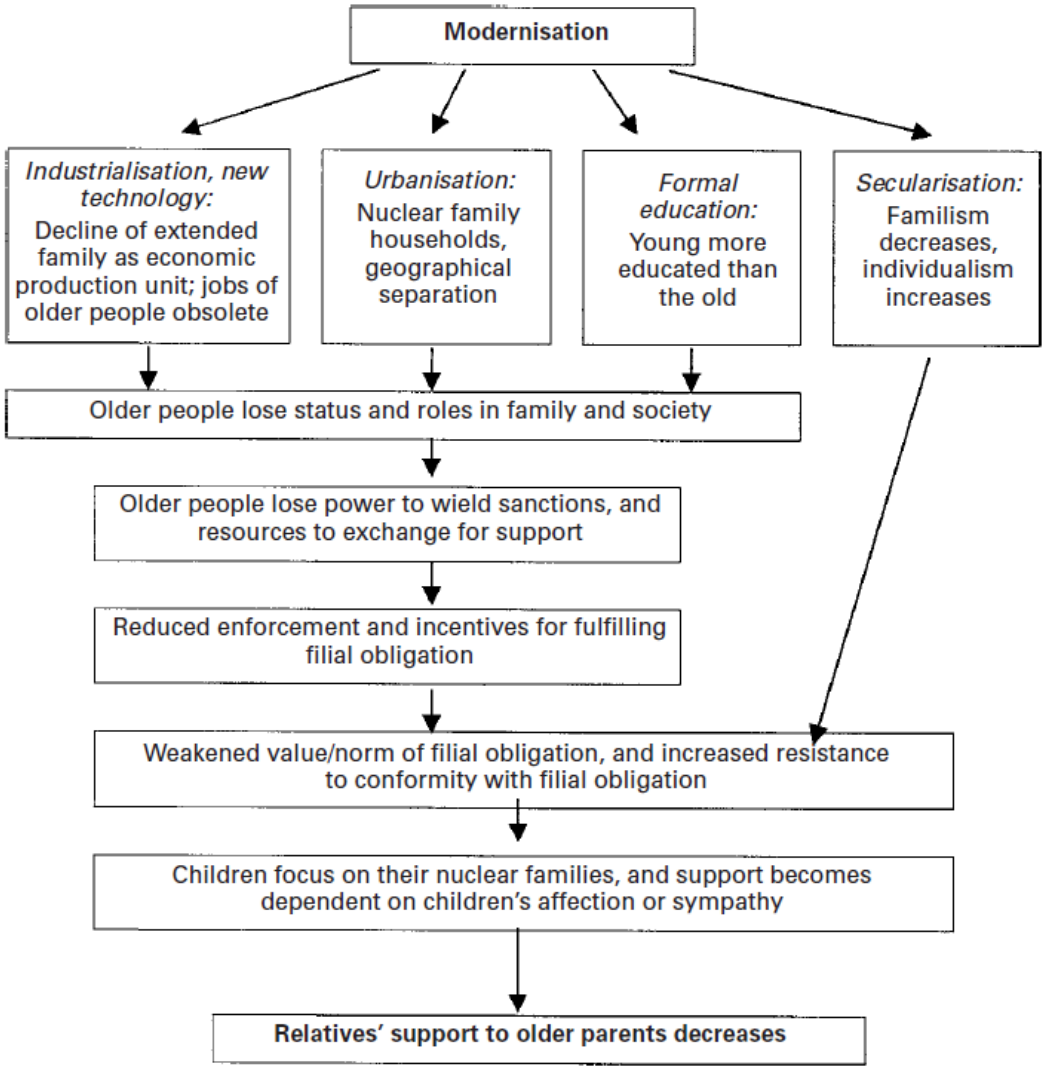
modernisation theory to explain the plight of present-day older Africans. “Material constraints” theory suggests that economic factors are the leading cause for to a reduction in family provision for older relatives (Craib, 1997). Older people, according to this theory, are not provided for out of an *inability*, rather than an *unwillingness*, to provide resources (Aboderin, 2004b). Secondly, urbanisation was certainly seen as a problem by older people, who experienced an existential distress at what was perceived as abandonment, caused by the rural-to-urban economic migration of adult children. It was conceived of as the opposite of what constituted “close” care, which involved living in close proximity with the care-giver, and the provision of attentive supervision and company[47]. The third key aspect of changes relating to modernisation, was more contentious. On one hand, education was seen as the key to ensuring reciprocal care by securing better livelihoods and employment opportunities for the younger generation. Providing education was an essential part of “raising” children, and the role of responsible adults. Nevertheless, education was also discussed as a means to uphold and imbue the younger generation with values of respect. The sub-theme *“Mzee upo katikati kuamua na kuwapatanisha”*: The elder is in the middle to decide and reconcile, described how education could help the younger generation to “leave the modern system”.

As Aboderin has argued, there are significant weaknesses in the “Ageing and Modernisation” theory (Aboderin, 2004b). It has been criticised for its assumption of a linear change in development from “traditional” to “modern”, which implies that LMICs will undergo the same processes of “development” as occurred during industrialization in the high-income “west” (Aboderin, 2004a). The theory also fails to account for individual motivations and relationship factors which influence the provision of care, and attribution of status to older people in society (Aboderin, 2004b). Aboderin suggests an explanatory model for the correlations between modernisation and reduced material support for older people (*Figure 8-1*). Indeed, these findings highlight, that although the influences and discourse of modernisation are present in these data, it by no means defines and completely explains the experiences of older people.

This thesis has shown evidence of the endurance of the traditional value of reciprocity underpinning the decisions and motivations of adult children to provide, or withhold care and support to older parents. Where this did not lead to the care of older people, sometimes the care of children or grandchildren were prioritised by individuals hoping to secure their own future care. Other instances found adult children, or older spouses struggling and *unable* to provide adequately, due to financial pressures (consistent with the material constraints discourse). Thus, these findings support the argument that where reductions in material

support for older people occur, it is likely the result of pragmatic decisions made around limited resources, and judgements on "deservedness". These conclusions are similar to that of Josien de Klerk who investigated care and neglect of older people in Tanzania, and agreed that there was a moral dimension to caregiving decisions and actions (de Klerk, 2018). The enduring value of reciprocity, has also been observed to be problematic, particularly for older men *"who drank heavily and never managed to keep a wife or support their children"* (Whyte, 2017, p245), and who are perhaps less visible in the ways they provide care, due to gendered divisions of labour.

Figure 8-1 Proposed explanation for the causes of decline in support for older people



(Aboderin, 2004b)

These findings highlight that experiences of ageing with frailty were often associated with perceptions of being treated with a lack of respect (*Figure 5-6*). This was in tension with expressions of "traditional" respect, seen in sub-themes *"Wanaheshimu sana wazee"*: They very much respect elders, and *"Wazee ni hazina"*: the elders are treasure. Overall, drawing

from these findings, it can be concluded that respect is also reciprocal. In contemporary Tanzania, authentic respect, as well as reciprocal care, are earnt and generally not automatic and unprompted. Respect depends on living responsibly, and accruing wealth and land to secure the livelihoods of future generations. The extent to which older people experienced a lack of respect suggests that the culture of respectful greetings perhaps conceals an underlying "drying up" of genuine respect, as was described by van der Geest (2011), and which was consistent with the discourse of sub-theme *"Wazee, hawana umuhimu na vijana"*: Elders, they're not important to young people. However, the assumption that "modernisation" has displaced older people's valued knowledge, and thus their respected identity roles as teachers and leaders can be contested given that older people still saw themselves as leaders in the project of economic and social development (*"Maendeleo"*: development). In a sense, this political discourse has provided a generation of older Tanzanian people with a unifying ideology, which has enabled the development of a modernised "elder" role. A similar "modernisation" of the traditional "elder" role was described by McIntosh in Kenya, whereby traditional male Mijikenda elders strengthened their social status and power by offering their support and ritualistic blessings to local politicians (McIntosh, 2009). Referring to *Figure 6-3*, it can be seen that care was received or provided on a scale from being an unprompted reward, to being arranged and acquired. Yet, the respect which older people felt they deserved, in contrast with care, could not truly be either arranged or acquired, perhaps explaining some of the expressed distress at finding themselves aged and somewhat having to negotiate respect.

8.9 How do these datasets link together?

The overall research question "what is frailty in Tanzania?" was addressed from a biomedical perspective by the quantitative results, while the qualitative findings have largely been used to challenge and critique the dominant biomedical discourse. Taking a dialectic approach, the areas of convergence and divergence between datasets will be discussed below.

8.10 How well do the biomedical models of frailty converge with conceptualisations of frailty in Tanzania?

8.10.1 The phenotype model

Frailty when conceptualised as a phenotype, is defined as the presence of three physical attributes, from a set of five objectively defined measurements. According to these results, there was considerable concurrence between this model of frailty and Tanzanian lay understanding of frailty. The FP is underpinned by the theoretical framework the "cycle of frailty", whereby the frail older person, through a combination of chronic undernutrition and disease, expends less energy, feels fatigued, loses strength, loses skeletal muscle, and in a

cyclical deteriorating manner develops worsening frailty, disability and death (Fried et al., 2001). Taking each of the five components of the FP in turn, it is possible to compare the Tanzanian lay conceptualisation of frailty with the FP, and its underlying theoretical model.

Frailty was conceptualised as a progressive using-up of a finite "life energy" or strength (*"Nguvu zimepungua au zimeisha"*: the strength is reduced or used up). The measurement of strength, according to the Fried FP can be quantified according to hand-grip strength (HGS) (Fried et al., 2001). Older adults who experienced loss of strength, most often described it in terms of no longer having the energy to work, or having to cut back on strenuous activities such as carrying water or chopping firewood. Tiring of the body, (*"Mwili imechoka"*: the body has become tired) was regarded was an integral aspect of frailty, which may also refer to the embodied experience of "exhaustion", the next Fried FP component. Reduced physical activity (the third FP component), was closely related to the previous sub-theme, and was key to identifying with becoming frail, yet rather than reducing one's leisure activities, as was the case in the original FP criteria (Fried et al., 2001), in this study, reduced activities were discussed in terms of an inability to work productively for the benefit of others (*"Hawajiwezi"*: They cannot do for themselves/ they have no means of their own). Slow walking speed, was frequently discussed as a visual marker of frailty in *"Miguu hatembei"*: The legs don't walk. Unintentional weight loss and a reduced appetite were sometimes mentioned as markers of frailty, yet more commonly frailty was discussed in terms of lacking nutritious food and missing meals due to food scarcity and income insecurity in *"kwasababu ya kukosa lishe na chakula bora"*: because of missing nutrition and good food.

8.10.2 The comprehensive geriatric assessment

Despite having noted many areas of similarity between the qualitative findings and the phenotype model, this study's results best align with a conceptualisation of frailty that is broader and multidimensional. Frailty was described as a form of "being in scarcity", which was not only a scarcity of physical strength, but of resources (particularly of food, care and healthcare), which were not part of the FP construct. Indeed frailty according to these qualitative data also encompassed many social, psychological and cognitive factors. The lay conceptualisation highlighted a lack of social support and subsequent extreme psychological distress (*"Watoto wako safirini basi anadhoofika"*: your children are travelling then you become frail), cognitive decline (*"Udhaifu wa afya na akili"*: frailty of health and mind), an inability to subsist (*"Hawajiwezi"*: They cannot do for themselves/ they have no means of their own), and a lack of access to healthcare (*"Tunapata dawa"*: we get medicine) as

important aspects contributing to the multidimensional concept of frailty as “being in scarcity”.

Therefore, broader multidimensional models of frailty which include assessments of cognition, mood, and nutrition, (such as the CGA and FI) appear more congruent with the lived-experience and understanding of frailty in this context. Expert consensus has also concluded that certain factors, such as nutrition, mood and cognition are important parts of an assessment for frailty, in addition to the physical aspects measured as part of the FP (Rodriguez-Manas et al., 2013). Thus, the CGA aligned particularly well with Tanzanian conceptualisations of frailty, given that these assessments tended to take into account the older person’s social circumstances and living environment the most. In conducting the CGA, the assessing physician and Tanzanian research colleague visited the older person at home, and were able to speak with relatives and take note of important factors in their living environment which might contribute to their health status, or make them more vulnerable to disease and adverse events. For example, factors such as poor lighting or an uneven floor surface which may increase the risk of falls, or a poorly ventilated cooking area, which may predispose to chronic lung disease, were noted (*Table 4-4*). Additionally, quantitative CGA data analysis found that frailty significantly increased the odds of being financially dependent on others, of having problems using transport and being at “high risk” of malnutrition (*Table 4-2*). Together, these data add weight to the need for a broader multidimensional model of frailty to be applied in this setting.

8.10.3 The deficit accumulation model

Qualitative results found that many conceived of ageing occurring through a gradual using-up of a finite amount of “life energy” or “life blood” throughout the life course, *“Nguvu zimepungua au zimeisha”*: The strength is reduced or used-up. The deficit accumulation approach mirrors this idea in that the process of developing frailty by deficit accumulation is also conceptualised as occurring gradually and cumulatively over the course of a lifetime. Also, both models recognise the limits of healthy human lifespans, where the Tanzanian understanding is of a finite amount of “life energy” thought to be held in the body fluids and blood. Similarly, the deficit accumulation model has found there to be a maximum number of deficits that can be tolerated. This maximum number of deficits which is survivable is consistent across populations and countries (Rockwood and Mitnitski, 2006).

In this study, women were found to have a higher prevalence of frailty compared with men. The “male-female health-survival paradox”, describes the finding that women tend to have higher levels of frailty, but paradoxically live longer than men (Gordon et al., 2017). This

trend has also been observed in LMICs, where the deficit accumulation model has been applied (Biritwum et al., 2016). In the qualitative aspect of this study, it was observed that older women tend to become more frail than older men, and this was explained by the fact that women have expended more of their finite "life blood" during childbirth in young adulthood. This finding is concurrent with previous qualitative research coming from rural Malawi, where spending of "life blood" was also used to explain ageing (Freeman, 2018). The fact that the same idea was found in this study suggests that the concept of frailty, applied through the deficit accumulation model, may have broader conceptual applicability across other areas of southern Africa.

The observation that frailty can also occur in younger people is also concurrent with the deficit accumulation model of frailty (*"Kunywa kinwaji bila kula"*: drinking alcohol without eating). Frailty was observed in younger people, due to the effects of alcohol dependency and poor nutrition and similarly, the deficit accumulation model has been used to illustrate the heterogeneity of health across populations with age (Rockwood and Mitnitski, 2007, Mitnitski and Rockwood, 2006).

However, the deficit accumulation approach fundamentally diverges from the lay understanding of frailty in two key areas. First, according to the "childlike" dependency formulation, frailty was a form of natural age-related dependency, and therefore not problematised. The language of "deficits" does not accept the accumulation of "diseases, disabilities, signs and symptoms" (Rockwood and Mitnitski, 2007), as an expected consequence of living. Rather it implies that the process of ageing is a process of increasing deviation from the young, healthy, and "normal" body. The FI, through which deficit accumulation is measured, lists the ways in which the body is becoming dysfunctional and deficient. Although the deficit accumulation model of frailty is on the surface an objective reproducible and stable model of frailty, which can be applied cross-culturally (Biritwum et al., 2016, Searle et al., 2008), it is in fact highly subjective given that it depends on value-laden judgements about what functions an ageing body "ought" to carry out. When counting up "health-related deficits", it really depends on what is considered to be "healthy". In order to count something as "deficient", one needs to determine what would be "sufficient". The deficit accumulation approach does not make any allowance for any change in what is considered "sufficient" or "healthy" with age. Yet, according to the "childlike" dependency formulation of frailty, the body *must* age following a life used expending one's energy in the work of caring for others.

Secondly, according to the concept of frailty as "being in scarcity", it was implied that much of the current scarcity-related frailty could be prevented or rreversed by addressing these areas of scarcity, for example, through the provision of better nutrition, care, and healthcare. In this formulation, if deficits accumulate to produce frailty, they are not seen as accumulating due to the ageing process, but due to circumstances of scarcity. Again, ageing itself is not problematised according to this thinking; rather the problem was a scarcity of resources to allow the older person to age and become frail, in a dignified manner.

8.11 The connection between frailty and death

Both qualitative and quantitative components of this study found frailty to be linked with death. According to the quantitative follow-up data, frailty was significantly predictive of mortality according to all measures, with adjusted HRs between 2.38 and 4.97 (*Table 7-1*). The association between frailty and mortality was also shown in the only previous study to apply the FP model in SSA (Payne et al., 2017). Payne et al. found adjusted HRs for time to death between 1.45 and 4.63 in the frail group. This thesis produced results in the same range, given the FP adjusted HR for risk of death was 3.36 (95% CI 1.37 to 8.22, p=0.008).

Twenty six deaths occurred over the follow-up period, 22 of which were of participants deemed frail at baseline. The verbal autopsy questionnaires (VA) revealed that the majority of deaths, n=16 (62%) were due to NCDs. The most common underlying VA cause of death was cerebrovascular disease, accounting for four deaths, the biggest risk factor for which is hypertension. Hypertension was shown to be prevalent by both self-report and measurement, and frailty increased the odds of a diagnosis of both hypertension and stroke, with ORs of 2.56 and 14.13 respectively (*Table 4-7*). These findings emphasise the findings of an investigation into the causes for hospital admission among older people in Tanzania, Sudan and Nigeria (Akinyemi et al., 2014). The authors found that NCDs accounted for 79.9% of hospital admissions in Tanzania, the majority of which, (24.3%) were admissions relating to cerebrovascular disease (Akinyemi et al., 2014).

The mortality rate was calculated at 1 in 10,000 person-days, adjusting for the frailty-weighted cohort, however direct comparisons with other studies is difficult due to differing methods. One previous study in Hai District found that greater age, increased dependency for ADLs, self-reported memory problems, using a walking aid, and being underweight, were independent predictors of three-year mortality in community-dwelling adults aged ≥ 70 years (Gray et al., 2016). Death rates were compared with expected death rates in the UK, and Tanzanian age-adjusted mortality rates were lower than expected (Gray et al., 2016). The authors suggested that in the absence of adequate healthcare, older adults with frailty may die

at younger ages, leaving a fitter older population. Unfortunately, this thesis was unable to test this hypothesis adequately, but the levels of chronic comorbidity, particularly of untreated hypertension, suggest that inadequate management of chronic NCDs may indeed be contributing to frailty and its associated mortality.

There was a strong connection made between frailty and death throughout the qualitative data too. The problem of providing an appropriate burial for frail older people, particularly for the more vulnerable older people "from outside" (the village), was raised as an important issue, discussed in *"Hawana mahali pa kuzikwa"*: They have nowhere to be buried. Frailty was understood to be a state of dependency, requiring of care, and death was also strongly linked with concepts of care. Van der Geest, studying the anthropology of ageing in Ghana, described the organisation of a fitting burial for an older deceased person as being *"the ultimate care for the old person"* (Van der Geest, 2002a, p17). Throughout the sub-theme *"Maisha ni mwenyezi Mungu akiamua"*: Life is how Almighty God decides, older people discussed the importance of their faith in helping them live with difficult circumstances with a "strong heart", and also to accept the inevitability of death, (which was often euphemistically framed as God "deciding", "taking" or "loving" the deceased person).

Here then, is where the connection between frailty and death diverges across the two datasets. In accordance with the biomedical view of frailty, mortality was categorised and analysed as an "adverse outcome". However, the problem from the Tanzanian perspective was not the death itself, but managing its aftermath appropriately. For the frail "outsiders" the problem was the potential consequences for the village, of a burial in the "wrong" place. And for those with family, the main issue was seen as providing a dignified and appropriate burial, as the last act of care for their deceased frail relative. Caring for the deceased older person by honouring them with a large public ceremony, was also a form of caring for the family's reputation and honour (Van der Geest, 2002a). But frailty may have made the provision of a fitting funeral more difficult for the family, given that VA data found that costs accrued due to the older person's last illness had prohibited other household payments (reported in 16 from 22 deaths of frail individuals) (*Table 7-2*). Contextually, frailty was largely defined by requiring care, or being in a state of scarcity of care, and similarly death provided another occasion of providing care, and was perceived as a problem when there was a scarcity of resources to provide that care.

8.12 Difficulties accessing healthcare

Both sets of data highlighted that frailty in this context was associated with a lack of access to adequate healthcare. Qualitative data discussed frailty as being caused by a lack of adequate

treatment of chronic health problems (*"Magonjwa sugu":* Resistant or chronic diseases), and was experienced as a scarcity of affordable and accessible healthcare (*"Tunapata dawa"*: We get medicine). The health of frail older people, as dependents within households, needed to be balanced against other household needs and priorities. This meant that older people's chronic illnesses were largely neglected. Part of the problem of ageing without individual agency in this context meant that usually, only acute episodes of illness were prioritised to receive medical attention. Family members took decisions and also bore the responsibility for raising funds in the event of acute illness (*"Kweli mimi ndo bima ya afya"*: For sure, I am the health insurance). Consequently, older people's ability to rally family members to come to their assistance in the event of a health emergency was seen as a form of resilience in Obrist's work in coastal Tanzania (Obrist, 2016). Frail older people were also seen as not getting the *deserved* care due to poor implementation of the exemption from user-fees for adults aged ≥60 in government-run facilities (*"Hawajapata vitambulisho"*: They have not yet received their cards).

Many aspects of the quantitative data point toward a lack of access to healthcare: Frailty by FP was significantly associated with an increased adjusted odds of poor self-evaluated health, and of having received a diagnosis of hypertension, stroke, or arthritis (*Table 4-7*). Both datasets demonstrated physical barriers experienced by frail individuals in accessing healthcare due to disability and difficulties walking, living long distances from the hospital or health facility, and difficulties using transport. This can perhaps be most easily demonstrated by the fact that frailty increased the odds of requiring a home assessment five-fold (*Table 4-7*), however there are currently no community healthcare services in Hai District capable of providing home-based care for older people. Though not associated with frailty, health insurance coverage for frail participants was low, at 21.1%, while only 14.6% had used any form of financial protection to access healthcare over the previous 12 months (*Table 4-3*). According to longitudinal data, there was a marked disparity between the high number of acute illness episodes occurring in frail individuals, and the relatively low number of subsequent hospital admissions (*Figure 7-7*). This finding can be understood when taking into account the fuller picture provided by the baseline quantitative and qualitative findings, and can to be attributed to the many contributory factors, which delayed or prevented frail people in particular from accessing healthcare.

8.13 Sex, gender and frailty

There are likely to be both biological and psychosocial factors at play in explaining the "male-female health-survival paradox" or the "sex-frailty paradox" (Gordon and Hubbard, 2019).

While this paradox is well established, it has not been fully explained, and this study has provided unique cross-cultural data to contribute to the debate. The prevalence of frailty was higher in females across each of the frailty models (section 4.9). This is a finding that is consistent with findings across the different frailty measures, from both HIC and LMIC settings (Biritwum et al., 2016, Gordon et al., 2017, Gray WK, 2016). Women reported higher levels of exhaustion and lower levels of physical activity compared with men, and 25.4% were categorised as meeting the FP "slowness" criterion, compared with 12.2% of men (*Table 4-6*). Yet the qualitative findings revealed how psychological and social factors may be disproportionately contributing to frailty in women as compared with men, due to gender-based discrimination, and gendered expectations of care work. In this context, widows faced particular gender-based difficulties such as disinheritance of land, and pressures to either stay unmarried, or to re-marry for their financial and social security (*"Wanawake ndio tunaonewa sana wazee"*: Women yes we are oppressed as older people). Older women were more often the subjects of witchcraft accusations compared with men (*"Umbeya"*: Bad talk or gossip), and often shouldered the responsibility of care, for both older husbands and younger dependents (*"Mimi ndo mama huku nyumbani"*: I am the mother in the house). The disproportionate impact of frailty on women is also likely to have affected the younger generation of predominantly female care-givers. Wives, daughters and daughters-in-law provided most of the daily "close" care in the majority of households where qualitative interviews were conducted. Additionally, the finding that frailty produced a three-fold increased odds of a household member having to either reduce, or stop paid employment in order to provide care, suggests that frailty is likely to have impacted on the wider household finances, through women's reduced earnings.

8.14 Where are the tensions or disparities within these findings?

Taking a dialectic stance toward mixed methods involves taking an interest in the areas of tension produced between the qualitative and quantitative results. These areas of conflict, may reveal new and fuller meanings, and deepen knowledge (Greene and Caracelli, 2003).

8.15 The ageing body in Tanzania

Quantitative data categorised people by age using the national pensionable age as an acceptable cut-off point for old age (National Social Security Fund, 2018). Old age has been variably defined in the literature however, making comparisons between studies more difficult. For instance, a cut-off point of >50 years was used by the World Health Organization Study on global AGEing and adult health (WHO SAGE) (Biritwum et al., 2016, Hoogendijk et al., 2018), and ages 40 years and above were included in a study of frailty in

older people in South Africa (Payne et al., 2017). Confirming participants' ages was a challenging process. Participants' ages were estimated through a validated method based on recollections of historical events (e.g. Tanzanian independence or the end of the Second World War), and for women, ages were often estimated by the age of their first child, or their age at marriage (Paraiso et al., 2010). Yet for older people in this study, their chronological age did not matter except for the purposes of being able to prove their eligibility to access free healthcare services (*"Hawajapata vitambulisho"*: They have not yet received their cards). According to these qualitative data, where frailty was seen as a returning to "childlike" dependency, losing one's ability to work was the key signifier of becoming aged. In this context, old age was marked by a change in social roles, as pertaining to work and care for others. Adulthood was asserted through one's working for others, and elderhood, by social roles of leadership for the purposes of guiding the younger generation (*"Mzee upo katikati kuamua na kuwapatanisha":* The elder is in the middle to decide and reconcile). The real meaning of old age, was defined based on the functional capacity of the body to work and care, or the higher cognitive processes required to "decide and reconcile" rather than by chronological age.

The tension produced by the converging of these two forms of data, is that the quantitative methods of attempting to estimate the prevalence of frailty in "old age", was in fact produced according to an arbitrary cut-off point. In contrast, the qualitative data described much more richly, the meaning of old age, and its close association with work. Indeed, the application of chronological cut-off points by the Tanzanian government in order to mark eligibility for pensions and access to free healthcare, may be pragmatic, or due to international influences, as it seemed fairly irrelevant to older rural-dwelling Tanzanians' understandings of old age. Biomedical measures of frailty attempt to move away from chronological definitions of old age, toward a measure of physiological ageing, which in fact, seems more congruent with Tanzanian conceptualisations, given its focus on physical function. Thus, eligibility for access to healthcare based on frailty or pre-frailty may in fact be more culturally appropriate than imposing cut-off points by age, which have produced inequitable barriers to accessing healthcare, particularly for older people without formal education.

Additionally, there was a tension between the datasets caused by the attempted definition and categorisation of work. The quantitative aspect of the study assumed distinctions which in reality were much less distinct. For example, the initial demographic questionnaire asked whether a person was "self-employed" or "not working for pay" (*Table 4-1*). This produced data that are difficult to interpret. Given that the majority were rural subsistence farmers, the

productivity from their work was a good harvest which provided food for the household, with surplus sold for cash. This form of work could not be accurately classified as either "self-employed" (adults work, not for themselves but for the benefit and sustenance of their families) or "not working for pay" (with a good harvest one could earn money). There was also no clear point of stopping or retiring from this work. When older people reduced or stopped their farming activities, they tended to continue with less strenuous farming work, such as growing salad or coffee, or collecting grass for the cattle, and it did not preclude household work, the work, primarily of women. As described in the qualitative results, all forms of work continued until one's tool for working, (the body), became physically unable, and therefore frail.

8.16 Successful ageing in the Tanzanian context.

Previous sections have discussed the parallels between each of the specific biomedical models of frailty and contextual conceptualisations, however, as explained in the previous section, ultimately many of these parallels between "western" biomedical and Tanzanian conceptualisations of frailty, are superficial. Underlying, there is a tension between the individualised view of health and wellbeing, and traditional African ethics which give primacy to family and community. From a "western" biomedical perspective, frailty is seen to be in opposition with most concepts of "successful ageing".

Rowe and Khan's seductive model of "successful ageing" describes successful agers as those who avoid disease, pro-actively maintain a healthy body and mind, and remain actively engaged in society (Rowe and Kahn, 1999), thus avoiding dependency on anyone else for care. At its heart, Rowe and Khan's successful ageing theory is an aspirational promotion of youthful independence, and a delaying of "agedness" for as long as possible. This is in contrast with what they term "usual" aging, which would encompass those living with frailty; those who succumb to disease, physical and cognitive impairment and social isolation.

"Successful ageing" by this definition is another "western" cultural construction, which places the responsibility for optimising and maintaining individual health, on the individual. The qualitative results presented highlight several potentially modifiable methods to reduce frailty in old age: The sub-themes ("*Chakula bora"*: Better food), ("*Mazoezi"*: Physical exercise) and ("*Kunywa kinwaji bila kula"*: Drinking alcohol without eating) discuss how having a nutritious diet, engaging in physical activity through work, and avoiding alcohol excess might all prevent frailty developing. It was also suggested that treating chronic disease in a timely fashion could prevent becoming frail "early" ("*Magonjwa sugu"*: Resistant or chronic diseases). Yet, in these poor, rural subsistence farming communities, an older individual's

ability to modify their diet in order to improve their protein and vitamin intake is limited by the household's income. It was very rare to find any individual who truly exercised for leisure, instead keeping physically active was for most a necessity in order to survive. Recall 'Babu Obadia' (82), who felt frail, yet was required to continue farming to support himself and his wife: *"When I wake up in the morning I pray to God first so as He can give me strength to work"* (5th July 2017). And while chronic or resistant diseases were recognised as being an important contributor to frailty in old age, access to healthcare was limited by social, financial, bureaucratic, and physical barriers. Hence, the criticisms of the concept, which excludes those facing the inequity of multiple disadvantages from ageing successfully (See Frailty as scarcity). As outlined in *Table 5-2*, this form of frailty (as "being in scarcity") was not compatible with Rowe and Khan's "successful ageing".

In contrast, frailty according to the return to "childlike" dependency formulation, was compatible with Tanzanian notions of a successful life and successful ageing: Being dependent and cared for in old age indicated a successful life; given that the older person had succeeded in the work of raising a family with the values and resources necessary to provide care. And successful ageing; because they were receiving care in acknowledgement and reward for their life's work for the family. This Tanzanian form of "successful ageing" reinforces that Rowe and Khan's theory was developed from a "western" cultural perspective, where the individual is prioritised. Physical frailty is incidental and unimportant in the Tanzanian view of success, because the essence of success in Tanzanian terms is in finding reciprocity and mutual respect. This finding is entirely concurrent with Whyte's reflection that *"successful, or at least good aging is contingent upon interdependence"* (Whyte, 2017, p245). Whyte, suggests that these different paradigms of success in ageing hinge on different values. Whereby the "western" paradigm relies on self-maintenance, making the care of body and mind a virtue, in East Africa; *"desirable interdependence implies different values; it makes a virtue of caring for relationships with those who will provide support when the time comes. The body is a means of social engagement and usefulness to others, not primarily something to be nurtured for its own sake"* (Whyte, 2017, p245).

Two alternative "western" theories of successful ageing were introduced in section 2.21. Both of these emphasise "independent functioning" as a virtue. "Selective Optimisation and Decompensation", and "Preventive Corrective Proactivity" are in essence, relating to an individual's adaptation to loss, and their use of resources (Baltes and Smith, 2003, Martin et al., 2015, Kahana and Kahana, 2001). The compatibility of these models of successful ageing have been compared with the two Tanzanian formulations of frailty in the table below (*Table*

8-1). The Tanzanian view of successful ageing is radically different therefore, because it suggests that irrespective of the current functioning of the frail body, it is the care for that body which represents success. It was noted by de Klerk in their investigation of care and neglect of older people in northwest Tanzania, that while the *functioning* of the frail older body was not an indication of success or indeed, of failure in ageing, rather the "well-nurtured and clean" body was indicative of the quality of the care they received, *"thus making the elderly body a reflection on the state of family relations"* (de Klerk, 2018, p146). In reviewing the CGA problem lists formulated for the most severely frail in this study, it was surprising to see the extent of the attentive care provided, particularly in view of care-givers' limited resources. Remarkably, this was often evident in the condition and cleanliness of participants' bodies, for example despite being bed-bound following a stroke, or due to advanced dementia, older people rarely suffered from pressure sores (*Table 4-4*).

However, this formulation of successful ageing should not be romanticised, as Whyte warned, *"'desired interdependence' is problematic in practice with different, unequal, and uncertain possibilities"* (Whyte, 2017, p245). This was evident in the qualitative results, for example 'Mzee Massawe' who did not have a wife or children to support him after living the life of a "vagrant" (Appendix Q), and 'Babu Elirehema', who after five marriages, had not maintained good connections with his children. Consequently his son 'Baba Jumanne' did not feel a strong sense of a debt of care owed, and preferred to put his energies into his own children, securing his own future. Indeed in the context of widespread economic difficulty, moral duty to care intersects with having the material resources to care. These findings also show that even those who were aging successfully, and living the with frailty of "childlike" dependency (for example 'Bibi Hosiana', 'Bibi Eliaika' and 'Babu Materu') invariably also experienced the frailty of scarcity at times. Thus the overwhelming experience of frailty, was of struggle and perseverance (*"Unatakiwe uwe na roho nguvu sana"*: You need to have a very strong heart).

Table 8-1 Are "western" models of successful ageing compatible with frailty in Tanzania?

Successful ageing theory	Compatible with frailty as returning to "childlike" dependency?	Compatible with frailty as "being in scarcity"?	Summary
Rowe and Khan's successful ageing (Rowe and Kahn, 1999)	No- emphasis on maintaining physical and cognitive functioning in order to maintain independence	No- the lack of resources and access to healthcare precludes any pro-active self-management and prevention of chronic disease	Rowe and Khan's successful ageing has a focus on optimising the individual and their body, even "engagement with life" is framed as the individual's responsibility
Selective Optimisation with Decompensation (Baltes, 1997, Baltes and Smith, 2003)	No- in the "childlike" social role older adults with frailty are not expected to carry out any activities or maintain any responsibilities	Perhaps- according to the scarcity model of frailty older people are continually adapting to deteriorating health and reduced resources	The ability of an older Tanzanian to optimise their capabilities is limited by their limited access to resources, but potentially bolstered by a community that allows for their decompensation e.g. visiting them at home
Preventive-Corrective Proactivity (Kahana and Kahana, 2001)	No- there is no "proactivity" involved in accepting the role of "childlike" dependent	To some degree- this model allows for the limitations of race, education, class and gender affecting these participants	Proactivity in the Tanzanian context would require the co-operation of family and/or neighbours

8.17 Limitations

Many of the methodological limitations have been discussed in the methods chapter (Village ten-cell leaders, Conducting cross-language research), in chapter 7 (sections 7.5.3, 7.5.4, 7.5.5) and in the discussion chapter (Biomedical models of frailty and its sub-sections). The following sections reflect on the challenges and limitations of the use of mixed methods in this study, including any gaps left.

8.17.1 Challenges in capturing the outcomes of frailty

The outcomes of frailty have not previously been investigated in rural SSA using mixed methods and this is a strength of this thesis. To date, mortality and dependency have been associated with frailty in SSA (Payne et al., 2017, Gray et al., 2017). However, this study attempted to investigate other potential outcomes, which have been associated with frailty in HIC settings, such as falls, institutionalisation, and hospital admissions (Fried et al., 2001, Ensrud et al., 2008, Rockwood et al., 2004). The qualitative investigation provides important insights into the lived-experience, which adds to the quantitative findings, broadening the investigation of frailty-associated outcomes beyond that of the hypothesised medical adverse outcomes. Thus, the outcomes, measured quantitatively, have proven to be fairly narrow, and lacking in the depth and detail which has been provided through qualitative insights.

8.17.2 Institutionalisation

Institutionalisation is rare in northern Tanzania, with only one government-funded institution in the whole of Kilimanjaro region, which could house up to 16 older people. It was not possible to investigate institutionalisation as an outcome of frailty through quantitative methods, however SSIs with residents revealed physical frailty to be an important factor leading to their institutionalisation. Chronic ill-health, led to worsening disability and to catastrophic health expenditure, which in the absence of family support, eventually led several participants to be housed at Amani Residential Home (known simply as Amani). This was the trajectory for 'Mzee Eliakimu', 'Mzee Ali', and 'Mzee Masana', with each of these participants describing themselves as living with frailty (Appendix P). Therefore, it can be concluded that institutionalisation is an unusual, but important outcome of frailty in this setting.

8.17.3 Psychological and social outcomes associated with frailty

The qualitative results have also described in depth some of the broader psychological and social outcomes of frailty, which were generally captured in the experiences of people living with the frailty of scarcity. From causing problems for the village regarding burial arrangements (*"Wanatoka nje"*: They come from outside), to being forced to beg from neighbours (as was the case for 'Bibi Helena', 'Bibi Zakia' and 'Mama Josephine'), or supplement the household income with children or grandchildren's labour (*"Wajukuu ni mzigo"*: The grandchildren are a burden). While begging was mentioned as a form of income for older people with ADL disability in Tanzania (Nyaruhucha et al., 2004), it has not previously been explicitly discussed as a potential consequence of frailty.

Social and psychological outcomes associated with frailty included experiences of disempowerment, fear of crime, and feelings of abandonment (*Figure 5-6*). Thus it can be concluded that, on their own, the outcomes of frailty investigated quantitatively were medically focused, and thus failed on their own to capture some of the most important outcomes associated with frailty in this context. Reflecting on the previous section relating to attitudes toward death (The connection between frailty and death), it is contentious whether many Tanzanians would consider the death of an older person with frailty (of the "childlike" formulation), to be an "adverse outcome".

In summary, the tension between the two datasets exist where the quantitative data has held a narrow biomedical view of what constitutes "adverse outcomes", and arguably has defined death inappropriately as an adverse outcome. While the qualitative results have revealed a host of psychological and social adverse outcomes, which are arguably of more importance to older people living with frailty in this context.

8.17.4 The challenge of investigating practices of care

In the course of investigating the practices of care for older people, social norms and expectations were often expressed. This was expressed throughout the qualitative theme *"Kutunza wazee ni wajibu"*: Taking care of the elderly is a responsibility, and its sub-themes and can be effectively described through the "Cultural-Conformable" discourse (Baart, 2018). The strongly expressed duty of care for elders was based on a perceived "African way of caring", which as Van der Geest has argued, has until recently been a global tradition (Van der Geest, 2018). Given that participants were rarely interviewed alone, and many interviews were intergenerational, there may have been a strong incentive for participants to uphold the desired narrative of familial care. In particular, FGDs held with elected community representatives may have reinforced the expression of these social norms from the perspective of nationalism. Not only was intergenerational care and respect an ideology posed in opposition to "western" attitudes and practices, but this was often argued to be a uniquely "Tanzanian way of caring". As previously mentioned (in Conducting culturally sensitive focus group discussions), the use of existing organisational structures in this study has likely led to the promotion of nationalism and to messages that align with political discourses. Thus, these data seem to agree with the Tanzanian government's policy of the "family will remain the basic institution of care and support for older people" (Ministry of Labour Youth Development and Sports, 2003).

In addition to forming an important theme, this ideology was frequently expressed during informal individual discussions with Tanzanian research colleagues. Ethnographic methods may have further illuminated these issues, allowing for a triangulation of data, and exploration of the extent to which what people said about care for older people was congruent with their behaviours. For example, ethnography has successfully been employed to investigate attitudes towards older people in Ghana, where a similar social pressure would have been present, potentially biasing interview-based data (Van der Geest, 2011, Van der Geest, 2002a). While ethnography was not formally employed in this study, the qualitative interviews were conducted over a six-month period of immersion into the field and alongside the quantitative surveys which involved house-to house visits and daily interviews with older people and their care-givers, which informed the data analysis and interpretation.

8.18 Researching as an act of "taking" from those "in scarcity"

Both sets of data have revealed the suffering of older people, their families and communities. For example, quantitative data demonstrated a high prevalence of pain, and showed an association between malnutrition risk and frailty. Qualitative findings demonstrated that frailty was socially and culturally constructed as a form of scarcity state, which was also experienced at a community level, where neighbours and other community members became concerned and involved in the lives of local people living with frailty. Therefore, researching this topic involved regularly being confronted with older people's unmet essential needs. A tension was produced in response to being confronted by this material poverty, which was laid bare by the mixed-methods approach.

The positivist paradigm conceived of frailty as an objective entity to be measured, and the research process as an act of data "collection". This contrasted with the constructivist paradigm, which viewed the research process as a mutual co-production of meaning. Thus, the researchers (the author and research colleagues) went from listening to participants' stories and co-creating meaning from their experiences of frailty, as a form of "being in scarcity", to data "gathering", with little acknowledgement of participants' scarcity states. Even the terms data "collection" or "gathering" suggest a reaping of rewards, and as outlined in *Table 3-1*, this study has largely employed what can be described as a "semi-colonial" approach, where data was "collected", taken, and mostly disseminated internationally (Murphy et al., 2015, Costello and Zumla, 2000). The quantitative data "collection" made a few tokens of acknowledgement of the study participants' scarcities; for example through giving gifts of sugar and checking participants' blood pressure. However, this seems like a

token gesture, in view of results which show that many participants were missing meals, and unable to access healthcare.

The conflict revealed through the tensions between positivist and constructivist paradigms led to the realisation that the study's aims were not aligned to addressing the study population's often urgent, unmet needs. Data dissemination and evaluation work conducted on the follow-up visit was in response to this, and attempted to balance some of the study's "taking" with a "giving back" of preliminary findings, in a form which might be understood and useful. This helped to align the study a little more with a "partnership" model of working (Costello and Zumla, 2000). Yet, this was still an inadequate response to the level of unmet need: For example, the leaflets that were produced and distributed, which made basic dietary recommendations, could be considered patronising at best, and insulting at worst, without also providing the means and assistance for older people to make those dietary changes. The local dissemination activities undoubtedly did not change the "situated ethics" of the study and highlight the failure to align study aims with community priorities earlier. Indeed, the main beneficiaries of this thesis have undoubtedly been the author and UK-based research colleagues, through publications and career advancement, in a perpetuating of privilege and power imbalance.

A discourse analysis of ethics in global health texts concludes by recommending that present-day global health disparities should be placed in historical context, acknowledging the ongoing impacts of colonialism (Brisbois and Plamondon, 2018). By framing the current health problems of LMICs in the context of both historical and ongoing injustice, the solutions, it is argued, would not be assumed to be technical and to be addressed by "cutting-edge research". In order to practice ethical and effective global health research, the solutions suggested include fostering community empowerment and responsiveness to community needs and priorities (Brisbois and Plamondon, 2018). Methods such as patient and public involvement, or participatory action research should be explored as methods for improving the alignment between the research aims of global health, and participants and their communities' needs.

8.19 Critiques of the concept of frailty in relation to this study

The following two sections raise fundamental questions about the motivation and aims of the study, which sought to investigate the "multiple and slippery" meanings of frailty cross-culturally (Kaufman, 1994). These sections illustrate that insights gained into contextual differences have thrown doubt on the assumptions underlying the study's very conception.

8.19.1 How culturally appropriate is the concept of frailty?

On one hand, as discussed above, the fact that being unable to work and care for others was the key marker of becoming frail, makes the concept highly culturally appropriate. Additionally, in the absence of medical and social systems, which have used frailty as a diagnosis or label in the third person (Grenier, 2007), there seemed to be less stigma and shame associated with identifying as frail in this sample. Older people who saw themselves as frail, were comfortable to admit it and did not resist the description. According to both groups of data, this was the case; The prevalence of self-reported frailty was 45.4% (95% CI 38.2 to 52.5) adjusting for frailty-weighting (*Figure 4-16*) and 20 from the 25 participants interviewed by semi-structured interview (SSI), identified themselves as living with frailty, despite only two being categorised as frail according to the B-FIT screening tool (Appendix P). This is in sharp contrast with "western" cultural settings, where the frailty label is almost universally rejected and resisted by older people (Becker, 1994, Puts et al., 2009, Grenier, 2006, Warmoth et al., 2015). Admitting to living with frailty in this study was perhaps seen as more of a factual statement of having "weaknesses of the elderly" (according to its direct translation). It meant either accepting that one had reached the dependent stage of life, or acknowledging one's state of scarcity of resources and/or care. The fact that older people could identify with the concept so readily suggests perhaps, that it is a useful and culturally appropriate concept.

As discussed, becoming frail meant losing one's adult status, and becoming like a child who is in need of care. There are some similarities between this idea and the Kenyan Gusii's understanding of the life course, which was symbolically represented by the movement of the sun. *"When (the sun) sets in the west and becomes cooler and less bright, it is described as being elderly and finally it sinks to its death in the west"* (Okemwa, 2002, p183). With symbolic representations of ageing and the life course described as natural phenomena such as this, there is a suggestion that culturally, the expectation of becoming frail and dying are much more normalised in traditional East African cultural contexts. Hence, participants of this study could claim that they were "living with frailty" acknowledging that their time had come to be "raised", and that their role at this life stage was to receive care gratefully. Acknowledging one's frailty meant acknowledging one's need for family care.

According to the second conceptualisation of frailty as "being in scarcity", the "weaknesses of the elderly" was an aberration from the expected life course and experienced as a lack of the expected inter-generational reciprocal care, provided by either the family, or government. Dramatic changes to Tanzanian society, which has moved away from Nyerere's socialist one-

party state, to a free-market economy and multi-party democracy (Mmari, 1995), has put pressure on the citizen-government reciprocal relationship (*"Kwa sababu wazee wamefanyakazi sana Tanzania"*: Because the elders have worked so much for Tanzania). Admissions of frailty in this context could be interpreted as a plea for the government to better address the needs of the older generation. This sentiment was also echoed in nostalgic reminiscences for the *"Ujamaa"* period in another qualitative study from the rural outskirts of Dar es Salaam (Kamat, 2008). In Kamat's study, older people exclaimed *"maisha magumu"* ("life is hard"), and remembered what they perceived to be better times, when the socialist government provided subsidised food and free healthcare (2008). These factors suggest that acknowledging one's frailty, in this context might also mean acknowledging one's need for resources and care, which were lacking.

Despite the fact that study participants readily claimed they were living with frailty, in evaluating the cultural appropriateness of the concept for application in rural Tanzania, it is important to remember that the biomedical model of frailty was constructed in "western" societies where ageing is conceived of as a decline and deviation from normative health and youth (Gilleard and Higgs, 2000a). *"The biomedical model [of the ageing process] is constructed to reflect our society, which focuses on individual capacities and defines any decline in these as a problem to be diagnosed"* observed Devisch et al. (2002, p282). If *ageing* is framed as a "problem to be diagnosed", it follows that biomedical concepts of *frailty* also reflect this thinking, resulting in an entity to resist and avoid. However, it has been suggested that such a model may ironically lead to *"fostering the problem it seeks to define"* (Devisch et al., 2002, p282). That is to say, as we get better at "diagnosing" ageing in its problematic form, namely frailty, the outcome is an increasing isolation and depersonalising of the ageing experience. This isolation and depersonalisation can be best described by Gilleard and Higgs' "social imaginary" of the fourth age (Gilleard and Higgs, 2010) (section 8.6.1).

By contrast, the fear associated with frailty in the rural Tanzanian context, was not of being "placed into care", given the rarity of such institutions. Rather, older people feared a rejection of the values which underpinned their lives; that of respect and reciprocity. In contrast with "western" culture, on reaching the "childlike" frailty of old age, Tanzanian elders *hoped* to age without agency, allowing adult children to take care-giving decisions on their behalf, and "raise" them in their turn. This form of lacking social agency was not fearful, given that the capacity to take decisions and act independently were relinquished to one's caring family. Older people in the Tanzanian setting are thus protected from the same "social death", which

can occur in the "western" fourth age (Higgs and Gilleard, 2014, Lloyd et al., 2016). In receiving care, the older person was not disengaged from society, rather their connections to it were being recognised.

While frailty, by both formulations was not desired, it was not abhorred in the same way that frailty in "western" cultures can be. The qualitative findings have succeeded in revealing the contrast between the "western" biomedical model of ageing and frailty, and the rural SSA cultural framework for thinking about ageing and frailty. The dissonance between these two paradigms suggests that the concept of frailty, as it has been devised in "western" and biomedical spheres is not culturally appropriate, despite older people's readiness to identify with the term.

8.19.2 Is the concept and measurement of frailty useful in this context?

Tanzanian healthcare policy states that all adults aged ≥60 years should be exempt from paying healthcare costs (Frumence et al., 2017, Maluka, 2013). Data from the qualitative component of the study demonstrated that this was poorly implemented, for example with delays in receiving identity cards which would allow older people to prove their ages, and with low medicine stocks in government facilities requiring out-of-pocket payment for medications at private pharmacies *("Vidonge magodown zimekwisha"*: Tablets have gone down or got finished). The costs of implementing the government's policies of exemptions and waivers are managed at the district level, which has led to varied approaches to its implementation and confusion about which eligibility criteria are actually being used (Maluka, 2013). A possible application for frailty screening therefore, could be to help prioritise between older people. Frail individuals could be identified and prioritised on the basis that they have higher levels of comorbidity and a higher risk of death. Or pre-frail individuals could be identified and provided with exemption, on the basis that access to healthcare at this stage may prevent further deterioration to disability and worsening frailty. Frailty screening, by a locally-validated instrument such as the B-FIT screening tool, could be applied in order to implement an exemption policy for healthcare costs. This might reduce the bureaucratic barrier that currently exists for older people in proving their age and eligibility, and may also make the policy more affordable. Yet, more research is needed to investigate whether implementation of an exemption policy according to frailty status would be beneficial and acceptable to older people with frailty and pre-frailty. The ultimate goal for Tanzania is "Universal Health Coverage" (UHC), defined as access to needed healthcare for all, (inclusive of all ages), and protection against financial risks arising from paying for healthcare (Mtei et al., 2014). In which case, research should also investigate whether the aim

of achieving UHC would be aided or undermined by the introduction of rationing based on clinical screening.

It has been suggested that screening tools may be used in low-resource health settings to improve task-shifting (Gray et al., 2017, Stone et al., 2018). Task-shifting has been applied with some success for the management of NCDs, such as hypertension, diabetes and asthma (Joshi et al., 2014) and might provide a solution to the significant lack of geriatrics specialists across the continent, and lack of current undergraduate or postgraduate training in the specialism (Dotchin et al., 2013). Frailty screening could allow non-specialist community health workers to identify older people who may need community outreach from hospital settings, (due to mobility or disability) or help to identify households and anticipate their need for additional support, (for training or resources) in order to provide better home-based care for their older person with frailty. However, the role of a frailty screening tool may be made largely redundant by local people's knowledge of the older people in their communities. Individuals were identified as requiring a home assessment, by the village enumerator (a member of the village health committee (VHC)), and being assessed at home was associated with a five-fold increased odds of frailty (adjusted OR 5.32, 95% CI 2.26 to 12.54) (*Table 4-7*). The B-FIT screening tool was also not co-produced with Tanzanian researchers, and thus is not providing a solution to a Tanzanian-identified problem. Given this lack of ownership, brought about through the "semi-colonial" model of working, it can be concluded that the B-FIT screening tool is less likely to be adopted outside of its current research context.

The utility of a frailty screening tool is also thrown into doubt by the qualitative results' finding that living with frailty, as a form of "being in scarcity", led to the phenomenon described as "scarcity mindset" (*"Nini kinakufanya uwe na furaha?"*: What is it that makes you happy?). Scarcity mindset theorises that attention is paid to the most immediate and pressing need, at the expense of other important, but less urgent priorities (Shah et al., 2012). Intense focus on the day to day management of the household, and resultant constant trade-offs were also used to explain the reproductive decisions of people living in Malawi (Norris et al., 2019). It was found that wealthier households could afford the cognitive "bandwidth" to plan and space their children. This theory is useful to apply to healthcare seeking behaviour in frailty; common NCDs such as cataracts or hypertension, were rarely prioritised by participants and their households in order to seek healthcare. While, to a wealthy outsider it seems sensible that an older person would seek treatment for their cataracts or hypertension, in order to maintain their health and ability to work for longer. However, for the person

experiencing scarcity, if other more urgent and overriding needs are present, these chronic health problems will not be prioritised even if, ironically, their neglect may lead to worsening frailty, and subsequent increased scarcity of resources.

Having a means of screening for frailty to enable preventive interventions or anticipatory planning is therefore unlikely to change the current behaviour of seeking healthcare for acute illness episodes while neglecting chronic conditions. Importantly, the health system is also not currently aligned to primary and preventative management of chronic NCDs, where screening might take place, to the frustration of many educated and motivated VHC members (*"Kujuliana afya zao"*: to enquire about their health).

8.19.3 Should the concept of frailty be "applied" in this context?

This is different, but aligned to the question; "how culturally appropriate is the concept of frailty?" In answer to this question, it was argued that the concept of frailty is superficially congruent across cultural settings, however underpinning values mean that the concept has little cultural resonance.

The fact that this study has demonstrated that frailty is prevalent, according to biomedical models, and that many identify as living with frailty, suggests that the concept should be used. The concept of frailty as described in the qualitative component of this study, could provide a framework for discussing how to address the problem of frailty (as "being in scarcity"), through better provision of care, healthcare, and resources. This framing of frailty as primarily a social issue, is reminiscent of discourses of frailty in the early days of UK geriatric medicine, which established as a speciality in 1948 (Pickard, 2014). In this period frailty was used to refer to individuals who required social, rather than medical care; *"(frailty) signalled a decrepitude 'natural' to old age that was hence not the domain of medicine"* (Pickard, 2014, p554). Thus, an "application" of the term on this basis, drawn from the qualitative investigation, would be culturally appropriate. However, "applying" a concept in a one-size-fits-all manner is likely to be problematic.

The ethics section of the methods chapter, (section 3.24) spends time reflecting on and discussing the "situated" ethics of this project. Examining these structural and systemic factors which influenced the project, led to the conclusion that this study mostly followed a "semi-colonial" rather than "partnership" model of working (Walsh et al., 2016, Costello and Zumla, 2000). Of particular relevance to answering the question of whether the concept of frailty should be "applied" in this context, is the fact that the study flouted one of the first principles recommended for conducting ethical global health partnerships, which is "set the

agenda together" (Murphy et al., 2015, KFPE, 2018). Recommending that the concept of frailty be "applied" in a Tanzanian context, could be seen as a "semi-colonial" imposition, when considering the ongoing structural and systemic factors which gave the UK research partners the power to dominate the research partnership. Assuming that the "western" biomedical model of frailty, and our use of the concept is desirable and should be "applied" in the same way, reveals a naïve entitlement, and could lead to the introduction of a culturally incongruous concept. This could lead to intangible harms to older people who are ageing successfully according to their conceptualisation. Ultimately, the question of whether the concept should be "applied" in the rural Tanzanian context, should be decided by Tanzanian stakeholders.

8.20 Implications of findings

This thesis has many important implications for the Tanzanian setting, particularly for health and social care policies. Additionally, while not the aim of this study, these insights have led to some interesting reflections on "western" cultural and HIC medical settings. As a researcher, the process of undertaking this work has also led to reflections of personal significance. Each of these areas will be outlined in the upcoming sections.

8.21 Implications for "western" cultural settings

Distilling the findings of the study, it can be concluded that frailty is culturally situated and socially produced. Comparisons with this specific Tanzanian socio-cultural construction of frailty, reveal some uncomfortable implications for the UK and other "western" cultural HIC settings.

8.21.1 Acceptance of finitude vs anti-ageing

Frailty is a value-laden term, despite our attempts to naturalise it and measure it in terms of objective physical functions. Frailty, according to "western" cultural thought, is a failure. To have a frail body, is to have an unattractive, unhealthy body, which has failed in its function of keeping the individual independent, autonomous, and participating in the system of capitalist consumption and individualist self-expression (Gilleard and Higgs, 2002, Gilleard and Higgs, 2000b). This is Rowe and Khan's "usual aging", which each individual is responsible for resisting, and working to avoid, for as long as possible (Richardson et al., 2011). Nevertheless, it is rare to succeed, with a longitudinal study of older American men finding that a third met Rowe and Khan's criteria for "successful ageing" at age 85, while <1% achieved "successful ageing" at age 95 (Bell et al., 2014). Yet, resisting ageing and "agedness" is what we, in "western" cultures do, with the converse seen as "fatalistic". Older people in Tanzania have not lived their lives expecting, or taking for granted their old age.

Framed in a context of high levels of religiosity, they are grateful for their long life, and are more accepting that frailty represents a nearness to death (*"Maisha ni Mwenyezi Mungu akiamua"*: Life is how Almighty God decides). Perhaps due to the preponderance of Christian and traditional African ancestral beliefs, death is more accepted as part of old age, not as a tragedy, but as the natural course (Stroeken, 2002, Kodzi et al., 2011). Death is marked by the whole community, with more concern over whether the burial is an appropriate honouring of the deceased, than with delaying or preventing death (Whyte, 2005, Van der Geest, 2002a). Whether these attitudes will inevitably change with modernisation, as was suggested by Cowgill's modernisation theory (Cowgill, 1986b), is a subject to be debated. Yet, the acknowledgement that human life has limits, conceptualised in these data as having a finite amount of life energy, is undeniable, and could be used to challenge the anti-ageing and anti-agedness discourse found in many in "western" cultures.

8.21.2 Independence vs inter-dependence

"Western" cultures hold frailty in a state of "abjection", particularly with "being placed into care" seen as a feared form of social death (Gilleard and Higgs, 2015, Lloyd et al., 2012). The fear meanwhile in Tanzania is of not receiving care. Higgs and Gillard have suggested that *"recognising and valuing the social being of a person"*, is important in the care of frail older people with dementia (Gilleard and Higgs, 2015). This is evident in Tanzania, where the maintenance of personal relationships is key to receiving care in frail old age (based on inter-generational reciprocity) (Van der Geest, 2002a, Whyte, 2017). The Tanzanian socio-cultural environment has also been heavily influenced by socialist ideals of "national solidarity" and "unity" (Nyerere, 1973), and these findings show that these ideas also motivate care provision for older people (*"Kwa sababu wazee wamefanyakazi sana Tanzania"*: Because the elders have worked so much for Tanzania). According to Tanzanian thought, it is absurd to consider that individuals should be independent, at any age, but especially in old age. It is widely understood, and can be summarised in the philosophy of *"Ubuntu"*, that people ought to be interconnected, and interdependent. Indeed, according to this philosophy, this is what constitutes being human: people are people through their interconnectedness and interdependence (Kamwangamalu, 1999). Perhaps challenging "western" cultural assumptions that independence is always desirable or indeed, really the reality, would be one way of reducing the harmful "othering" associated with frailty (Higgs and Gilleard, 2014). More recognition of our social, if not physical interdependence, might also improve the experiences of living with frailty, with less implicit blame placed on older people for becoming dependent on others for care. While broad cultural change happens slowly, perhaps

in the shorter term, more careful use of language, for example considering using the term “interdependent”, instead of “dependent” in everyday language and in medical spheres, might lead people to question their assumptions.

8.22 Personal reflections

The implications of this research project for me personally, and as a researcher are far-reaching.

My attitudes and ideas have changed and developed gradually, over the course of two years spent living in Tanzania. When I initiated this PhD project, my attitudes were well-intentioned, but naïve. I believed that I had geriatric medical expertise, which I knew was lacking in Tanzania, and simplistically felt that any research conducted would undoubtedly be better than none, i.e. I believed that research done with good intentions, by experts with skills and knowledge to offer could not do harm. The answer to a large data gap is surely to produce data. It didn’t occur to me to question whether, as a white, western foreigner I was best placed to conduct such research. I also hadn’t realised that good intentions, are not enough to prevent unintended or systemic harms from being perpetuated. In large part, thanks to becoming closer to Tanzanian colleagues and friends, and increasingly starting to see the research from their perspective, I became aware for the first time of my whiteness, among many other identities and areas of privilege. I was forced to develop some humility, and started to question the entitlement which had led me to research frailty in Tanzania to begin with.

My approach to the concept of global health research has developed immeasurably throughout the course of the project. My learning on the topic of global health as a campaigning, equity oriented research paradigm evolved through reading and reflection, but in large part, was inspired by conducting mixed methods research. Throughout the qualitative aspect of the study, I had to grapple with and confront the fact that frailty, to a large extent in rural Tanzania was the experience of being disenfranchised and living with poverty. Qualitative research methods enabled me to really listen. Despite the fact that initially, I did not understanding the full meaning or implications of what participants were telling us. The value which the qualitative component brought to the study, is that it caused me to learn from participants, rather than seeing participants as useful only for the data which I already knew I wanted to collect from them. This act of listening and learning disrupted the power dynamic producing a useful tension in the study, and has led to important revelations both for this study, and for my understanding of global health research.

My approach towards future research in global health will be much more cognisant of power and privilege imbalances in the research partnerships, and from the outset I will be striving to address and balance those inequities (section 3.27.2). However, on reflection, I doubt I would have developed such an awareness of "situated" ethics of the research had I not spent such a lengthy time in Tanzania, learning Swahili and developing an understanding of cultural differences. Therefore, for my future work I now know the value and importance of avoiding being, what might be thought of as a tourist-researcher. Short-term research field trips may seem an efficient use of time, but in fact leads to research that is not developed in partnership, so produces little impact for the intended beneficiaries. The tourist-researcher is also more likely to produce shallow or incorrect findings, because of an assumption of the universality of "western" cultural values. In order to produce meaningful research, I have discovered the importance of taking time and effort to become more aligned with, and embedded in the research setting.

8.23 Frailty is prevalent, however it is measured

Whether by self-report, through the qualitative investigation, or by any of the biomedical models of frailty employed, frailty is prevalent. The implication of this finding is that, as the proportion of older people increases in Tanzania and in SSA more generally, the prevalence of frailty is likely to increase too. The proportion of older people is increasing most rapidly in SSA, despite its being the youngest continent, and in terms of absolute numbers there are already more older people living in SSA than in Europe (WHO, 2015). Consequently, if frailty is prevalent when the proportion of older people in Tanzania comprises 4.6% of the population, it is likely to affect a growing number as the proportion of older people reaches 7.2%, as is predicted by 2050 (United Nations Department of Economic and Social Affairs Population Division, 2019). In order to avoid, what has been described as "the lament trope" (Makoni, 2008); the reactionary outcry to "an increased number of older people in an unprepared continent", this study has not made assumptions that frailty in ageing is a problem. Instead, the study has sought to investigate the experiences of older people in this study's setting to understand their perceptions of the problem. Frailty was perceived, at once to be an inevitable dependent stage towards the end of life, and also an aberrant ageing "too soon" or "too quickly". This second form of frailty was certainly perceived to be a problem by participants of this study.

To give a balanced view, however, if 19.1% were living with frailty according to CGA, then the great majority, 80.9% were ageing with remarkable resilience, in the context of low financial security and poor healthcare coverage. The concept of measuring both "deficits" and

"resilience" is gaining popularity within geriatric medicine (Nicholson et al., 2017, Hale et al., 2019). Indeed, this was in fact frailty's early conception, as the interplay between assets and deficits (Rockwood et al., 1994). Perhaps one of the key implications of this study, is that alongside the many scarcities of frailty, there were undeniable strengths. Future work could explore the factors which enabled older people's resilience in this context.

8.24 Addressing old age poverty may help to address frailty?

As a geriatrician-in-training it is tempting to conclude that the problems of older people might be answered by the skills of geriatricians. It would be easy to conclude that a significant burden of frailty, requires more healthcare professionals with geriatrics expertise, to plug the gap in specialist care of older people (Dotchin et al., 2013). One participant stated there was a need for medical specialists in the care of older people, and this was also mentioned in Tanzanian policy ("Madaktari kwa ajili ya wazee"*:* Doctors for the sake of the elders). However, the geriatrician's skill is really in the management of frailty and its associated complexity and multimorbidity. Far better, it might be argued, to take a public health approach to preventing frailty.

These data show that many older people felt they were living in frailty due to their "being in scarcity" in the context of old age. Frailty was associated with an almost six-fold increased odds of being financially dependent on others, and a two-fold increased odds of being at "high risk" of malnutrition (*Table 4-3*). Frailty is known to be inversely associated with socio-economic status (Hoogendijk et al., 2018), and in this thesis frailty was confirmed to be significantly associated with illiteracy and not having a formal education (a proxy for low socio-economic status). Addressing poverty, it is assumed, would reduce frailty. The qualitative findings also support the fact that a scarcity of resources and care was the type of frailty which really mattered to people. Frailty of this kind, it follows, might be best addressed by poverty reduction, through policies aimed at improving the financial security of older people, (such as the implementation of a universal non-contributory pension, or generating employment for younger adults). Work done by organisations such as HelpAge International in campaigning for universal pensions or better implementation of healthcare policies in favour of older people should be seen as positive steps (HelpAge International, 2016).

In terms of considering frailty prevention, one might assume that poverty reduction and reduced financial barriers to accessing healthcare might prevent frailty through the mechanism of better management of chronic NCDs such as hypertension and diabetes. This is based on the assumption that people with more resources will make the "right" choices for their health. Spending money on health-enhancing necessities such as better nutrition and

healthcare, may lead to better management of chronic conditions, with prevention of their disabling sequalae (such as disability from stroke, or visual impairment from diabetic retinopathy). However, there is little conclusive evidence that non-contributory pension schemes directly improve the health of older people (Lloyd-Sherlock et al., 2012). Lloyd-Sherlock argues, that without also addressing healthcare quality and health awareness, removing financial barriers will not lead to improved management of chronic health conditions. This was illustrated by very high rates of undiagnosed and untreated hypertension, despite near universal pension provision in South Africa.

While chronic medical conditions undoubtedly play a role in the development of frailty, a life course approach to ageing views the development of frailty, not only as a consequence of factors in the present (such as the presence of chronic disease), but as an outcome of the effects of early life (Hanson et al., 2016). The rate of decline in function in old age depends on the level of peak function attained earlier in life, which in turn depends on early environmental influences. This approach may explain some of the differences found between high and low-income settings in physical components, which are closely related to the concept of frailty, for example, HGS and walking speed. Normative HGS data were lower in "developing" countries (Dodds et al., 2016), while the WHO SAGE countries had slower mean walking speeds than mean speeds reported in a systematic review of large HIC studies (Capistrant et al., 2014, Studenski et al., 2011). Broader economic development might address these inequities seen on a population level, between HIC and LMICs.

8.25 Frailty and non-communicable diseases

While much research into healthcare access in LMICs has focused on maternal and child health, older people's needs in relation to the management of chronic NCDs and multimorbidity been neglected (Cesari et al., 2016, Schatz et al., 2017). This thesis has shown a high prevalence of unmanaged symptoms, for example chronic pain and visual problems, with relatively low proportions of formal diagnoses: Poor screening and management of chronic NCDs is indicated by the finding that 54.5% had measured high blood pressure, while only 29.5% reported a diagnosis of hypertension (*Table 4-7*).

A low level of health awareness was raised as an important factor in the sub-theme *"Kujuliana afya zao"*: to enquire about their health, where VHC members argued for early testing and management of chronic NCDs for the promotion of better health in old age. A mixed-methods study in Northern Tanzania has highlighted a lack of understanding about chronic disease as a barrier to effective management of hypertension (Galson et al., 2017). However, the authors raised many other structural and system problems in terms of point-of-

care access, for example long waits and understaffing leading to poor communication between healthcare workers and patients, and unrealistic expectations of cures for chronic NCDs as a result. A potential benefit of frailty screening through task-shifting (section 1.5.6), may be that it helps to free-up healthcare workers' time to provide better health education and higher quality NCDs management. Undoubtedly, this thesis provides evidence of a need for better quality healthcare, more aligned to the needs of older people, particularly addressing chronic NCDs. As mentioned in section 8.11, better management of NCDs may influence prevalence frailty and its associated mortality.

8.26 Challenges of social care in frailty

This section develops the discussion of section 6.16 and reflects on the implication of these data on care of frail older people in this context. The sub-theme *"Wazee wakipatiwa mahali"*: The elders should be given a place, seems to support the Tanzanian government's policy that the institutional long-term care of older people should be a "last resort" (Ministry of Labour Youth Development and Sports, 2003). According to these findings, there was a broad rejection of institutionalised care for older people with homes and families. It is possible that in the public forum of the focus group discussion it was too much of a taboo to advocate for institutional care for anyone other than the "abandoned" or "outsiders", who were not receiving care from within the family. The rejection of institutional long-term care, is not equivalent to rejecting the "calculating-innovative" discourse, synonymous with the care receiver as a consumer of care (Baart, 2018). Rejecting institutional long-term care may also not be a past-oriented "cultural-conformable" stance, where traditional and idealised notions of care are emphasised (Baart, 2018). Rather, it could be argued that this position of rejecting institutional long-term care as a model of care for older people, was in fact a forward-looking and empowered rejection of past colonialism (which produced many of Tanzania's current institutions) and a rejection of the dominance of associated "western" norms and values. The support of the UK-based NGO for Amani was appreciated, yet this reliance on foreign donors was also experienced as disempowering (*"Ninapenda serkali inisaidie"*: I would like the government to help me). Similarly, the study of retirement homes in Kinshasa, found that institutional care was associated with *"foreign practices of care for older people"* (Pype, 2018, p64).

Tanzanians may be advocating for a different model of care for frail older people, which does not follow the same "foreign" model, but rather concurs with their own cultural values. These qualitative findings describe the components required for the provision of "good" care for frail older people. This involves being "raised" (or provided for as children) within the family,

at home (ideally on the family-owned land), where they will be able to receive the deserved "close" attentive care, which is provided in acknowledgement of their past work of raising the family. These data show that care of this type enables what is deemed a good (even successful) old age, and facilitates the rituals of care in death (a fitting burial on family land). Institutionalisation meanwhile, was seen as a form of displacement and abandonment of the older person (both in life, and at the point of burial), and was only acceptable for those surviving according to the "functional-subsistence" discourse (Baart, 2018). The "functional-subsistence" discourse epitomised the state of scarcity experienced by many older people living with frailty in these data (for example, 'Mzee Massawe' and 'Bibi Helena').

The Ghanaian government has taken a similar policy stance to that of the Tanzanian government in its approach to care provision for older people, and has been criticised for a lack of vision and naiveté (Van der Geest, 2018). Both governments have emphasised the responsibility of the family in providing support for older relatives, with Ghana's government promising "education and training programmes targeted at improving caregiving to older people" (Van der Geest, 2018). Van der Geest rejects the notion that family-based care is an inherently "African" way of caring, arguing that it was a global tradition which has only changed recently in the "west". This discourse, it is argued is a convenient way for governments to ignore their responsibilities to frail older people. Indeed, this study's data suggests that it is not primarily education and training which families require in order to provide better care for their frail older relatives, rather it was more household resources.

This is consistent with the "material constraints" discourse, which is used to explain the decline in material support for older people, often in the context of modernisation theory (Aboderin, 2004b, Aboderin, 2004a). According to this theory, the younger generation are *unable*, rather than *unwilling* to provide financial and other material support for their older relatives (section 1.3.3.1). This thesis has shown that household "material constraints" are likely to be an important factor influencing the type and quality of care which frail older people receive. In addition, this thesis has described the underlying motivations for care provision for older relatives. Formal systems to support the care of older people, either through the government or by other means, should be developed with the values of reciprocity and respect, "closeness" and embeddedness in place. Any future models of care for frail older people in Tanzania, based on the "structural-adaptive" or "calculating-innovative" discourses of care should consider these qualities and values of care in order to be culturally acceptable to older people living with frailty, their families and communities.

8.27 Future research topics

This study has made a substantial contribution to this field, but there is still much more work which could be done, which was outside of the current study's scope. Ultimately, the agenda for this research was set without stakeholder involvement. Having analysed and reflected on the methods employed, although conforming to norms of ethical practice, they were found to be fairly consistent with a "semi-colonial" model (*Table 3-1*) (Costello and Zumla, 2000). This form of working, is both less likely to produce meaningful research impact, and is ethically problematic, given that global health research aims to address inequity (Koplan et al., 2009), while these methods serve to perpetuate it. With this in mind, these research ideas have been developed, from questions raised by this study's findings. But any further research should attempt to work from a more equitable partnership model, and develop these ideas collaboratively.

8.28 Research methods for more equitable global health partnerships

Impactful global health research, which leads to meaningful results for stakeholders, and which is translated into policy and practice requires a true collaborative approach. The question remains of how to best achieve this goal, particularly given the weight of structural and systemic forces which make the "semi-colonial" model of working the default (Walsh et al., 2016). Patient and public involvement (PPI) has been simply defined by the UK's INVOLVE network, established in 1996, as research carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them (NIHR, 2019). However, PPI in LMICs health research has rarely used this terminology, formally applied its methods, or evaluated its impact (Cook et al., 2019).

This study has demonstrated that it was possible to usefully include PPI in order to disseminate preliminary data to older community-dwelling adults, and to involve them, and volunteering VHC members in a consultatory capacity in order to evaluate the impact of this study (Appendix K). These methods were employed late in the research cycle however, and therefore the potential benefits for improving the ethical practice and research impact of this thesis were not fully realised. Cook's review of the LMIC literature found a preponderance of PPI work has focused on so called "hard-to reach" groups such as people with mental health problems, or at risk of HIV infection. PPI methods have not yet been attempted in research with older people in LMICs, the frail and disabled of which, it could be argued are among the most disenfranchised and hard-to-reach groups. PPI could be a route to empowering research participants and their communities, and may help to re-balance some of the power disparities common in research "partnerships" between high and LMICs (Cook et al., 2019). Future work

in this area could include better evaluation of the impact of PPI in LMICs and the adaptation of PPI tools/toolkits for use in LMIC settings (Cook et al., 2019).

8.29 The relationship between undernutrition and frailty

Undernutrition was seen as causing frailty through "being in scarcity" (*"Kwa sababu ya kukosa lishe na chakula bora"*: Because of missing nutrition and good food), and would thus be an area for future research which was closely aligned with older people's priorities and needs. Quantitative findings also suggested a link between malnutrition and frailty (*Table 4-3*). There is also a strong theoretical underpinning for chronic undernutrition or malnutrition leading to frailty through the "cycle of frailty" theory underpinning the FP (Fried et al., 2001). Additionally, nutrition across the life course was one of the factors used to explain the disparity between "developing" and "developed" norms of HGS (Dodds et al., 2016). However investigating the association between undernutrition and frailty, was not the aim of this thesis.

Future research could attempt to better characterise the association between undernutrition and frailty, given that older people in SSA are at an increased risk of undernutrition, with up to 48% found to be underweight according to this review (Kimokoti and Hamer, 2008). The authors highlight the multiple challenges facing older people across the sub-continent relating to their risk of undernutrition, including HIV/AIDS and humanitarian emergencies. Given that the FP has been criticised for underestimating frailty in the obese (Bergman et al., 2007), and that sarcopenic obesity is known to have associations with worsening disability, compared with sarcopenia alone (Hirani et al., 2017), an investigation of the relationships between frailty, obesity, and sarcopenic obesity would be a novel and potentially beneficial area to investigate. Particularly, this type of research might help to increase the focus on frailty and older people's health within the context of the international public health discourse on tackling obesity as part of the WHO's NCDs strategy (WHO, 2013).

8.30 Frailty as a means of improving healthcare quality

Improved quality of healthcare for older people is also on the international policy agenda, through guidelines such as the WHO's Integrated Care for Older People (ICOPE) (WHO, 2017a). These guidelines aim to improve existing community healthcare services and systems, in order to respond to the increasing chronic multimorbidity and frailty which will characterise ageing populations globally (Prince et al., 2015). The ICOPE guidelines include recommendations on managing problems associated with mobility loss, malnutrition, visual impairment, hearing loss, cognitive impairment, and depression (WHO, 2017a). While the ICOPE guideline is not intended to detect and manage frailty, there is an evident overlap with

the assessment domains of the CGA. Other efforts include the EASYcare project, which developed an instrument with the aim of identifying the unmet healthcare needs of older people in community settings, and was based on a simplified CGA (Philp, 2015). This instrument was found to be widely acceptable when piloted in Iran, Colombia, India, Lesotho, Tonga, and the United Kingdom (Philip et al., 2014). In Tanzania, the instrument was incorporated into the WHO "Community Strengths Framework", which aimed to enhance the capabilities of older people to contribute to community life (Msambichaka et al., 2014). There is considerable scope to investigate the value of frailty screening and assessment within health-systems in order to improve the quality and integration of care for older people.

8.31 Frailty and social vulnerability

The social vulnerability index is a tool developed by Canadian researchers who have sought to investigate older people's social frailty (section 2.10.3) (Andrew et al., 2008, Bunt et al., 2017). Alongside the production of a FI, an additional index of 23 variables was produced, to address the problem of multiple overlapping influences of varied social, psychological and economic factors on older people's lives and wellbeing (Andrew and Keefe, 2014). Adjusting for age, sex and frailty status, each social "deficit" was associated with an increased odds of mortality (Andrew et al., 2008). Future research leading on from this thesis might investigate whether social vulnerability is a helpful construct in the Tanzanian context. Showing that context-specific social, psychological and environmental factors are important in older people's health outcomes might help to bring the social issues facing older people, particularly those living with frailty, to the attention of policy makers. Context-specific and cultural factors are likely to produce social "deficits" different from those developed in Canada. Drawing on these qualitative results, feeling abandoned by one's children may be an important component of social vulnerability in this setting (*"Watoto wako wanaosafiri basi umedhoodfika"*: Your children are travelling then you become frail). Equally, this exploratory work may highlight contextually-specific social strengths, or "resilience" factors, which might be supported.

8.32 Frailty and HIV in sub-Saharan Africa

From demographic and health survey data of over 400,000 individuals across 27 SSA countries, it was found that while HIV prevalence rates are decreasing in the total population, they are increasing in older adults (Vollmer et al., 2017). In Tanzania, HIV prevalence rates in older adults (45 to 49 years) are already higher (8.5%) than HIV prevalence in the total population (5.1%) (Vollmer et al., 2017). However as Vollmer et al. discuss, these surveys

have usually been limited to adults aged ≤60, thus the prevalence in older age groups has yet to be quantified.

This thesis found a low prevalence of HIV-infection in community-dwelling older people, with only four participants randomised to CGA disclosing their HIV-infected status. The low prevalence of HIV-infection is a major limitation of this study, in terms of its transferability to other areas of SSA with higher community prevalence rates. However, the couple interviewed qualitatively, 'Baba Thomas' and 'Mama Josephine' illustrated how living with both frailty and HIV-infection exacerbated their hardships (Appendix Q). There is a developing evidence-base for frailty as a non-infectious consequence of HIV-infection (Bernard et al., 2017). The combination of lifelong anti-retroviral medications and their side-effects, cardiovascular risk-factors which increase with age (such as hypertension and obesity), and the chronic inflammation of HIV-infection, have all been suggested to mediate accelerated ageing and increase the risk of frailty (Bernard et al., 2017). This is an important research gap, especially in SSA where a growing number of adults are ageing with the infection (Siedner, 2017).

This topic suffers from what could be thought of as an academic blind spot. Neglected within the realm of "typical" infectious diseases research in SSA, which has focused on child and maternal health, and not within the traditional realm of geriatrics expertise. These silos have been perpetuated for too long, leading to calls for better integration between NCDs and communicable diseases within both healthcare services and research (Temu et al., 2014). There is evidence that HIV, directly and indirectly through caregiving, has affected older people's functional abilities and wellbeing (Nyirenda, 2013). Thus, perhaps a mixed-methods study would best allow for the impact of stigma and socio-economic disadvantage to be investigated, alongside the physical phenotype of frailty in HIV. This is imperative in view of the fact that social and cultural factors may play an important role in mediating and affecting the outcomes of frailty in HIV-infected individuals (Brothers and Rockwood, 2019)

8.33 Conclusion

To conclude, each of the research questions, which were formulated and outlined in the introduction, will be answered in turn:

8.33.1 Quantitative component research question

- Can the biomedical models of frailty be applied to measure and characterise frailty and its outcomes in this context?

The associated aim of which was, through quantitative methods, to measure the prevalence characteristics and outcomes of frailty using biomedical measurements.

The study has succeeded in "applying" the biomedical models of frailty, with relative success, given that prevalence rates and patterns have been consistent with previous similar research. Detailed reflections on the adaptations required, and challenges encountered in doing so, are provided in earlier sections that provide a summary of the quantitative results in relation to each of the biomedical models/methods employed. The characteristics of frailty in this context were also described through CGA-derived problem lists, which provided a "gold standard" for frailty diagnosis for the first time in research carried out in SSA. Capturing the outcomes of frailty, by quantitative methods was somewhat less successful. It can be robustly concluded that frailty is significantly associated with an increased risk of death, by all measures employed. Further discussion as to the strengths and limitations of the investigation of the frailty-associated outcomes have been detailed earlier in the sections; sections 8.4, and 8.18. Despite the successful "application" of these frailty models, the ethics and utility of doing so have been questioned, particularly in light of the fact that the whole enterprise of investigating frailty in this context was initiated without local Tanzanian consultation. This raises the question, to what extent these models were "imposed" rather than "applied", and has important implications for future work.

8.33.2 Qualitative component research questions

- How is frailty conceptualised?
- What is the lived-experience of frailty?
- How are frail older people cared for?

The aim was through qualitative methods, to co-construct an understanding of frailty in context, through the lived-experiences of older people and their communities.

Two formulations of frailty were developed from these qualitative data. These formulations of frailty as a return to "childlike" dependency, and frailty as "being in scarcity" were often contrasting, but also co-existed in frail individuals and their families. Perhaps the two formulations reveal something of the tensions in Tanzanian society between traditional ideals and present-day pragmatism in the face of economic hardship. That is, the endurance and adaptation of the "traditional" in the face of pressures relating to "modernisation".

Certainly, the answers to the three questions have been shown to be intimately connected. Whether frailty was conceptualised as requiring and receiving care ("childlike" dependency) or requiring and lacking care (frailty as "being in scarcity"), care was the determining factor. Thus the question of how frail older people are cared for, became tautological. Much of the time, the experience of living with frailty was an experience of a distressing lack of deserved

reciprocal care and respect. Importantly, in this context frailty as "being in scarcity" affected the family and older person's household, as well as their neighbours and village communities. Therefore, it can be said that frailty was also experienced by the community.

This study has contributed substantially to understanding how frail older people are cared for in rural Tanzania, including developing an understanding of the qualities and values of desired care and attitudes towards institutional care for older people. However, given that the quantitative investigation focused on the biomedical aspects of frailty and not on care, corresponding data on household composition, gender distribution of unpaid care work and types of caregiving activities are missing. Yet, from these qualitative data presented, it can be concluded that the frailty of "scarcity" was considered the problematic form of frailty. In view of this fact, researchers and medical professionals, particularly of "western" cultural and HIC biomedical backgrounds, should tread carefully when working in this context to avoid assuming their norms apply. An individualistic and problematising focus on the individual's ageing body and its function, may be harmful and culturally inappropriate, compared with taking a community approach to addressing inequity, and supporting desired care.

8.34 What is frailty in rural Tanzania?

This overall research question, implies that frailty in the context of rural Tanzania might be different, hence the need to investigate it. However, frailty as defined by the biomedical models has been successfully applied to measure frailty, which is prevalent in this community setting in 9.09% to 39.18% of those aged ≥60 years. Adaptations to the measures withstanding, frailty by these models detected frailty, and replicated the expected epidemiological patterns. This thesis can also conclude, that frailty is culturally situated and socially produced and frailty, as it was experienced and understood in Tanzania, was either a natural conclusion to a long life, or an aberrant form of ageing due to a scarcity of resources. Future global health research in this field should seek to better align research with the priorities and needs of communities, and should endeavour to work in a truly collaborative manner in order to maximise the potential to address the frailty of scarcity, as a form of social inequity, through translation of research into policy or practice change.

Appendices

Appendix A Rockwood's Clinical Frailty Scale

Clinical Frailty Scale*

1 **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 **Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 **Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 **Severely Frail** – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. **Terminally Ill** - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common symptoms in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In moderate dementia, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In severe dementia, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005; 173:489-495.

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Appendix B Comparisons of findings from reviews of frailty in LMICs

Study	Countries included	Prevalence of frailty by FP	Prevalence of frailty by FI
World Health Organization Study on global AGEing and adult health (WHO SAGE) 1st wave (Biritwum et al., 2016, Hoogendijk et al., 2018)	China, Ghana, India, Mexico, Russia and South Africa	China 8.6%, Ghana 11.2%, India 13.2%, Mexico 10.9%, Russia 8.4%, South Africa 14.5%	40-item FI, >0.2: China 13.5%, Ghana 37.9%, India 56.9%, Mexico 30.4%, Russia 30.8% South Africa 38.0%
Systematic review and meta-analysis (Siriwardhana et al., 2018)	47 studies included in meta-analysis from Brazil, Colombia, Mexico, China, Malaysia, India, Russia, Barbados, Cuba, Chile, Turkey, Dominican Republic, Peru, Venezuela, Ecuador, Lebanon and Tanzania	Pooled meta-analysis of 30 studies 12.7% (95% CI 10.9% to 14.5%)	Pooled meta-analysis of 4 studies 18.0% (95% CI 5.8 to 35.0)
Systematic review (Gray WK, 2016)	70 studies from Mexico, Cuba, Peru, Chile, Hungary, Romania, Barbados, Colombia, Tunisia, Ghana, Egypt, South Africa, Iran, Jordan, India, Sri Lanka, Burma, Indonesia, DPR Korea, China, Thailand	20 community-based studies, range 8.1% to 39.2%	36 community-based studies, range 11.6% to 27.8% in
Review (Nguyen et al., 2015)	9 community-based studies from Brazil, Mexico, China Russia, India, Peru	5 studies range 5.4% to 23.2%	3 studies range Mean FI score 0.11 to 0.16 +/-0.1

Appendix C The operationalisation of the Hai District Frailty Phenotype compared with Fried's Frailty Phenotype

Component measured in both	Hai District Frailty Phenotype	Fried's Frailty Phenotype
Weakness (low HGS): Average of three measurements in the dominant hand using the JAMAR hand-held dynamometer.	Frail criterion met if average HGS in the dominant hand <21Kg in males or <10Kg in females based on the median HGS in African adults aged 61-70: 18 (10-25) women, 30 (21-38) men *(Leong et al., 2016)*.	Stratified by gender and body mass index (BMI) quartiles: Cut-off for grip strength (Kg) criterion for frailty Men: BMI ≤ 24 ≤29 BMI 24.1–26 ≤30 BMI 26.1–28 ≤30 BMI > 28 ≤32 Women: BMI ≤ 23 ≤17 BMI 23.1–26 ≤17.3 BMI 26.1–29 ≤18 BMI > 29 ≤21
Slow walking speed: Walking at usual pace, 4.5m (15 feet) use of walking aid is permitted.	The slowest quintile of the sample's walking speed was taken as cut-off: ≥11.12 seconds to walk 4.5m distance (not stratified by gender or height).	Slowest quintile stratified by gender and height Men: Height ≤173 cm ≥7 seconds Height >173 cm ≥6 seconds Women: Height ≤159 cm ≥7 seconds Height >159 cm ≥6 seconds
Self-reported exhaustion: CES–D Depression Scale questions were used. Frailty criterion if either was felt to be present a "moderate amount of	The CES-D questions were verbatim translated into Swahili by a Tanzanian doctor and statements read aloud and scored in the same manner as the Fried FP.	CES–D Depression Scale questions, the following two statements are read. (a) I felt that everything I did was an effort; (b) I could not get going. Frailty criterion if either was felt to be present a

Component measured in both	Hai District Frailty Phenotype	Fried's Frailty Phenotype
the time" or "most of the time" over the past week.		"moderate amount of the time" or "most of the time" over the past week.
Unintentional weight loss:	Has the participant/older person lost weight during the last 3 months? Frailty criterion were met if the participant answered either "yes, more than 3kg", or "yes, between 1 and 3 kg".	"In the last year, have you lost more than 10 pounds unintentionally (i.e., not due to dieting or exercise)?" If yes, then frail for weight loss criterion, OR ≥5% of body weight lost in the past year unintentionally.
Low physical activity	Taken from the International Physical Activity Questionnaire: "During the last 7 days, on how many days did you do moderate physical activities like gardening, cleaning, bicycling at a regular pace, swimming or other fitness activities?" Those who answered "0", were categorised as meeting frailty criterion.	Based on the short version of the Minnesota Leisure Time Activity questionnaire Kcals per week expended are calculated using standardized algorithm. This variable is stratified by gender, with frailty criterion met if less than the lowest quintile of energy expended. Men: <383 Kcals/week Women: <270 Kcals/week.

Appendix D The domains, variables and coding used in constructing the Frailty Index

Item number	Variable	Coding
Assessment Domain: Function		
1.	In the past 30 days, how much difficulty did you have in standing for long periods such as 30 minutes?	0=None (no) 0.25=Mild (a little) 0.5=Moderate 0.75=Severe (very much) 1.0=Extreme or cannot do
2.	Because of your health condition, in the past 30 days, how much difficulty did you have in taking care of your household responsibilities?	0=None (no) 0.25=Mild (a little) 0.5=Moderate 0.75=Severe (very much) 1.0=Extreme or cannot do
3.	In the past 30 days, how much difficulty did you have in learning a new task, for example, learning how to get to a new place?	0=None (no) 0.25=Mild (a little) 0.5=Moderate 0.75=Severe (very much) 1.0=Extreme or cannot do
4.	In the past 30 days, how much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	0=None (no) 0.25=Mild (a little) 0.5=Moderate 0.75=Severe (very much) 1.0=Extreme or cannot do

Item number	Variable	Coding
5.	In the past 30 days, how much have you been emotionally affected by your health condition?	0=None (no) 0.25=Mild (a little) 0.5=Moderate 0.75=Severe (very much) 1.0=Extreme or cannot do
6.	In the past 30 days, how much difficulty did you have in concentrating on doing something for ten minutes?	0=None (no) 0.25=Mild (a little) 0.5=Moderate 0.75=Severe (very much) 1.0=Extreme or cannot do
7.	In the past 30 days, how much difficulty did you have in walking a long distance such as a kilometre [or equivalent]?	0=None (no) 0.25=Mild (a little) 0.5=Moderate 0.75=Severe (very much) 1.0=Extreme or cannot do
8.	In the past 30 days, how much difficulty did you have in washing your whole body?	0=None (no) 0.25=Mild (a little) 0.5=Moderate 0.75=Severe (very much) 1.0=Extreme or cannot do
9.	In the past 30 days, how much difficulty did you have in getting dressed?	0=None (no) 0.25=Mild (a little) 0.5=Moderate

Item number	Variable	Coding
		0.75=Severe (very much) 1.0=Extreme or cannot do
10.	In the past 30 days, how much difficulty did you have in dealing with people you do not know?	0=None (no) 0.25=Mild (a little) 0.5=Moderate 0.75=Severe (very much) 1.0=Extreme or cannot do
11.	In the past 30 days, how much difficulty did you have in maintaining a friendship?	0=None (no) 0.25=Mild (a little) 0.5=Moderate 0.75=Severe (very much) 1.0=Extreme or cannot do
12.	Because of your health condition, in the past 30 days how much difficulty did you have in your day-to-day work/school?	0=None (no) 0.25=Mild (a little) 0.5=Moderate 0.75=Severe (very much) 1.0=Extreme or cannot do
Assessment Domain: Cognition and mood		
13.	IDEA cognitive screening tool	0=Good cognitive function: score 8-12, 0.5= Moderate cognitive function: score 5-7, 1=Poor cognitive function: score 0-4,

Item number	Variable	Coding
14.	Can the older person assist in small works of the house?	0=Yes, no difficulty 0.5=Much/small amount of assistance 1=Cannot do
15.	Can the older person give advice?	0=Yes, no difficulty 0.5=Much/small amount of assistance 1=Cannot do
16.	Can the older person preside over feasts and ceremonies?	0=Yes, no difficulty 0.5=Much/small amount of assistance 1=Cannot do
17.	Depression EUROD score	0=≤4 1=≥5 (Probable depression cut-off score)
18.	Overall in the last 30 days, how much of a problem did you have with worry or anxiety?	0=None 0.33=Mild 0.66=Moderate 1=Extreme
19.	Overall in the last 30 days, how much of a problem did you have due to not feeling rested and refreshed during the day (for example, feeling tired, not having energy)?	0=None 0.33=Mild 0.66=Moderate 1=Extreme
Assessment Domain: Comorbidity		
Have you ever been told you have a diagnosis of any of the following?		
20.	Diabetes	0=no 1=yes
21.	Hypertension	0=no

Item number	Variable	Coding
		1=yes
22.	Cataracts (Have you been told you need an operation on your eyes?)	0=no 1=yes
23.	Stroke	0=no 1=yes
24.	Heart disease/failure	0=no 1=yes
25.	Chronic respiratory condition, such as asthma or COPD	0=no 1=yes
26.	Arthritis or rheumatism	0=no 1=yes
27.	Do you think you have a hearing problem?	0=no 1=yes
28.	In the last 30 days, how much difficulty did you have in seeing and recognizing an object at arm's length or in reading?	0=No difficulty 0.33=Mild difficulty 0.66= Moderate difficulty 1=Extreme/cannot do
29.	In the last 30 days, how much difficulty did you have in seeing and recognizing a person you know across the road (i.e. from a distance of about 20 meters)?	0=No difficulty 0.33=Mild difficulty 0.66= Moderate difficulty 1=Extreme/cannot do
30.	Overall in the past 30 days, how much of a problem did you have with bodily aches and pains?	0=No difficulty 0.33=Mild difficulty

Item number	Variable	Coding
		0.66= Moderate difficulty 1=Extreme/cannot do
31.	Have you fallen down in the past year?	0=No 0.5=Once 1=Twice or more
Assessment Domain: Health attitudes		
32.	In general, how would you rate your health?	0=Very good 0.25=Good 0.5=Neither good nor poor 0.75=Poor 1=Very poor
33.	Do you consider yourself currently ill?	0=no 1=yes
34.	Do you consider yourself to be living with frailty?	0=no 1=yes
Assessment Domain: Physical performance		
35.	High BP: BP ≥140 mmHg and/or diastolic BP ≥90 mmHg	0=no 1=yes
36.	Mid-upper arm circumference (cm)	0= ≥ 22.0 cm 1= ≤ 21.0 cm
37.	Calf circumference (cm)	0= ≥ 31.0 1= ≤ 30.0 cm

Appendix E Qualitative Research Colleague Reflexive Questionnaire

Research colleague reflexivity and positionality

A key gatekeeper facilitating my access to Amani Residential Home (Amani), was Prosper Regnald (PR). I met PR through a friend who worked for a UK-based NGO and initially made several visits to the residential home with the charity's foreign volunteers. Over these visits, I realised the benefits of including the residents in the study. These older people could provide examples of their exceptional, cases of becoming institutionally cared-for in this setting, and would thus provide a fascinating comparison with older adults' lives in the community.

PR was training as a secondary school geography teacher however prior to starting his studies, he worked as a volunteer co-ordinator with the NGO. As part of this role he was responsible for foreign volunteers on short-term placements, and would visit the residential home with them two or three times per week. Over two years of working with the NGO and visiting the residential home, he had developed close relationships with all the older residents and had gained the trust of the government-employed staff. PR reflected that this professional experience *"brought me close to frail older people, I got to know them well. It changed my way of thinking so much. I learnt how much they need us in their lives. They need a friend who can listen to their problems."* When asked to reflect on what he had learnt through his involvement in the research, PR answered; *"Also it's important for our government to consider special treatment for the elders in the healthcare services like providing insurance to them."* Therefore PR's position toward the research topic was highly aligned with participants' priorities who had raised access to healthcare as a major *"changamoto"* (meaning challenge or appeal) of older people. In reflecting on how the elders at Amani would have related to him, he believed that they were able to talk openly with him *"because they come from the same communities as I did, they were once like me but they grew older, and if their problems are not addressed then I am likely to face the same problems when old"*. Thus PR worked in the roles of gatekeeper, interpreter and interview facilitator and demonstrated high levels of empathy and agreement with the perspectives of the residents.

Two further colleagues were key gatekeepers allowing access to rural communities in Hai District. A retired clinical officer in his seventies, Dr Kissima (JK) had worked clinically in the local district government hospital, and lived in the neighbouring district. He had experience of working in research projects affiliated with Northumbria Healthcare NHS Foundation Trust and Newcastle University since 1992, meaning years of experience working closely with UK-based researchers and students in the district. His roles in the research project included co-ordination with village enumerators, facilitating and interpreting during

FGDs and SSIs. Despite his lack of formal training in qualitative research, his social stature, years of experience and biculturalism made him an indispensable asset to the study. His important role is also likely to continue for future research projects in Hai District.

JK reflected, that although he had experienced the chronic multimorbidity of older people in his clinical work, the topic of frailty was a relatively new concept to him; *"All these complaints were thought due to old age and not much advice was given, other than painkillers and rest, frailty was not given much attention."* However, through the experience of working on the study he became inspired to *"share knowledge"* with other colleagues in order to *"to give more attention to older people with frailty."* He was also aware of his social stature in the communities we visited, saying that he was received by ten-cell leaders and older people with *"very much respect and love, especially when they knew that we are doctors"*. This significant social capital was a necessary factor enabling the research team's access to participants, but may also have been a factor contributing to an unwitting coercion to participate.

Jane Rogathi (JR) has an BSc in Nursing, an MSc in Epidemiology and Applied Biostatistics, and has completed a PhD using qualitative methods investigating gender-based violence and reproductive health. JR's PhD studies took her to Denmark, Vietnam and the UK. She also has many years of experience working on research projects affiliated with the same UK institutions. In this study she assisted with the purposive selection of participants, FGD facilitation, transcribing and translating interview recordings, and participating in reflective discussions on data interpretation. JR is also likely to continue to work with UK-based researchers and students on short-term research projects in the future.

When asked what she had learnt through participating in the research JR responded: *"It is clear that people with frailty are not cared for in their life, some are living in a very bad condition."* When reflecting on how a woman of her standing, education and experience would have been received by older people in the villages JR denied any barriers to trust and communication due to her status saying; *"It was a very nice experience the way "wazee" (elders) received us, they feel that they are respected when we visit them and they feel happy."* These reflections are closely aligned with the theme *"Kutunza wazee in wajibu"*: Taking care of the elderly is a responsibility, revealing reflexively that, as a younger adult, she feels a strong duty of care towards older people. It is necessary to pause here to reflect to what extent would JR and JK be comfortable to critique the research given their ongoing professional relationships and financial stake in the affiliated UK institutions future work.

1. **What in your life experience (both in your personal and professional backgrounds) has influenced your attitudes toward frail older people?**

   PR: Working on the *"wazee"*(elders) project as a coordinator brought me close to frail older people, I got to know them well. It changed my way of thinking so much, I learnt how much they need us in their lives. They need a friend who can listen to their problems.

   JK: In my past work experience, many older people used to come with multiple complaints. All these complaints were thought due to old age, and not much advice was given other than pain killers and rest, frailty was not given much attention.

   JR: I used to see and read a lot about ageing and frailty, and I wanted to see how is it in our situation in Tanzania? Then this pushed me to get an understanding of what is happening to our older people who have frailty.

2. **What have you learnt through your involvement in the research project (which you did not know before) about frailty in Tanzania?**

   PR: The research opened my eyes wide that all over my country there are older people who need assistance only that they have not yet been reached. Also, it is important for our government to consider special treatment for the elders in the healthcare services like providing insurance to them.

   JK: After having seen that most older people are not well cared for in their frailty, and not much is known about frailty, I developed much interest in the topic of frailty so that I can share knowledge with my other colleagues, to give more attention to older people with frailty.

   JR: I wanted to know first if our people have frailty, and how they are taken care of, and does the community understand "frailty"? It is clear that people with frailty are not cared for in their life, some are living in a very bad condition.

3. **In general, how do you think older research participants related to you? (For example with fear, mistrust, or welcoming and with respect?) What factors influenced how they related to you?**

PR: They related to me because they come from the same communities as I did, they were once like me but they grew older and if their problems are not addressed then I am likely to face the same problem when old. Considering having the same government and health services is important.

JK: The reception by the older people and ten-cell leaders was very respectful and with love, especially when they knew that we are doctors and we were there for their healthcare.

JR: It was a very nice experience the way the *"wazee"* received us. They feel that they are respected when we visit them, they feel happy. They are missing people to be with. Many times they are alone with no one to talk to because people are busy with other activities, or even going to live in the towns and they are left alone at home, so when they are visited they feel happy. They were so happy to see us visiting them and talking with them.
Every "Mzee" was treated with respect and confidentiality and we were like sons and daughters to them though I am a health worker. But, they were willing to discuss issues and ask questions if they felt like doing so. There are times when we laugh together and times when we feel sad so they were open and free to talk to me.

Appendix F Topic guides

Original Topic guide

In the UK and other high income countries we use the concept of “frailty” to describe some older people. Here are some examples of people who could be described as living with frailty (read case vignettes):

Katika Uingereza na nchi nyingine zenye kipato tunatumia dhana ya "uhafifu" kuelezea baadhi ya watu wakubwa. Hapa ni baadhi ya mifano ya watu ambao inaweza kuwa kama wanaoishi na uhafifu wa wazee:

Interviews with the residents of Amani Residential Home will start with;

“Please tell me in your own words the story of what happened leading to coming to live here at Amani”?

Tafadhali niambie kwa maneno yako mwenyewe hadithi ya kile kilichotokea na kusababisha kukuja kuishi hapa katika Amani?

“Please tell me about your experiences of living here at Amani”?

Tafadhali nieleze kuhusu uzoefu wako wa kuishi hapa katika Amani?

Prompting and probing questions will be used as appropriate as/when the following topics are raised.

Quality of life/norms of ageing

- In your opinion what is a normal part of ageing, and what is not? Give examples to illustrate your opinion.

Kwa mtazamo wako kawaida umri wa uzee ni upi ambao sio ni upi? Toa mfano kuelezea mtazamo wako.

- What is the role of an older person/elder in the household/community?

Mzee ana wajibu gani katika familia au jamii?

- Do you think older adults can contribute to the family/community? How?

Unafikiri wazee wanaweza kuwa na mchango katika familia/jamii, kwa namna gan/kivipi?

- What do you consider to be a “good life” in old age? Or to older people; What is it that makes you happy in your life?

Wewe unadhani "maisha bora" uzeeni ni yapi? Ni nini kinachofanya uwe na furaha katika maisha yako?

- At what age would you consider someone to be old/elderly?

Ni umri gani unaweza kusema mtu ni mzee?

- How do you feel about becoming old yourself?

Unajisikiaje wewe mwenyewe utakapokuwa mzee?

- Do you usually treat older adults differently? How? Give examples.

Je, huwa unawatendea wazee tofauti? Kwa namna gani? Toa mfano.

Care needs

- Who should be responsible for caring for the elderly?

Je, nani anawajibu wa kuwatunza wazee?

- What do you see as the main challenges or stresses when caring for an older relative?

Unapokuwa unawahudumia wazee shida au changamoto kubwa ni ipi?

- What support is available to care for older people in Hai District/Kilimanjaro region?

Katika kuwahudumia wazee wa Wilaya ya Hai Kilimanjaro msaada gani unapatikana?

- How can you access this support?

Unapataje msaada huu?

- (If relevant) How do you feel about caring for your older relatives?

Unajisikiaje unapokuwa unamhudumia ndugu yako ambaye ni mzee?

- (If relevant) How do you feel about being cared for by your younger family members?

Unajisikiaje mzee anapokuwa anahudumiwa na mwanafamilia mwenye umri mdogo?

Elder safety

- How can you protect an older person's safety?

Unawezaje kutunza usalama wa wazee?

- What do you think when older people are accused of witchcraft? Please give examples if you have experience.

Unafikiri nini wazee wanaposhutumiwa kuwa wachawi? Tafadhali kutoa mifano.

- What would you do if you were concerned an older person was being treated badly or harmed by someone caring for them?

Ungefanya nini kama utashirikishwa mzee anatendewa vibaya au anaumizwa na mtu ambaye anawahudumia?

Death and dying

- How do you feel when an older person in the community dies, compared with a younger person?

Unajisikiaje mzee anapokufa katika jamii ukilinganisha na kijana/mtoto/mtu mwingine ambaye si mzee?

- When, how and where is it good for an older person to die?

Lini, jinsi gani na wapi ni vizuri kwa mzee kufa?

- What normally happens if an elderly person dies at home?

Nini kinatokea mzee anapofia nyumbani?

- What are the procedures for registering a death of an older person in the community?

Utaratibu wa kusajili/andikisha kifo cha mzee ni upi?

Second topic guide

- What are the roles of older adults?
- What do you hope for in your old age? *or* How do you feel about getting older?
- What is it like being and older person in your village today? *or* What are the challenges older people face?
- What in your opinion is frailty in old age? *or* What do you understand by the term "frailty"?
- Do you think that you are frail?
- What are the causes of frailty?
- Are there frail older adults in this village/residential home? Please give examples from your experiences to illustrate.
- What do you think are the priorities for older adults in your village?
- Do you have questions about the study or relating to older people and their health?

Follow-up questions after reading the case vignettes:

How do you see their lives?

Who has the best life and why?

In your opinion are they frail, and why?

What are the differences between the lives of older men and older women?

Appendix G Case Vignettes

Vignette 1

Mrs Jones is 83 years old and lives in London, England. She is a retired bus driver and lives alone in a house with stairs. She has a chronic breathing problem which limits her in her daily activities. Because she has no family living close she is relies on a neighbour to take her out to the community centre once a fortnight. She has care-givers (organised by social services), three times per day who help with preparing meals, washing and dressing. For a while Mrs Jones has been unable to get upstairs so she now has a bed in the living room. She spends her days mainly watching television and often feels lonely. She has lots of medical problems in addition to her chronic breathing problem, including arthritis with chronic back and knee pain, and visual problems. Last year she fell and broke her hip and spent a month in hospital after her operation with a severe chest infection.

Bibi Jones ana umri wa miaka 83 na anaishi London, Uingereza. Yeye ni dereva mstaafu wa basi na anaishi peke yake katika ghorofa. Yeye ana tatizo sugu la pumu kwahio hii mipaka yake katika shughuli zake za kila siku, na kwa sababu yeye hana familia wanaoishi karibu yeye ni hutegemea jirani kumpeleka nje kwa kituo cha jamii mara moja katika wiki mbili. Yeye ana walezi (iliyoandaliwa na huduma za afya), wanaokuja mara tatu kwa siku wanamsaidia na kuandaa milo, kufua na kuvaa. Kwa wakati, Bibi Jones hajaweza kupanda ghorofani, hivyo yeye sasa ana kitanda katika sebleni. Yeye hutumia siku yake hasa kuangalia televisheni na mara nyingi anahisi upweke. Yeye amekuwa na matatizo ya kiafya pamoja na kuongeza tatizo lake sugu kinga, ikiwa ni pamoja na matatizo ya viungo na mgongo na maumivu ya goti. Kwa mfano, mwaka jana alianguka na kuvunja mguu wake na alitumia mwezi katika hospitali baada ya operesheni yake na maambukizi kali kifuani.

Vignette 2

Mr Massawe is 75 years old who lives in Machame, Hai District. He has been a farmer of coffee and banana crops throughout his life. He had a stroke two years ago due to high blood pressure. He lives in a house with his wife and daughter-in-law. They also have a house-girl who is a 10 year old child of a neighbour, to help with their household chores. He needs help with lots of things, for example he can’t eat meat because he finds it difficult chewing and his appetite is poor. Mr Massawe has difficulty walking, but he can walk short distances slowly using a stick and with someone helping him. His memory has been gradually getting worse. He cannot remember the names of all his children and sometimes he seems not to recognise his wife. He likes to sit outside in the shade on warm days, but because he has difficulty hearing he cannot take part in most conversations unless you sit very close and talk loudly and

slowly. Because of these things he is increasingly unable to really take part in ceremonies or church activities in the village anymore.

Mzee Massawe ana umri wa miaka 75 ambaye anaishi Machame, Wilaya ya Hai. Amekuwa mkulima wa kahawa na ndizi katika maisha yake. Alikuwa na kiharusi miaka miwili iliyopita kutokana na shinikizo la damu. Yeye anaishi katika nyumba na mke wake na mkwe wake. Wao pia wana msichana wa nyumba ambaye ni mtoto wa jirani (umri wa miaka 10), kusaidia na kazi zao za nyumbani. Yeye anahitaji msaada kwa kila jambo, kwa mfano hawezi kula nyama kwa sababu yeye anaona ni vigumu kutafuna na anakosa hamu ya kula. Mzee Massawe ana ugumu kutembea, lakini anaweza kutembea umbali mfupi polepole kwa kutumia fimbo na mtu kumsaidia. Kumbukumbu yake imekuwa ikipungua hatua kwa hatua inazidi kuwa mbaya. Yeye hawezi kukumbuka majina ya watoto wake wote na wakati mwingine anaonekana si kutambua mke wake. Yeye anapenda kukaa nje katika kivuli siku za joto, lakini kwa sababu ana shida ya kusikia hawezi kushiriki katika mazungumzo, labda uzungumze karibu naye na kuzungumza kwa sauti kubwa na polepole, kwa sababu ya mambo hayo anazidi kushindwa kwa kweli kuhudhuria katika sherehe au shughuli za kanisa katika kijiji tena.

Appendix H Example annotated transcript

EGL: good afternoon this is the 14th July 2017 this is the second semi-structured interview with an elderly couple, I am EGL.

JR: *Bibi sema jina lako* Grandmother[48], say your name

Bibi Zakia: *Jina langu* my name?

JR: *Eee* Yeah

Bibi Zakia: *Si nilisema jina langu saa hiyo* I said my name that time

JR: *Sasa si unajitaja kwani si unajua mwenyewe jina lako* Now you say it yourself you are the one who knows it

Bibi Zakia: *Sasa nilisema jina hapo nilitaja sasa ninasema mara mbili tena?* But I said it already and now I say it for the second time again?

JR: *Haya, unaitwa Zakia?* Ok, you are called Zakia?

Bibi Zakia: *Si hilo nilitaja* Yes, I already mentioned it (laughing, confused)

JR: *Na babu anaitwa?* And Grandfather you are called?

Babu Shuma: *Mimi naitwa Mzee Shuma bwana* My name is Mr Shuma madam

JR: *Asante Mzee Shuma* Thank you Mr Shuma

EGL: *Tunashukuru* We thank you

JR: My name is JR

[48] JR translated it as Madam, which conveys the respect attached to it in English, but not the literal meaning.

Bibi Zakia: *Baba yangu anaitwa Shuma huyu yaani wanachangia jina na baba yangu aliyonizaa.* My husband is called Shuma, this man has same name as my father who bore me.

JR & EGL: *Asante, sawa* OK, thanks

EGL: OK, so you are both living here together, and who is living with you in the house?

JR: *Sasa mama hapa unaishi wewe na baba tu au una watoto wengine, wajukuu?* So mother you live here with just with this father or do you have other children, grandchildren?

Bibi Zakia: *Ni hawa hapo wajukuu wangu (she pointed to a young girl and little child) nikwambie mama mimi ninakueleza ukweli mimi sio mtu wa kangalakangala*[49]. Those there are my grandchildren (pointing to a young girl and infant), I tell you mama I speak the truth, I am not a person of lies.

JR: *Ndio* Yes

Babu Shuma: *Unaona hii familia iko nyumbani hapa sio hii tu wengine wako makazini, wengine wakokwa wapi, wengine wako kwa mabwana, mimi nina wajukuu ishirini na mbili.* You see this family is here at home but they are not the only ones, others are at work, others are with their husbands, I have twenty two grandchildren.

JR: *Ahaa una wajukuu ishirini na mbili ahaa sawa!* Oh you have twenty two grandchildren, I see!

Babu Shuma: *Halafu kwa vitukuu, nina vitukuu kumi na mbili, vitukuu vilivyozaliwa na wajukuu zangu.* And regarding great grandchildren, I have twelve great-grandchildren, children born of my grandchildren.

JR: *Ahaa, sawa hongera sana baba kwakweli.* Oh, I see, congratulations father, for sure.

EGL: *Hongera, una watoto wengi!* Congratulations, you have many children!

[49] Repeated word for emphasis, it is an informal word. She's saying she is a reliable trust-worthy person.

Bibi Zakia: *Na wajukuu* And grandchildren

EGL: Are there any of their children who live in the village anymore?

JR: *Watoto wenu wanaishi nyumbani kwao kwenye miji yao?* Are your children living in their homes in their towns?

Babu Shuma: *Eee, wanaishi kwenye miji yao na kuoa wote wanaoa hakuna watoto wangu ambae hajaoa.* Yeah, they live in their towns and all are married, there are none of my children who aren't married.

JR: *Wote wameoa na kuolewa*[50]*?* All are married?

Both Babu Shuma & Bibi Zakia: *Eee!* Eee! Yeah!

Babu Shuma: *Mpaka vijukuu vimeoa na wana watoto wao.* Even the grandchildren are married and have their children.

JR: Ahaa, Ok Ah, OK

Bibi Zakia: *Mpaka watoto wangu wana wajukuu, watoto wangu nazaa mie wana wajukuu wengine wanasoma shule.* Even my children have grandchildren, my children, I bore myself[51], have grandchildren some are studying in school.

JR: She is saying yes, they are not living with them, they are living in the village.

EGL: Who is supporting them, who is looking after them are there any grown up children who is live in the village close by?

[50] This verb is different for each gender. Men marry or take a wife "kuoa", while women are married "kuolewa". That is marriage is a passive action for women and active for men. They are talking about the marriage of their children as a success, but also to convey that they are fully grown and have their own responsibilities.
[51] In the UK we would not have to make that distinction between my children and my children that I gave birth to! I guess this comes from the use of family and personal pronouns for everyone.

JR: *Na labda kuna mtoto ama kuna mjukuu yeyote anaishi ambaye anaishi karibu na nyinyi ambae anawasaidiasaidia*[52]*?* And is there any child or grandchild at all who is living nearby, living close to you, to help and help you both?

Bibi Zakia: *Wapo watoto wetu.* Our children are there.

Babu Shuma: *Wapo vitukuu hivi mnavyoviona lakini baba zao wako hapa wengine wako sido, wengine wapo hapahapa.* There are these great grandchildren who you are seeing, but their fathers are here, others are in another village, others are right here.

JR: *Ahaa, wako wapi? Hapahapa kijijini ama wako mikoani?* OK where are they? Here in the village or in other regions?

Babu Shuma: *Wewe huoni lile banda lile pale lina watoto wengine wamekuja likizo wanapumzika pumzika tu, hapa hatuna watoto wengi wajukuu wapo lakini hawapo hapa kwangu wako hapahapa jirani, wanasoma shule mpaka sasa wako shuleni.* Don't you see that in that shelter over there, there are other children who have come to rest, just resting is all, here we don't have many children, there are grandchildren here but they don't stay here at my place they are at my neighbour's place, they are studying up to now, they are at school.

JR: *Ahaa!* Ahaa!

Bibi Zakia: *Ahaa! Nimeshachelewa kwenda kusali, wanaadhini sasa.* Ok! I am already late to go to pray, they are calling to prayer now.

JR: *Mama umesema unataka uende kusali?* Mother, you said you want to go to pray?

Bibi Zakia: *Nimeshachelewa mpaka niende nioge nivae.* I am already late, until now I have to go and take a shower and get dressed.

JR: *Basi tusikucheleweshe kama unataka kwenda sawa tuishie hapa.* Then we shouldn't make you late if you want to go let's end here.

[52] Repeated words are used to exaggerate the word's meaning, or describe doing something in small amounts repeatedly.

Bibi Zakia: *Hapana ongeeni tu.* No just speak.

Babu Shuma: *Unasemaje eti?* What are you saying?

Bibi Zakia: *Nilisema nilitaka kwenda kusali lakini nimechelewa adhana inaadhiniwa nikasema basi.* I said I wanted to go to pray but I am late its already the call to prayer, so I said fine then.

Babu Shuma: *Utakwenda ijumaa linguine*. You will go next Friday.

JR: *Ee! Mtusamehe hatukujua kama mnaenda kusali maana tumevuruga*[53] *utaratibu ila tunashukuru kwa kutuvumilia.* Ee! Forgive us we didn't know you were going to pray, which means we have messed up your timetable, but we thank you for your patience.
Babu Shuma: *Yani ukiwa na shida Mwenyezi Mungu nae anajua kuna shida maana yeye ndie anayajua matatizo yako.* When you have a problem Almighty God knows there is problem and its meaning because he is the one who knows your problems.

EGL: *Tunashukuru,* We thank you. So I want to ask about their life, what activities are they doing? *Kawaida,* (normally) from when they are waking up, what do they do normally, *labda chai*? (maybe they have breakfast?)[54]

JR: *Na katika maisha yenu labda hapa yale maisha ya kawaida mnafanya nini? Labda katika maisha yenu kiamka mnafanya nini?* And in your daily lives, your usual life what do you both do, maybe when you wake up, in your lives? When you wake up what do you both do?

Bibi Zakia: *Tunatafutatafuta chakula hamna tunaishi hivyo hivyo ukiondoka ona tunaishi hivyohivyo, ndio hivyo.* We search and search[55], there is no food, we live like that, when you leave you see we live like that, yeah that's it.

[53] Vuruga= verb meaning to stir up, to excite, to exasperate or to mess up.
[54] Revealing the extent to which I take food for granted, it is always the start of my day, but for Bibi Zakia and Babu Shuma each meal is uncertain, every day the only routine is uncertainty.
[55] JR's original translation says "We do some work" but the verb "tafuta" means to look for, to search or to find out. Essentially working is the same as searching for food. By this meaning. The fact that it is a repeated verb means that they either search a lot, or struggle repeatedly to search for food.

JR: *Kwahiyo sasa kwenye chakula na vitu vingine ukiamka asubuhi unafanya nini, mchana unafanya nini na jioni unafanya nini?* So about food and other stuff, when you wake up what do you do, in the afternoon what do you do and in the evening what do you do?

Bibi Zakia: *Hivyohivyo ukipata, Mungu anasaidia hivyohivyo, kidogo.* It's just like that, if you get (something) God is helping like that, a little.

JR: *Kwahiyo asubuhi?* So in the morning?

Bibi Zakia: *Ndo hivyohivyo tunatafuta ukipata kidogo, majirani wakusaidie.* Just like that we search, if you get a little, the neighbours they help you.

JR: *Mh!* Mh!

JR: *Asubuhi?* In the morning?

Bibi Zakia: *Asubuhi hivyohivyo tu anasaidia ukipata kidogo, na majirani wakisaidia.* In the morning, just like that, they help you to get a little, and the neighbours help.

JR: *Ndio mh! Sawa* Yes mh! OK

Bibi Zakia: *Kitu mbaya kuiba*[56]. Stealing is a bad thing.

Bibi Zakia & Babu Shuma: They started talking together, we did not understand

JR: *Naomba tuongee mmoja mmoja.* I beg you to talk one at a time.

Bibi Zakia: *Mpe mzee aseme.* Give it to him to speak
Bibi Zakia: Talking in her own language Nyiramba

JR: *Mnaongea Kinyiramba tena! Tuongee Kiswahili.* You are both speaking Nyiramba again! Let's speak Swahili

[56] This reference to stealing suggests that the couple have been tempted to steal food, due to their desperation. The switch to their local language may have been to try to conceal this desperation, or because of a personal conflict between them on this issue.

Bibi Zakia: *Anasema amelima shamba, shamba lenyewe limekauka na jua, akienda pahala anapewa mtaji anapewa hivyo hivyo.* He said he has cultivated the farm and the farm has dried up with the sun, if he goes to the village he gets some money just like that.

JR: *Sawa nilikuwa namtafsiria huyu mwenzangu kwa kuwa hafahamu Kiswahili.* Ok I was translating for my friend because she doesn't know Swahili.

Bibi Zakia: *Eee* Yeah

Babu Shuma: *Unaona jinsi ninavyokueleza kuna matatizo hapo nyuma ukipita hivi nyumba yangu imebomoka*[57] *hapa mbele hapa nyumba imebomoka, kupata msaada mpaka nyumba yangu iinuliwe hamna.* You see the kind of thing I am telling you, we have problems here if you go there behind my house it's collapsed and here in front it's collapsed, until I get help, let my house be broken, there's none.

JR: *Lakini baba umesema una watoto?* But father you said you have children[58]?

Bibi Zakia: *Watoto nao wana shida hivyohivyo.* Children also have problems like this[59].

Babu Shuma: *Watoto nao wana shughuli zao*[60] *wengine wako Kenya huko ni karibu, mpaka upige la mgambo ni lini huko*[61]. The children they have their own business, others are in Kenya there its close, until you rush is when you go there.

JR: Na hawajawahi kuja kukutembelea hapa? And haven't they come to visit?

Babu Shuma: *Walikuja kunitembelea miaka nenda rudi na njaa kama hii.* They came to visit me in a year long ago, in (a time of) hunger[62] like this.

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[57] Bomoka = (v) to collapse, to demolish Here I don't think they have actively demolished their house, rather it is falling down due to disrepair and lack of maintenance.

[58] The implication being that children are the safety net and will help to address problems such as this.

[59] In keeping with the material constraints discourse, but it is easier for older people to believe that their children want to support them, but are unable, rather than believe that it is due to wilful neglect.

[60] Their work, job, business or activity

[61] Meaning, it doesn't take long to get there if you go directly

[62] Rather than "rainy" and "dry" seasons, when there is a poor harvest or a significant period of drought, people refer to "hungry" seasons and "times of plenty".

JR: *Hawajaja kukupa chochote?* Haven't they come to give you anything?

Babu Shuma: *Hakuna, Mmmh toka Uhuru Kenyata ni rais hawajawahi kufika hapa.* Nothing, mmmh since when Uhuru Kenyetta was president they haven't ever come here[63].

EGL: How does it make him feel?
JR: *Na sasa babu unajisikiaje sasa kwa hali hizi ambazo sio nzuri unazosema unajisikiaje wewe?* And now father, how do you feel about these situations that are not good that you told us about, how do you feel?

Babu Shuma: *Mimi nikwambie ukweli mama, huu mwili huu niliobeba huu hauna matatizo, matatizo ni hii miguu hii, kutembea siwezi na mgongo unasikia na hapa kipande hiki hapa (showing on the ribs). Nataka nipate risiki kidogo nipate chakula ili niweze kunisaidia bila hivyo mwili unalegea, sio nina homa aaa, mwili unalegea kabisa na kwa kongoro kongoro, hata nikitaka kuondoka mpaka nikamate kibambaza ama nikamate, ukiona hivi mpaka kwahiyo mimi natafuta hata nani anipe hata kachai ninywe nakosa niko na shida mama niko ndani ya shida, ndio shida yangu.* Let me tell you the truth mother, this body here that I have carried doesn't have problems. My problems are these legs here, to walk, I cannot, and my back you can feel and here to the side (showing his ribs). I want to get a little sustenance, to get food so as to help me otherwise without, this the body is getting weak, it's not that I have fever, my body is becoming completely weakened, like a donkey, a donkey. If I want to go get up I have to cling to the staff. I look for anyone to give me even some tea to drink, but I don't get any, I have problems mother we are in difficulty, yes that's my problem.

JR: *Pole* Sorry

Babu Shuma: *Ila makazi sio mabaya, makazi ni mazuri kaika kijiji cha mtakuja hakina upepe pepe sana, hakuna umbea lakini sio umbea wa kupeleleza peleleza[64] majumba ya watu ni ubea wa hapo nyubani kwako basi anapepeza ananyamaza, sio ule wa kutembeleana a umbea hapana, hamna huo kukaa hakuna matatizo, matatizo Mungu akitaka anakuchukua tu basi unazikwa basi umekwisha.* But the residents are not bad, the residents are nice here in this

[63] He was elected president in Kenya in 2013. This was not dwelt on, perhaps because it highlighted their discomfort at being largely abandoned by their large family.

[64] To investigate or to spy on

village there is not much gossip of spying on people's houses, the gossip of messengers, its only gossip of their own homes that's it, they spy and stay quiet, not that of visiting each other to gossip, no, staying here there are no problems. There's the problem of if God wants to take you, you are buried and finished that's it.

EGL: Does he think he has frailty?

JR: *Babu unafikiri una udhaifu wa mwili?* Grandfather, do you have frailty of the body?

Babu Shuma: *Naam?* Yes?

JR: *Unafikiri mwili wako umedhoofu*. Do you think your body is becoming weakened?

Babu Shuma: *Mama, mimi nilikuwa mzima*[65]. Mother, I was once healthy.

JR: *Unafikiri mwili udhoofu sana labda?* Do you think your body is becoming very weak maybe?

Babu Shuma: *Mwili unaanza kuchoka mama, hasa makanyagio*[66] *yanauma haya, hizi nyama hizi zinauma hizi (showing the ribs) sio zinauma kwa kuvuta hivi zinachoka.* The body is starting to tire mother, especially these heels are painful, these muscles are painful (showing his ribs) they are not hurt but because I am pulling them, they are tired.

JR: *Zimechoka?* They are tired?

Babu Shuma: *Zimechoka, sio kama kwa kuvuta hivi kuna kitu kinauma ndani hapana, zimechoka yani zimelegealegea*[67]*, uko kama mtoto unatamani utambae, mwili unakuwa hauna nguvu sana.* They are tired not because of pulling them something it's hurting inside, they are tiring that's it they are weakening, you become like a child you wish to crawl, the body hasn't got much strength.

EGL: Ohoo! aa I see, *Umepunguza uzito?* You have decreased weight?

[65] Healthy or whole
[66] More literally "These where I tread"
[67] The verb "-legea" means to be faint, to be weak, to relax, to be loose, but I think in this context weakening is closer to the intended meaning than loosening.

Bibi Zakia: *Wengine wanacheka sio kuumwa ni wanachoka, saa ingine unakutakiza au kuchoka kabisa, mwili unachoka kulegea huwezi kuondoka yaani utumie nini mpaka hii urudi kuchoka, unatumia nini? chakula au matunda gani? (wakati mwingine hakuna viungo vya vyakula)*. Others are laughing it is not getting sick, it is being tired, at times you become completely tired, the body becomes tired and weakened and you can't leave (the house), that's it. What can you use to get rid of this tiredness, what can you use? Which food or fruits? (Sometimes there is no food of the season.)

Babu Shuma: *Tumepigwa picha ya uzeeni inaitwa sijui nini hii?* We have had our old-age photos taken there, I don't know what it's called?[68]

EGL: My question was is he losing weight?

JR: *Unafikiri mzee unapungua uzito kwa sasa unaona uzito unapungua?* Do you think you are losing weight, now has your weight reduced?

Babu Shuma: *Ukienda pale hospitali nikiwa sijaugua nilikuwa na uzito wa kilo 52, 52 lakini sasa bado nilivyougua sijaweza kwenda hospitali kwahiyo hujui kama unapungua ama?* I went to hospital before I got sick I weighed 52kg, 52 but after I got sick I haven't gone to hospital so I don't know if I have reduced or not?

Babu Shuma: *Sijitambui sasa*. I have not discovered it now.

JR: *Wewe unavyojiona umepungua?* In your opinion are you losing weight?
Babu Shuma: *Eee, naona jinsi kwamba nimepungua kwa sababu mwendo*[69] *wangu wenyewe sio ule nilikuwa natembea zamani.* Eee, I think I have lost weight because even my pace is not how I walked in the past.

Babu Shuma: *Sasa mimi nataka ninyi wataalamu mnisaidieni! Ile kujisaidia saidia kila saa yaani haja ndogo.* Now I want you professionals to help me! Every hour I go for short calls[70].

[68] Referring to registering for proof of age ID in order to access the exemption from healthcare costs.
[69] JR's original translation used the word "gait" but the dictionary translation is speed, movement, distance or journey. I think pace fits well in this intended meaning, his walking has slowed down.

[70] "I frequently go" is JR's translation, but he says literally every hour I need to go to the toilet.

EGL: Probably the condition is a common problem in old age, the problem may be that the prostate is enlarging and is causing urinary frequency especially at night, it can disturb sleep. But at the hospital they have a urology department, maybe we can advise that he goes there?

Babu Shuma: *Sawa, sasa nikinywa uji nakojoa sana lakini nikinywa chai sikojoi, nikinywa nikizidisha yananipa mtatizo lakinini kama nikinywa maji kawaida tu hayanipi matatizo, sasa wewe kama mganga nini sina tatizo la choo kubwa sana naenda kama kawaida, hii kukojoakojoa*[71] *saa si kwamba inauma kama kaswende hapana, mkojo nakojoa kawaida tu.* Ok, if I take porridge I urinate a lot but if I take tea I don't urinate. If I drink too much water it's a problem but if I drink just a normal amount okay, there's no problem. Now you are like healers, I don't have problems with defecating, I go as usual to the toilet, but this urinating urinating all the time, it's painful like syphilis, no I don't urinate normally.

JR: *Ndio maana nimekwambia linaweza likawa tatizo dogo tu linaweza kuangaliwa pale hospitali kuna mtu wa kitengo cha mambo hayo.* Yes that's why I told you it could be a simple problem, you can be seen at (the regional hospital) where there are people dealing with such problems.

EGL: Can we ask *bibi* (grandmother) the same question, does she have frailty?

Babu Shuma: *Tatizo la macho, macho hayaoni nilipimwa macho.* I have an eye problem, the eyes don't see, my eyes were tested.

Bibi Zakia: *Wanakuja na gari wanasema macho ameshakwisha kuharibika.* They came with a car, they said the eyes are already completely destroyed.

JR: *Sawa ni watu wa (the regional) hospital wanakuja kumuona sasa naomba nikuulize bibi wewe unavyojiona hali yako uko sawa? Uko vizuri, wewe hali za kuchoka, kudhoofu unafikiri unazipata?* Okay, they were people from (the regional) hospital, coming to see him. Now, may I ask you grandmother do you think you are fine? Are you good, do you have feelings of tiredness, weakness do think you get them?

[71] JR translated this as "this frequent urination" but actually I think to repeat the word sounds less medical and is closer to what Babu Shuma said.

Bibi Zakia: *Ee, hivyohivyo kuchoka lakini natoka naenda kutafuta tafuta namletea mzee, sasa kama tukichoka wote tukikaa tutafanya nini sasa?!* Yeah, it's just like that, I tire but I go out to search and search and bring (something) to him (her husband), if we all get tired and we all stay sitting what will we do now?!

JR: *Kwahiyo wewe unatoka kutafutatafuta?* So you go out searching, searching[72]?

Bibi Zakia*: Natoka kutafuta, naenda kwa majirani, sasa tukikaa wote na hata mimi hivyohivyo tu, hii mifupa na miguu na kidogo… Napata nakula na mume wangu.* I go searching, I go to the neighbours, if we all sit and me too just like that, these bones and legs a little bit… If I get (food) and eat with my husband.

EGL: Next is how do the neighbours help? Are they coming here to help with practical tasks or are they sometimes giving money or food, how do they help?

JR: *Na mfano majirani mama, majirani wanakuja kukusaidia hapa nyumbani au mpaka uwafate huko uongee nao au wanakuja na kukusaidia na shughuli za nyumbani hapa?* And for example neighbours do they come to help you here at home or you have to follow them and talk to them or do they come and help you with home activities, here at home?

Babu Shuma: *Hapa (in this village), majirani hapa mkutane tu njiani "habari za asubuhi?" "nzuri" basi.* Here in this village, neighbours, you meet them on the way and you greet each other "good morning, how are you?" "Good" that's all.

JR: *Kwahiyo hawaji hapa?* So they don't come here?

Babu Shuma: *Hawaji hapa wala, lakini panapo matatizo tunajumuika wote kama kuna kilio, kama kuna harusi au kama kuna nini….. tunajumuika wote[73], lakini kukaa eti kama hivi tunaongea hiyo hapana kabisa yani ni kupunguza umbea kama unaelewa hapo.* They don't come here, but if there are problems we all gather like at a funeral, wedding or something…

[72] Searching in this context seems as though they are referring to begging, or asking for food/money. But has also been used to refer to looking for short-term informal work. Essentially, to search is to look for a way of surviving and subsisting.

[73] -Jumuika is the verb to be united, or to assemble, in this context he means the latter I think.

everyone assembles, but sitting like this talking like this no, not at all it is reducing gossip if you understand.

EGL: Ooh!! So they do not have visitors, their children are far away, they are not living with them, some are in Kenya. The ones who are close by they don't help and their neighbours don't visit them? *Hamna watu.* Nobody?

Bibi Zakia: *Hamna, labda watoto tu wapate huko waseme tusaidie wazazi lakini la kutembeleana hamna.* No, maybe if the children get (something) and they say let us help our parents but visiting you, no.

EGL: So do they feel isolated from the community or lonely?

JR: *Unafikiri labda mnakuta jamii labda inawatenga*[74] *labda mnajisikia upweke?* Do you think maybe the society is isolating you and maybe do you feel lonely?

Bibi Zakia: *Hawaji kutuma msaada, yupo huyu Imamu wetu Sheikh, basi kama upo msaada kidogo anamletea mzee, kuna hawa watu wanataka wewe uwafate wanatumia pombe, sasa pombe sisi hatutumii tunatumia tu chai sasa ndio wanataka muwatembelee make hivi mnakula pombe, ndio uongo sasa lakini sisi hatutaki.* They don't come to help, there is our Imam Sheikh, then if there is a little help[75] he brings it for him (her husband), there are these people who want to be followed, they use alcohol, but we don't use alcohol we just take tea, they want you to visit them because you will drink alcohol, that's a lie but we don't like it.

Babu Shuma: *Mama nakueleza hivi hapa katika mji wa Mzee Shuma hawanywi pombe, kitu adui kabisa ni pombe, sasa nakula chai, nakula soda basi, pombe yoyote bia sijui nini aaaaa, huko sisi hatupo wewe nipe soda ninywe nipe chai ninywe nipe ugali nile basi.* Mother let me tell you here in the town of Mzee Shuma they don't drink alcohol, it is a complete enemy, alcohol, now I take tea, I drink soda that's it, any alcohol, beer or I don't know what, we don't take it, give me soda I'll drink, tea, I'll drink, give me ugali I'll eat.

[74] Society separates from you, isolates you, ostracize you?
[75] I think they are talking euphemistically about donations of money or food

JR: *Mmh! unafikiri ndio sababu hawakutembelei kwasababi wanaona haunywi, hukai nao kunywa yale mapombe.* Mmh! Do you think that's why they don't visit because you don't drink, you don't stay to drink alcohol.

Bibi Zakia: *Uongo sasa, ili na wewe uchukue uongo wao na sisi hatutaki umbea.* A lie now, so that you also take their lies and we don't want bad talk.

Babu Shuma: *Wewe ukienda kwenye mapombe unatafuta maneno ya umbea sasa na sisi hatupendi maneno ya umbea umbea, ni hapa nyumbani tunaongea kama ni kelele tutapigiana hapa nyumbani na watoto wangu. Mfano fulani amekuja hapa amesema hivi na hivi, kesho ofisini, keshokutwa unapelekwa Bomang'ombe hii yote kuhangaika.* If you go to drink alcoholic drinks you are looking for words of gossip and now we don't like words of gossiping gossiping, we talk here at home, if it's noise we will make it here, it's with our children. For example, someone came here and said this and this, tomorrow in the office, the day after you are taken to the nearby town, all this you suffer.

EGL: So then the last question I want to ask is about the things they value in their life, the thing that gives them satisfaction that gives them value in their life?

JR: *Sasa kuna, katika maisha ya kila siku kila binadamu anakuwa anakitu ambacho anakipenda akikosa anasononeka unafikiri vitu unavipenda lakini huvipati?* In life every human being has something they like that when they miss it they suffer[76], do you think there is something you like but you don't have?

Bibi Zakia: *Ni kweli zaidi zaidi huyu kama hana macho anakaa hvyo si inakuwa kama huyu mwanamke ana kitu kizuri anakula nini, ananinyima kumbe tunakula hicho hicho tu, kwahiyo wewe unakuwa unajisikia vibaya. Sasa nimezoes, sasa mwenzangu huyu atasema nini nakula vitu vizuri kwahiyo nini sili, ni hicho cha chumvi tunakula tunalala sasa nini nakwazikwa.* It's true especially this one as he doesn't have his eyes, he thinks "this woman has something good that she's eating she is not giving it to me", but we are actually eating the same thing, so I feel very bad. I am used to it, but my husband what will he say? "What, is she eating good things?!" so it's the same food with salt, we both eat and we sleep but now it is not known.

[76] -Sononeka the verb means to grieve or suffer, JR translated it as "feel depressed"

Babu Shuma: *Mimi najisikia wa kukosa hela kwasababu kama nina hela mama ananiletea kasukari kidogo ananitengenezea chai nakunywa basi, halafu ninakaa tu ananipa chakula nakula.* I feel I am missing money because if I have money my wife brings me some sugar and she prepares tea then I drink, afterwards I just sit and she brings food and I eat.

JR: *Kwahiyo wewe unaona kama unakosa?* So do you see as though you are missing it?

Babu Shuma: *Kwahiyo hivyo vitu vyote roho yangu inapata mengi sana sana.* So all those things my heart gets really such a lot.

JR: *Unafikiri labda kitu gani wewe ungependa kuwa nacho ungejisikia tu vizuri ungekuwa unaishi vizuri? Kitugani wewe unapenda uwe nacho lakini unashindwa?* What do you think if you had you would be living well? What do you wish you had which would give you a good life, but you are lacking?

Babu Shuma: *Napenda niwe na chakula, kama nina chakula unajua ile chakula inaweza kunisukuma kunipunguzia matatizo kwasababu hata kuangalia hivi mitamwambia mama achukue kitu fulani akatembeze auze, anunue kitu fulani ulete tule, ndio maisha ya mwanadamu sasa hivi uniambie nitafute maisha ya kwenda kufanya kazi nitaweza wapi? Kama huyu huyu ukamuangalia hivi unafikiri ataweza kufanya kazi, usimuone hivi kwasababu anaongea ongea hapa ana mtoto wake ambaye ana umri wa miaka 58! Sasa yeye ana miaka mingapi?! Si amesogea*[77]. I wish to have food, if I have food you know that food it can boost[78] me, reducing my problems because as you see this I tell my wife to take something and she walks with it to sell it, and she buys something for food, yes the life of a human being right now. Like this you ask me to wipe out life and go to work, where can I? If you look at her you think she can work because she is talking talking. But don't see it like this because she talks a lot but she has a child who is 58 years old! So now how old do think she is?! No she has approached.

JR: *Sana* (a lot)

[77] She has approached is the literal translation, while JR translated it as "she has aged" so thus she has approached the end of life, approached old age…
[78] The literal translation is "to push" but in context, boost makes most sense. He is talking about how his lack of food leaves him without energy, which is leading to his frailty.

Babu Shuma: *Unaangalia jinsi tunavyokwenda?* Do you see how we are proceeding?
EGL: How do they feel to receive donations from the mosque, how do they feel that they have to rely on the kindness of the mosque.

JR: *Hamna shida* no problem we are finishing. *Sasa kama utakuwa umepata kamsaada kidogo kutoka pale msikitini labda Sheikh amekuja kukupa, amekuja tu kukuletea kamsaada kidogo, unafikiri kwamba unajisikiaje?* Now, if you get some small donation from the mosque, perhaps the Sheikh brings it, he comes to give it to you, he comes just to give you a small donation, when you think about that, how do you feel?

Babu Shuma: *Msaada?* A donation?

JR: *Ndio amekuja kukuletea kamsaada kidogo kutoka msikitini unajisikiaje?* Yes he has come to bring you some small donation from the mosque, how would you feel?

Babu Shuma: *Kama tunapata msaada tunashukuu Alhamdulillah! kwasababu huo msaada utakupunguzia mawazo mabaya, huo msaada utakuondolea tamaa, kutamani kitu ambacho huwezi kukipata, utaangalia kama sasa hivi mimi hapa nikiaka ninywe chai hiyo pale dukani kalete sukari hata ile sukari mtoto akileta tukinywa si ile roho inatulia utakuwa una tamaa tena saa hiyo inaweza kuwa kesho au keshokutwa au utataka nyama huwezi kununua*. If we are getting a donation we thank Alhamdulillah! Because that donation will reduce the bad thoughts, that donation will get rid of desire[79], being desire for what you can't have, you will see like now if I want to drink tea I send a child to bring sugar from the shop and my heart will be calm[80] no You will get a desire again that time, it can come tomorrow or the day after tomorrow, you will want meat but won't be able to buy it.

Bibi Zakia: *Pombe ni Shetani pombe ni Shetani utakuta una galagala hivi, unakula mapombe si haki unakula tu kitu cha maana tu ndani unatulia.* Alcohol is Satan, alcohol is Satan, you might be there rolling like that, drinking alcohol it's not right, you should eat something reasonable inside and be quiet.

[79] Tamaa means hope, ambition, desire and greed. I think JR's translation of "envy" doesn't quite fit this context.

[80] Tulia verb to be quiet or to be calm or to relax. JR translated it as at peace

Babu Shuma: *Hata kwenye radio wanasema ule mboga za majani zitakupatia nguvu hata sisi huku maporini tunatumia mboga za majani kwasababu yale majani yananipa nguvua saa ingine hayana mafuta si unaweka hapa unashukuru Mungu unasema Alhamdulillah, jioni tena unaweka, yanakujenga ule mwili, kama ulikua una vitamin C unapata vitamin, mwili wako unjisikia ukifanya hivi unajisikia sio ile unajisikia haoma aa!! kidogo kidogo tu.* Even on the radio they say eat vegetables and herbs, those are the things which give you strength, even us here in the bushland, we use vegetables and herbs because they give me strength. At times they don't have oil you serve it and thank God saying Alhamdulillah, in the evening you serve it again, it builds up your body, if you didn't have vitamin C you get vitamins, your body would feel that, you won't feel a fever aa! Just a little bit.

Bibi Zakia: *Mafuta hata ukienda hospitali unaambiwa usitumie mafuta sana au uongo*[81] *mama, usituwe sana tumia kwa kiasi, ndio anasema mboga za majani tunatumia sana.* Cooking oil, even in the hospital we were told not to use a lot of oil or is it a lie mother? Don't use a lot use it moderately, yes that's why he is saying we use mostly vegetables.

Babu Shuma: *Ila mama njaa?* But mother you have hunger?

Bibi Zakia doesn't respond

EGL: *Asanteni nashukuru*. Thank you all.

Jane: *Bibi huwa mnatibiwa bure kwenye Zahanati.* Grandmother is treated for free at the dispensary?

Bibi Zakia: *Ndio tunacheti wamepeleka Dar es Salaam, yani cheti cha wazee cha kuaguliwa tunakwenda hapo tunapata dawa na huduma hicyohivyo lakini sasa hapa bado mtaji hamna.* Yes we have a certificate they have taken to Dar es Salaam, the elders certificate is expected, we can go and there get medications and service, but until now there's no capital.

Jane: *Kwahiyo huduma za hospitali mnazipewa?* So you get hospital services?

Bibi Zakia: *Tunaenda hospitali tunapata dawa.* We go to hospital and get medications.

[81] Uongo= noun False/a lie

Jane: *Bila kununua wapewa bure?* Without buying, you get it for free?

Bibi Zakia: *Ndio wazee au uongo?* Yes the elders or is it a lie?

Jane: *Ni kweli.* It's true.

Babu Shuma: *Ukiwa hapa kwetu utapewa ukienda (district hospital) utapewa si unakitambulisho mana yeye amepata nini bado sijapata sasa wanasema wao wenyewe wataleta sijui nini na nini, ila maana yeye amepewa nini bado, lakini mama baada ya kupewa ameambiwa picha yake iko huku labda atakuja kubadilishiwa ila bado sisi tunamatatizo kidogo lakini uganga uganga huu ukikosa hapa unapelekwa (the district hospital).*If you are here you will get it, if you go to (district hospital) you will be given it because you can make yourself known (using your identification papers), she has already got hers but not me yet, they said they will bring it but after she got hers she was told her picture is still here, so they will change it but not yet we have some small problems, but if the health services are missing here we are taken[82] to (the district hospital).

EGL: *Tutamaliza tunashukuru sana.* We are done we thank you very much.

[82] Passive tense, accessing healthcare is something which is done "for" or "on behalf of" your older relative, as a form of care giving activity.

Appendix I Initial themes coded in English

Name	Sources	References	Modified On
Expectations of ageing	3	24	29/04/2017 10:30
Life histories of institutionalised older residents	1	3	29/04/2017 10:36
Needs	3	20	29/04/2017 10:32
Quality of life for institutionalised older adults	4	18	29/04/2017 10:39
Resisting frailty through lifestyle choices	1	4	28/04/2017 08:27
Respect for elders	1	11	28/04/2017 08:28
Roles of older adults	1	10	28/04/2017 08:28
Roles of the younger generation and society	2	10	29/04/2017 10:37
Safety and security	2	9	28/04/2017 08:57
Understanding of frailty	1	1	29/04/2017 10:32

Appendix J Ethical certificates and letters of approval

Faculty of Medical Sciences
Newcastle University
The Medical School
Framlington Place
Newcastle upon Tyne
NE2 4HH United Kingdom

Dr Emma Grace Lewis
Institute of Health & Society

FACULTY OF MEDICAL SCIENCES: ETHICS COMMITTEE

Dear Emma,

Title: Frailty in Rural Sub-Saharan Africa, a Mixed Methods Study
Application No: 01229/10058/2016
Start date to end date: 03/01/2017 to 31/12/2019

On behalf of the Faculty of Medical Sciences Ethics Committee, I am writing to confirm that the ethical aspects of your proposal have been considered and your study has been given ethical approval.

The approval is limited to this project: **01229/10058/2016**. If you wish for a further approval to extend this project, please submit a re-application to the FMS Ethics Committee and this will be considered.

During the course of your research project you may find it necessary to revise your protocol. Substantial changes in methodology, or changes that impact on the interface between the researcher and the participants must be considered by the FMS Ethics Committee, prior to implementation.*

At the close of your research project, please report any adverse events that have occurred and the actions that were taken to the FMS Ethics Committee.*

Best wishes,

Yours sincerely

Kimberley Sutherland
On behalf of Faculty Ethics Committee

cc.
Professor Daniel Nettle, Chair of FMS Ethics Committee
Ms Lois Neal, Assistant Registrar (Research Strategy)

*Please refer to the latest guidance available on the internal Newcastle web-site.

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2013

THE UNITED REPUBLIC OF TANZANIA

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Development Gender, Elderly & Children
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NIMR/HQ/R.8a/Vol. IX/2403

01st February 2017

Dr Emma Grace Lewis
Northumbria Healthcare NHS Foundation Trust
Tyneside General Hospital, North Shields, UK
C/O Dr Sarah Urasa,
Consultant Neurologist, KCMC
P O Box 3010 MOSHI,
Kilimanjaro

CLEARANCE CERTIFICATE FOR CONDUCTING MEDICAL RESEARCH IN TANZANIA

This is to certify that the research entitled: Hai Aging and Frailty Study: The Validation of a Verbal Autopsy Tool and Development and Validation of a Frailty Screening Tool for Older Adults in Tanzania, Hai District (Lewis E G *et al)*, whose Local Investigator is Dr Sarah Urasa, Consultant Neurologist, KCMC, Moshi, has been granted ethical clearance to be conducted in Tanzania.

The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is submitted to the Ministry of Health, Community Development, Gender, Elderly & Children and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health, Community Development, Gender, Elderly & Children and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine. NIMR Act No. 23 of 1979, PART III Section 10(2).
5. Site: Hospital sites: KCMC Moshi, Mawenzi Regional Hospital, Machame Lutheran Hospital, Hai District Hospital, Boma Ng'ombe in Hai, Kilimanjaro Region

Approval is for one year: 01st February 2017 to 31st January 2018.

Name: Prof. Yunus Daud Mgaya

Signature
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Prof. Muhammad Bakari Kambi

Signature
CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, COMMUNITY DEVELOPMENT, GENDER, ELDERLY &CHILDREN

CC: **RMO Kilimanjaro**
DMO/ DED Hai

TUMAINI UNIVERSITY MAKUMIRA

KILIMANJARO CHRISTIAN MEDICAL UNIVERSITY COLLEGE
P. O. Box 2240, MOSHI, Tanzania

RESEARCH ETHICAL CLEARANCE CERTIFICATE

No. 998

Research Proposal No. 890

Study Title: Validation of a Verbal Autopsy Tool and Development and Validation of Frailty screening Tool for Older Adults in Tanzania, Hai District

Study Area: Hai District

P. I Name: Dr. Sarah Urasa

Institution (s): Kilimanjaro Christian Medical Centre

The Proposal was approved on: 31st October, 2016

Duration of Study: one year

From: 31st October, 2016 **to** 31st October, 2017

.....

Rose Mwangi

Ag. Secretary – CRERC

Prof. Mramba Nyindo

Chairman – CRERC

THE UNITED REPUBLIC OF TANZANIA

National Institute for Medical Research
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NIMR/HQ/R.8c/Vol. II /907

20th December 2017

Dr. Emma Grace Lewis
Northumbria Healthcare NHS Foundation Trust
C/O Dr Sarah Urasa, Consultant Neurologist,
KCMC, Moshi
P.O. Box 3010
MOSHI, Kilimanjaro

RE: APPROVAL FOR EXTENSION OF ETHICAL CLEARANCE

This letter is to confirm that your application for extension on the already approved proposal, Hai Aging and Frailty Study: The Validation of a Verbal Autopsy Tool and Development of a Frailty Screening Tool for Older Adults in Tanzania (Lewis E G *et al*), whose Local Investigator is Dr Sarah Urasa, Consultant Neurologist, KCMC, Moshi, has been approved.

The extension approval is based on the progress report dated 16th August 2017 on the project with Ref. NIMR/HQ/R.8a/Vol. IX/2403 dated 01st February 2017. Extension approval is valid until 31st January 2019.

The Principal Investigator must ensure that other conditions of approval remain as per ethical clearance letter. The PI should ensure that progress and final reports are submitted in a timely manner.

Name: Prof. Yunus Daud Mgaya

Signature
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Prof. Muhammad Bakari Kambi

Signature
CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, COMMUNITY DEVELOPMENT, GENDER, ELDERLY & CHILDREN

CRERC FORM 07

TUMAINI UNIVERSITY

KILIMANJARO CHRISTIAN MEDICAL COLLEGE
P. O. Box 2240, MOSHI, Tanzania

RESEARCH ETHICAL CLEARANCE CERTIFICATE

No.998

Research Proposal No. 890

Study Title: Validation of a verbal autopsy tool and development and validation of frailty screening tool for older adults in Tanzania,Hai District

Study Area: Hai District

P. I Name: Dr.Sarah Urasa

Co**Institution (s):** Kilimanjaro Christian Medical Centre

The Proposal was approved by CRERC on: 31st October,2016

Duration of Study: One year

From: 31st October,2017 to 31st October,2018

Name: BEATRICE Z. TEMBA

Secretary – CRERC

Name : PROF.MRAMBA NYINDO

Chairman – CRERC

Appendix K Dissemination Evaluation Summary Report

Summary

Background: Patient and public involvement has been defined by the National Institute of Health Research UK, as "an active partnership between patients and the public and researchers in the research process". It is gaining increased interest as a means of improving research relevance, quality and impact.

Aim: To involve patients and the public in dissemination activities, and in evaluating the impact of the study. This summary report details the local and regional dissemination activities, including those which involved volunteer community members.

Methods: Three distinct groups were targeted with dissemination activities; the medical and academic community, health managers and finally, participants and the public. Study findings were disseminated through seminars and via purpose-designed information leaflets and posters, which were distributed by volunteers. Evaluation was carried out through anonymised feedback forms at each seminar, except for the last feedback meeting where minutes were kept.

Results: The majority of professionals felt that the topic of frailty was important and should be included in training. Most also felt that further research on the topic of older people's health was necessary. Positive impacts of the study as a whole included the dissemination of health information to participants and older people. Potential negative impacts were that some older people felt discriminated against due to not being visited equally, and the creation of an expectation of gifts in return for participation.

Older people generally welcomed the dissemination of data in the form of purpose-designed information leaflets, however requested that more tangible benefits of services and resources be offered.

Discussion: Volunteers, participants and the public were successfully involved in data dissemination activities. However, there is scope for much more involvement, earlier and throughout the research cycle, in order to maximise the research impact. As a result of the feed-forward consultation work conducted here the relevance and impact of future research in the district may be improved.

Kilimanjaro Christian Medical Centre, Grand round lecture

17th October 2018

Attended by 58 people, with feedback forms collected by 56 people (96.6%).

Of those who attended, their roles included one manager (1.8%), 25 doctors (44.6%), one nurse (1.8%), ten allied health professionals (AHP) (17.9%), eight students (14.3%) and eight clinical officers (14.3%) (and three (5.4%) unanswered).

- Teaching and training on frailty

Twenty-one (37.5%) said that they had received previous teaching on frailty, and the majority, 53 (94.6%) thought that frailty should be included in their training.

Education on frailty *"will increase knowledge and passion for geriatrics"* said one doctor, and *"will improve healthcare to this vulnerable group"*, according to another doctor. One manager also stated, *"that their problems are generally unrecognised, overlooked and considered part of normal ageing"*.

- Clinical experience of frailty

Forty-five, (80.4%) of the audience agreed that frailty was a problem they encountered in their work. Said one doctor, *"[the] majority of older people are neglected by their family. No food for them in their homes. Some not being taken to healthcare institutions when they are sick. Others are dumped in hospital to be taken care of by the health workers"*.

Another doctor stated they encounter *"a lot [of older people] in general medicine but with no specific problems"*. A nurse reported that *"Old people face many problems with loneliness and they are left behind in care and treatment"*.

- Future clinical practice

Most, 44 (78.6%) agreed that the presentation had improved their knowledge on the topic of frailty. When asked how their clinical practice would change, many responded saying they were now more aware of the topic and the multiple issues the older population encounter.

One doctor responded that *"special attention is needed when attending older patients, and to prioritise them"*. One doctor stated that the talk stimulated *"Knowing about the B-FIT and learning more about its use"*. One AHP stated *"I will consider screening older people for pain and hypertension"*.

- Further Research on Frailty and Older Peoples' Health

Fifty (89.3%) felt more research should be conducted on older peoples' health, while two disagreed, three were unsure, (one did not answer).

Suggested further research topics included management of non-communicable diseases (NCDs), improving quality of life for older people, investigating access to healthcare, and researching falls and nutrition in older people.

One doctor suggested; *"The feasibility of community-based interventions for the ICOPE objectives in resource limited settings"* would be a good topic for further research. Another doctor commented: *"I'm not convinced that more research is needed but more training to enforce the interventions or improve the appreciation of frailty."*

District Health Management Team meeting

18th October 2018

Feedback forms were completed for all 18 participants of the session. Their roles included five managers (27.8%), five doctors (27.8%), one nurse (5.6%), six AHP (33.3%) and one clinical officer (5.6%).

- Teaching and training on frailty

The majority had received no prior teaching on frailty (14 people, 77.8%), but most, (13 people 72.2%) felt it should be included in their professional training, while four left the question unanswered.

"Most of our clients in hospitals and health facilities are older people. Knowing about frailty will make it easier for us to treat them properly" said one doctor. According to another AHP *"Frailty is one of the problems that is overlooked. The population in Tanzania is ageing and our elders are increasing".*

- Clinical experience of frailty

Fourteen (77.8%) agreed that frailty was a problem for the population they look after. Common themes included poor access to health services, poor health education, chronic pain

and neglect by families. One doctor shared their experience of caring for frail older people, stating; *"they are brought to the health facility very late, very unwell and sometimes they don't have the money"*.

- Future clinical practice

All respondents felt that the talk had improved their knowledge on the subject matter with the majority stating it was relevant and would directly impact their daily work. This nurse summarised, *"I know many problems facing elders. In my working station I will plan on how to overcome these problems which I have learnt [about] through this presentation"*.

A manager stated "*this has shown me which areas to concentrate more on (planning and budgeting)."* Of note, one AHP claimed *"I will now concentrate on older people… because I never knew that older people have nutritional problems"*.

- Further Research on Frailty and Older Peoples' Health

The majority 16 (88.9%) thought more research was needed with common research priorities identified including nutrition, access to healthcare e.g. home-based treatment and health insurance, management of NCDs and lifestyle risk factors.

One doctor summarised thus: *"Most of them suffer from social problems and poverty. Research needs to find a way to solve their problems."*

Village Health Committee Members Meeting

23rd October 2018

Twenty-three people from the five studied villages attended this meeting and feedback was completed by 22 people. Their roles included 16 (72.7%) members of Village Health Committees (VHC), three dispensary workers (three left this section unanswered).

Dr John Kissima (JK) led the delivery of a presentation, lasting around one hour and giving an overview of the study. Afterwards we recruited volunteers to take part in data dissemination to participants and community members.

- Impact on future work

All respondents agreed that the presentation had improved their knowledge.

When asked if this if this would impact on their work, the majority referenced how the new knowledge they had gained would improve their ability to prioritise, advise, and help older people with health-related problems.

One VHC member responded that the meeting had helped them; *"to know more about the challenges that the elderly face in terms of health, family, and being able to take close care of them"*. Another dispensary worker replied *"This is part of my work and I am happy to add knowledge to my profession"*.

- Experiences of the health issues of older people

We asked attendees to comment on their experiences of the health issues of older people. In the words of one VHC member, their experience was that *"many need health insurance in order to get treatment and many live a lonely life and need help"*. A dispensary worker described their role being *"to provide to them health services including checking their blood pressure"*.

- Involvement in research

A minority of seven people (31.8%) stated that they had felt involved in the research, while 14 people (63.6%) did not. It's possible that those VHC members who felt involved, had worked in the role of village enumerators and had worked closely with the researchers to enrol participants.

- Further Research on Frailty and Older Peoples' Health

Seventeen respondents (77.3%) thought more research was needed. According to one VHC member the financial situation of older people should be the topic of future research, *"The economic wellbeing of the elderly, to be able to support their physical and mental health since most of them are frail due to poor economic conditions."* One dispensary worker was interested in *"the effects of alcoholism on the health of the elderly"* as a future research topic.

Dissemination feedback meeting with volunteer Village Health Committee members

1st November 2018

Fourteen from 15 volunteering members of VHCs attended the feedback meeting from the five studied villages. Feedback notebooks were returned by all 15 of the dissemination team. As a group they reached 640 people in total, taking an average of seven days to carry out the work, and speaking to an average of 42 older people each.

JK led the feedback meeting, encouraging the volunteers to speak freely, emphasising that we wanted to hear both positive and negative feedback, and inviting suggestions of how to involve them more in future research projects. Below, the feedback (as documented in the meeting minutes) are summarised by question or discussion topic.

- Practical issues in carrying out dissemination to study participants

There were issues with access, for example heavy rain during the nine days of data dissemination impacted on the number of people volunteers could visit. A few older people were not at home and had to be located around the village which posed another challenge.

There were also communication issues. Some volunteers were interrupted during their explanations of the information leaflet, and others faced language barriers, requiring a literate translator (fluent in Kiswahili and the local language of the elder) to be found. In the context of a lack of primary healthcare, understandably some elders requested further visits from doctors, or asked for equipment (e.g. wheelchairs). Occasionally, this became a barrier to discussing the information leaflet. Some older people refused to engage with the volunteers, due to previous negative interactions with healthcare professionals. Another practical issue

was the expectation of gifts (e.g. sugar or paracetamol) when they were visited by the VHC volunteers, as these were given during data collection interviews.

- What do you think were the positive impacts of the study as a whole (not just the dissemination work)? Taking into account your involvement in the study, and from the feedback you heard.

Many of the VHC members emphasised that the leaflets used appropriate language and images and gave useful and relevant information, and that the elders they visited were grateful for having been included. Another positive impact of the study as a whole was thought to be an increased awareness of hypertension diagnoses, and more people going for health assessments. One member recounted that elders felt encouraged to move around the house more and to eat meals with their neighbours as a result of recommendations in the information leaflet.

- What do you think were the negative impacts of the study?

One committee member recounted a lady feeling discriminated against as she was not visited as often as others. This suggests that the concept of randomisation was not well understood by participants, and perhaps also by VHC members. Another potentially harmful impact was the production of an expectation of receiving gifts (such as sugar or paracetamol) for participation in future studies, despite these gifts being well-received by participants and not felt to be coercive.

- What could we change or do better in the future?

Perhaps due to a lack of good quality primary healthcare in Hai District, there were requests for more health benefits for the community. VHC members and older people were satisfied with the leaflets and posters according to feedback, but some requested more specific advice regarding nutrition. Overall the volunteers were encouraged and pleased to be involved in this way and felt enabled to continue to spread this information within their villages. One VHC member intended to distribute leaflets at village meetings to those who were care-givers for older people.

- General feedback

In general, VHC members emphasised that inclusion was an important value to older people they spoke to. Volunteers also took the opportunity to highlight the priority needs of older people, which they felt was important to convey to us, as researchers. These were needs for;

- Health insurance
- Walking aids, wheelchairs, glasses

- Treatments for medical problems
- Transport or community-based care as they lived too far from healthcare providers
- Financial support such as the Tanzanian Social Action Fund (TASAF)
- Nursing homes for those without relatives who are lonely or "at risk of dying from lack of care"
- Better nutrition

An issue which was discussed at length was gaining exemption from healthcare payments and ensuring this was honoured. In summary, volunteers asked that future research bring about tangible benefits to older people in their communities, and urged us to act on the problems encountered.

Feedback from participants

23rd October to 31st October 2018

Each of the 15 VHC members were given a notebook and pen to document the comments and questions of the older people they spoke to. Anonymised comments/questions were gathered from 640 respondents from across the five villages after the volunteers had read and explained the information leaflet to them. Responses were given to five suggested questions, but no demographic or identifying details were collected.

- Do you think this education leaflet is useful?

Almost all responded positively to this question, n=639 (99.8%).

Many respondents specifically commented that it was important, 110 (17.1%). Others stated that they had learnt a lot through discussing the leaflet with the volunteer (1.4%):"*This education is very important as it makes me think differently"*.

- Does it highlight the health problems you face?

The great majority, n=636 (99.4%) agreed that the leaflet discussed health issues that were relevant to them: *"This brochure is a list of health conditions that affect our age"*

Twelve respondents agreed (1.9%), but added that they had additional challenges not mentioned in the leaflet: *"There are challenges especially being lonely and not getting help from my children"* and another; *"there are challenges like eating a single meal per day"*.

- Have you felt involved in the research project that came to your village?

This question was met with a variable interpretation, mostly, "involvement" seemed to be understood as enrolment to participate in the study. For example responding *"I was involved*

through screening". In total, 362 (56.6%) answered positively and 275 (43%) negatively, with two (0.3%) unsure.

- How could we involve you more?

Volunteers reported that respondents found this question difficult to answer, and there was variable interpretation. In general, given that "involvement" was understood as being enrolled to participate in a study, people gave comments such as: *"When doctors come to the village is when I get involved"*.

Another common interpretation was "involvement" as co-operation or sharing. As a result older people responded by asking to be visited more frequently at home 135 (21.1%), by receiving more health education 101 (15.8%) or healthcare services 37 (5.7%). *"We should be involved by being visited and given advice on how to live so, that we don't lack strength"*.

Other comments suggested that older people were ready to be more actively involved, for example: *"By having a special elders meeting at every village"* or *"By educating others in the community"*.

- Any other comments?

Generally, this opportunity to comment or ask a question was met with requests. Respondents felt overall, that research projects should be assisting them in practical ways, that benefits should be tangible, and should help to address their many and sometimes urgent needs at a village community level.

A third of respondents, 192 (30%) requested health insurance, or to be provided with healthcare as part of future research: *"To be given health insurance together with training on how to live"*. Many asked for health education, 167 (26.1%): *"We need treatment and education from researchers"*.

Others raised issues to do with access to healthcare: *"To be given transportation so we can reach the health centre easily"*. Many, 210 (32.8%) requested improved quality of healthcare and treatment: *"To improve health facilities to get better care"*.

Notably, one respondent commented; *"we ask for any kind of* (financial) *help, because we don't have any means to get food with high protein"*. Highlighting the difficulty of making recommendations to those without the means to act on those recommendations. Two respondents suggested income-generating schemes such as poultry keeping would be helpful.

Discussion

The dissemination sessions targeted three different groups; academic and medical, managerial and also participants and the public and methods were adapted accordingly.

Dissemination of results to patients and the public has rarely been attempted in rural Africa, and is a challenging undertaking in this setting. We were innovative in our approach, by employing enthusiastic community volunteers to disseminate the study findings through purpose-designed information leaflets. These volunteer VHC members showed immense dedication and successfully disseminated the main findings of the study, reaching 640 older people and their families over just nine days, while also gaining their feedback, on the study in general.

The practical challenges included reaching participants' rural locations, which during the short rains made travelling more difficult. Around half of older adults in Hai District have some difficulty, or are unable to read; either due to low levels of formal education or visual problems. Therefore, usual methods of data dissemination employed in high income settings, for example through websites, email and documents, would not be appropriate. Our methods of dissemination relied on recognised and respected community members who had volunteered for the task, visiting older people in person, sitting with them and discussing the content of the leaflets. In this manner, we enabled VHC members to fulfil their roles as advocates for the health of their communities.

The Grand Round Lecture provided the largest audience and a forum to update professionals at a regional teaching hospital on the issues surrounding frailty and ageing. From the feedback, the majority understood the importance and relevance of the study and notably 94% felt that the topic of frailty should be included in their professional training.

The DHMT meeting allowed the study results to be relayed to those with an influence on healthcare provision to the cohort; the DHMT are responsible for setting budgets and organising district level health services. The session aimed to introduce the topic of frailty, alongside relevant preliminary local prevalence data. During this seminar, a draft of both the leaflet and posters were reviewed, and changes were suggested and implemented. Upon reflection however, this was a missed opportunity to gain feedback from participants and the public on these resources while under-development. The practicalities of how to involve patients and the public in a consultatory manner such as this, has not yet been explored.

The final sessions aimed at disseminating study results to participants and the public through volunteer VHC members. The seminar with VHC members aimed to provide them with an

understanding of the study's findings, so that they would feel able to discuss them with older people in their communities. Purpose-designed resources (leaflets and posters) were given to the VHC members for distribution.

The majority of VHC members reported in their anonymous feedback that they did not feel involved in the study. Yet, following the seminar they demonstrated exceptional eagerness and an ability to represent their communities as advocates for their health. This suggests that future research could benefit from involving this group earlier, and throughout the research cycle, to maximise research impact, and to ensure better communication between researchers and study participants. Should volunteer VHC members be involved through PPI at the study design stage, research methods, such as randomisation procedures could be better communicated to study participants.

Overall, there was an enthusiasm across all groups for further research, with common topics of interest being nutrition, and NCDs management. Feedback from VHC members, participants and the public was that future research should bring more direct benefit to participants and their communities. This suggests that future research projects should balance investigation with intervention, so as to avoid the situation encountered here, for example giving nutritional recommendations to those without the means to implement the advice.

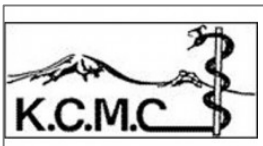
Feedback suggested there was a difficulty interpreting what researchers might mean by "involvement" in a research study. This is likely to be due to previous experiences of health research, which has been limited to enrolment as research participants. This is the first time that a research team in Hai District has involved lay volunteers, such as VHC members in data dissemination and a feed-forward consultation process. The success of this endeavour has shown that there is much more potential for PPI to maximise the quality and impact of future work.

Key Points

- Dissemination is a key part of the research cycle, for maximising impact, yet it is often neglected.
- This is the first time dissemination to key stakeholders (such as the DHMT, VHC members, older people) alongside feed-forward consultation has been conducted in Hai District.
- The topic of frailty in old age was widely felt to be relevant and important according to feedback.

- The concept of “involvement” in research among older people and study participants is in keeping with their previous experience of health research, where they have been involved only in the data collection stage, as research participants.
- The engagement shown by volunteer VHC members in dissemination activities demonstrates that PPI can be successfully carried out despite the many challenges.
- The feed-forward consultation, on the positive and negative impacts of this research project could help future research to maximise its research impact.

Feedback form used for the KCMC and DHMT meetings



NHS Northumbria Healthcare NHS Foundation Trust

Newcastle University

Ageing and Frailty in Hai District

Feedback Questions

Please Tick:

Manager	Doctor	Nurse	Allied Health Professional	Student	Other		Grade/Job title

	Yes	No	Unsure
Have you learnt about frailty before?			
Should this topic be included in your training?			
Why?			
Is frailty a problem for the population you look after?			
What is your experience of the health issues older people face?			
Has this presentation improved your knowledge about frailty and the care of older people?			
How will it change your work?			
Should frailty and older peoples' health receive more research?			
What do you think should be the priorities for research in older people's health?			

Asante sana!

English Village Health Committee Members Feedback Form

NHS Northumbria Healthcare NHS Foundation Trust

Newcastle University

Ageing and frailty in the Hai District

Feedback Questions

Please Tick:

Dispensary staff	Village Health committee

	Yes	No	Unsure
Has this presentation improved your knowledge about older people's health?			
How will this information change your work?			
What is your experience of the health issues for older people?			
Have you felt involved in the research carried out in Hai?			
How could your involvement in the research have been improved? Please suggest ways in which we could improve your involvement in research in Hai in the future:			
Should older people's health receive more research?			
What do you think are the priorities of research in older people's health?			

Asante sana!

Swahili Village Health Committee Members Feedback Form

Uzee na udhaifu wa wazee wilayani Hai

Maoni na maswali

Tafadhalii weka alama ya tiki:

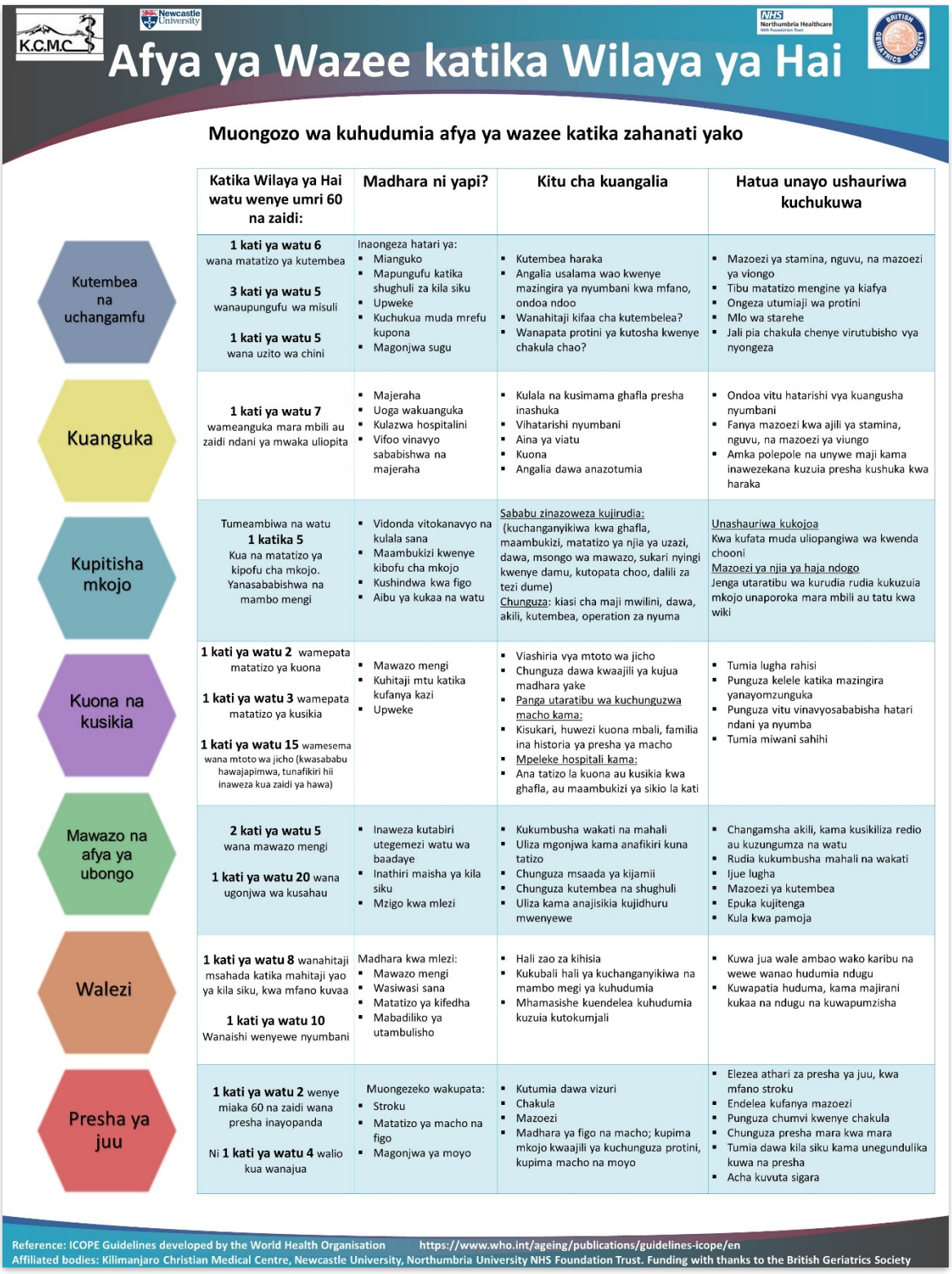
Uongozi wa zahanati	Mjumbe wa kamati ya afya ya kijiji

	Ndio	Hapana	Sifahamu
Je mafunzo haya yameongeza elimu yako kuhusu afya ya wazee?			
Ni jinsi gani hizi taarifa zinaweza kubadilisha kazi zako?			
Ni uzoefu gani ulionao katika maswala ya afya ya wazee?			
Unahisi ulishawahi kuhusishwa katika utafiti wa aina hii uliofanyika Hai?			
Ni kwa jinsi gani uwepo wako kwenye huu utafiti umeimarika? Tafadhali toa maoni yako jinsi tunaweza kuongeza uwepo wako katika utafiti siku zijazo:			
Je afya kwa wazee inahitaji utafiti zaidi?			
Kitu gani unafikiri kipewe kipaumbele katika utafiti wa afya ya wazee?			

Swahili Waiting Room Poster

English Waiting room poster

Swahili Dispensary Poster



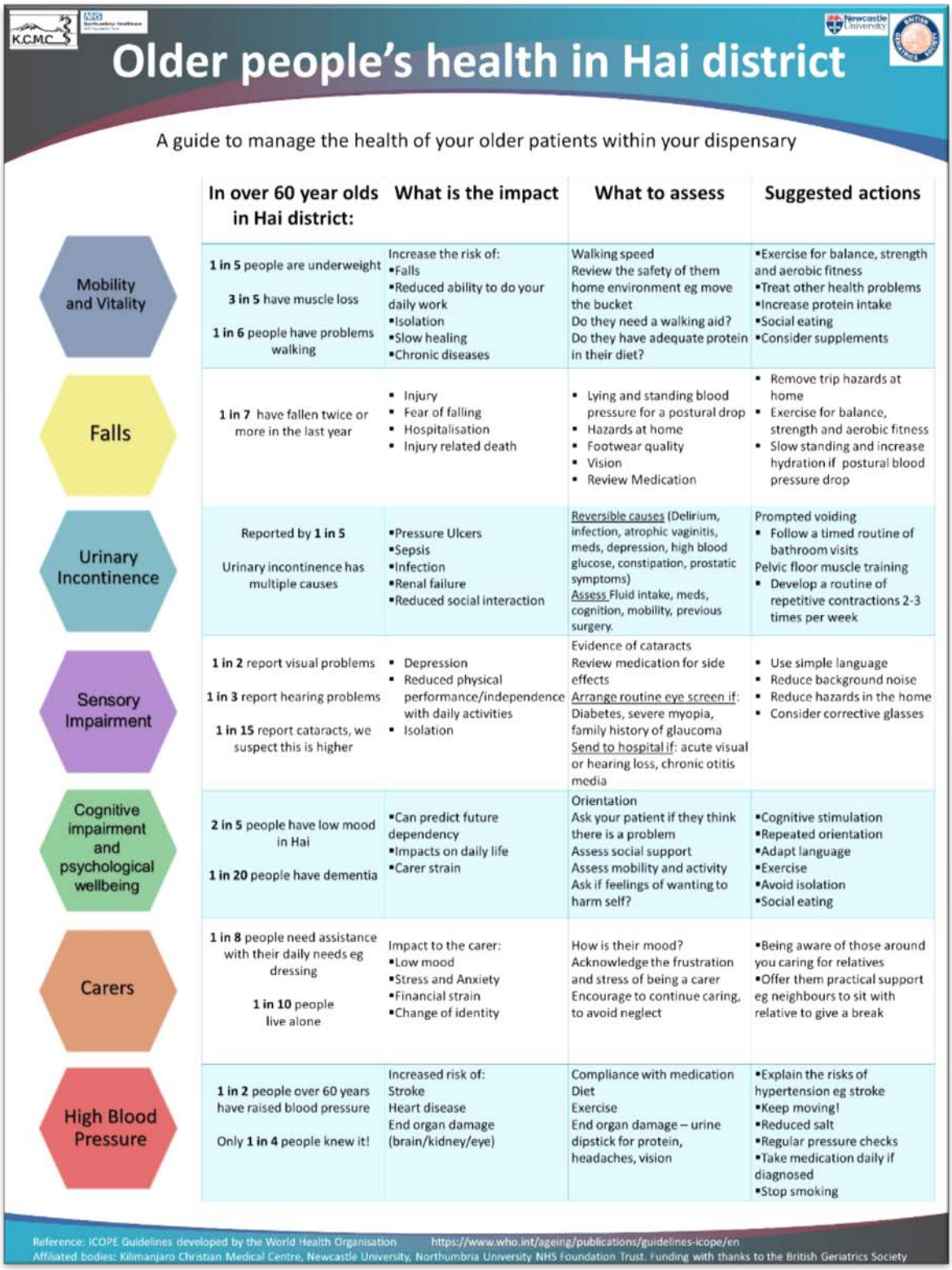
Afya ya Wazee katika Wilaya ya Hai

Muongozo wa kuhudumia afya ya wazee katika zahanati yako

	Katika Wilaya ya Hai watu wenye umri 60 na zaidi:	Madhara ni yapi?	Kitu cha kuangalia	Hatua unayo ushauriwa kuchukuwa
Kutembea na uchangamfu	**1 kati ya watu 6** wana matatizo ya kutembea **3 kati ya watu 5** wanaupungufu wa misuli **1 kati ya watu 5** wana uzito wa chini	Inaongeza hatari ya: ▪ Mianguko ▪ Mapungufu katika shughuli za kila siku ▪ Upweke ▪ Kuchukua muda mrefu kupona ▪ Magonjwa sugu	▪ Kutembea haraka ▪ Angalia usalama wao kwenye mazingira ya nyumbani kwa mfano, ondoa ndoo ▪ Wanahitaji kifaa cha kutembelea? ▪ Wanapata protini ya kutosha kwenye chakula chao?	▪ Mazoezi ya stamina, nguvu, na mazoezi ya viongo ▪ Tibu matatizo mengine ya kiafya ▪ Ongeza utumiaji wa protini ▪ Mlo wa starehe ▪ Jali pia chakula chenye virutubisho vya nyongeza
Kuanguka	**1 kati ya watu 7** wameanguka mara mbili au zaidi ndani ya mwaka uliopita	▪ Majeraha ▪ Uoga wakuanguka ▪ Kulazwa hospitalini ▪ Vifoo vinavyo sababishwa na majeraha	▪ Kulala na kusimama ghafla presha inashuka ▪ Vihatarishi nyumbani ▪ Aina ya viatu ▪ Kuona ▪ Angalia dawa anazotumia	▪ Ondoa vitu hatarishi vya kuangusha nyumbani ▪ Fanya mazoezi kwa ajili ya stamina, nguvu, na mazoezi ya viungo ▪ Amka polepole na unywe maji kama inawezekana kuzuia presha kushuka kwa haraka
Kupitisha mkojo	Tumeambiwa na watu **1 katika 5** Kua na matatizo ya kipofu cha mkojo. Yanasababishwa na mambo mengi	▪ Vidonda vitokanavyo na kulala sana ▪ Maambukizi kwenye kibofu cha mkojo ▪ Kushindwa kwa figo ▪ Aibu ya kukaa na watu	Sababu zinazoweza kujirudia: (kuchanganyikiwa kwa ghafla, maambukizi, matatizo ya njia ya uzazi, dawa, msongo wa mawazo, sukari nyingi kwenye damu, kutopata choo, dalili za tezi dume) Chunguza: kiasi cha maji mwilini, dawa, akili, kutembea, operation za nyuma	Unashauriwa kukojoa Kwa kufata muda uliopangiwa wa kwenda chooni Mazoezi ya njia ya haja ndogo Jenga utaratibu wa kurudia rudia kukuzuia mkojo unaporoka mara mbili au tatu kwa wiki
Kuona na kusikia	**1 kati ya watu 2** wamepata matatizo ya kuona **1 kati ya watu 3** wamepata matatizo ya kusikia **1 kati ya watu 15** wamesema wana mtoto wa jicho (kwasababu hawajapimwa, tunafikiri hii inaweza kua zaidi ya hawa)	▪ Mawazo mengi ▪ Kuhitaji mtu katika kufanya kazi ▪ Upweke	▪ Viashiria vya mtoto wa jicho ▪ Chunguza dawa kwaajili ya kujua madhara yake ▪ Panga utaratibu wa kuchunguzwa macho kama: ▪ Kisukari, huwezi kuona mbali, familia ina historia ya presha ya macho ▪ Mpeleke hospitali kama: ▪ Ana tatizo la kuona au kusikia kwa ghafla, au maambukizi ya sikio la kati	▪ Tumia lugha rahisi ▪ Punguza kelele katika mazingira yanayomzunguka ▪ Punguza vitu vinavyosababisha hatari ndani ya nyumba ▪ Tumia miwani sahihi
Mawazo na afya ya ubongo	**2 kati ya watu 5** wana mawazo mengi **1 kati ya watu 20** wana ugonjwa wa kusahau	▪ Inaweza kutabiri utegemezi watu wa baadaye ▪ Inathiri maisha ya kila siku ▪ Mzigo kwa mlezi	▪ Kukumbusha wakati na mahali ▪ Uliza mgonjwa kama anafikiri kuna tatizo ▪ Chunguza msaada ya kijamii ▪ Chunguza kutembea na shughuli ▪ Uliza kama anajisikia kujidhuru mwenyewe	▪ Changamsha akili, kama kusikiliza redio au kuzungumza na watu ▪ Rudia kukumbusha mahali na wakati ▪ Ijue lugha ▪ Mazoezi ya kutembea ▪ Epuka kujitenga ▪ Kula kwa pamoja
Walezi	**1 kati ya watu 8** wanahitaji msahada katika mahitaji yao ya kila siku, kwa mfano kuvaa **1 kati ya watu 10** Wanaishi wenyewe nyumbani	Madhara kwa mlezi: ▪ Mawazo mengi ▪ Wasiwasi sana ▪ Matatizo ya kifedha ▪ Mabadiliko ya utambulisho	▪ Hali zao za kihisia ▪ Kukubali hali ya kuchanganyikiwa na mambo megi ya kuhudumia ▪ Mhamasishe kuendelea kuhudumia kuzuia kutokumjali	▪ Kuwa jua wale ambao wako karibu na wewe wanao hudumia ndugu ▪ Kuwapatia huduma, kama majirani kukaa na ndugu na kuwapumzisha
Presha ya juu	**1 kati ya watu 2** wenye miaka 60 na zaidi wana presha inayopanda Ni **1 kati ya watu 4** walio kua wanajua	Muongezeko wakupata: ▪ Stroku ▪ Matatizo ya macho na figo ▪ Magonjwa ya moyo	▪ Kutumia dawa vizuri ▪ Chakula ▪ Mazoezi ▪ Madhara ya figo na macho; kupima mkojo kwaajili ya kuchunguza protini, kupima macho na moyo	▪ Elezea athari za presha ya juu, kwa mfano stroku ▪ Endelea kufanya mazoezi ▪ Punguza chumvi kwenye chakula ▪ Chunguza presha mara kwa mara ▪ Tumia dawa kila siku kama unegundulika kuwa na presha ▪ Acha kuvuta sigara

Reference: ICOPE Guidelines developed by the World Health Organisation https://www.who.int/ageing/publications/guidelines-icope/en
Affiliated bodies: Kilimanjaro Christian Medical Centre, Newcastle University, Northumbria University NHS Foundation Trust. Funding with thanks to the British Geriatrics Society

English Dispensary poster



Older people's health in Hai district

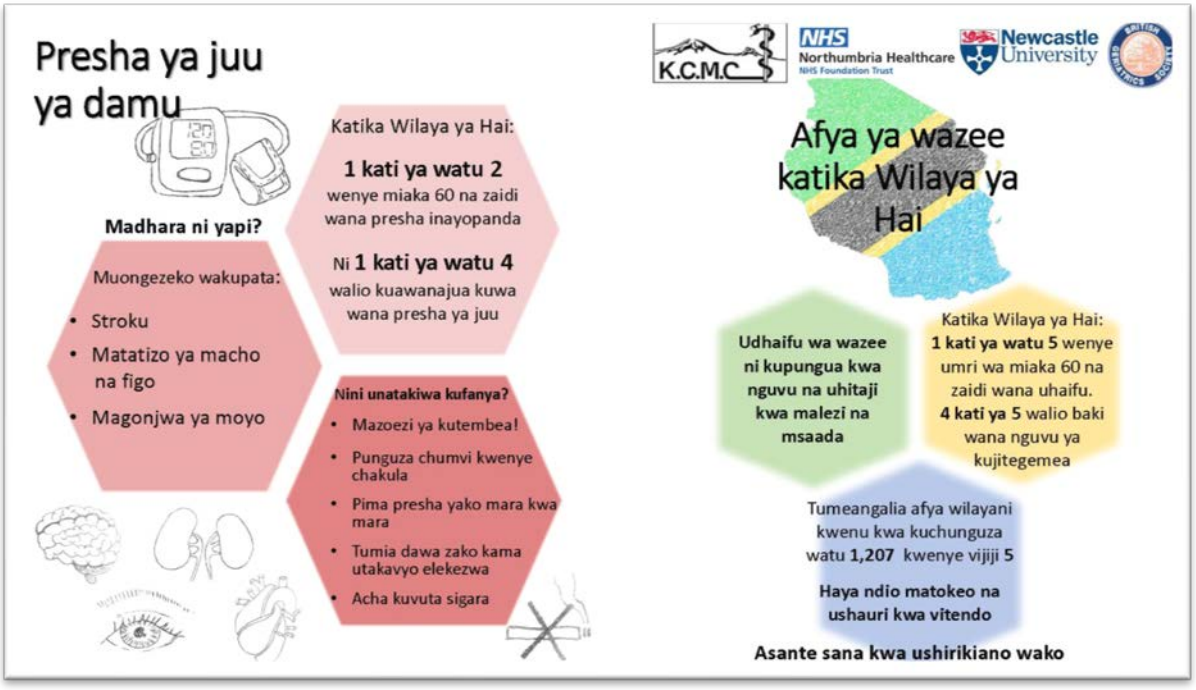
A guide to manage the health of your older patients within your dispensary

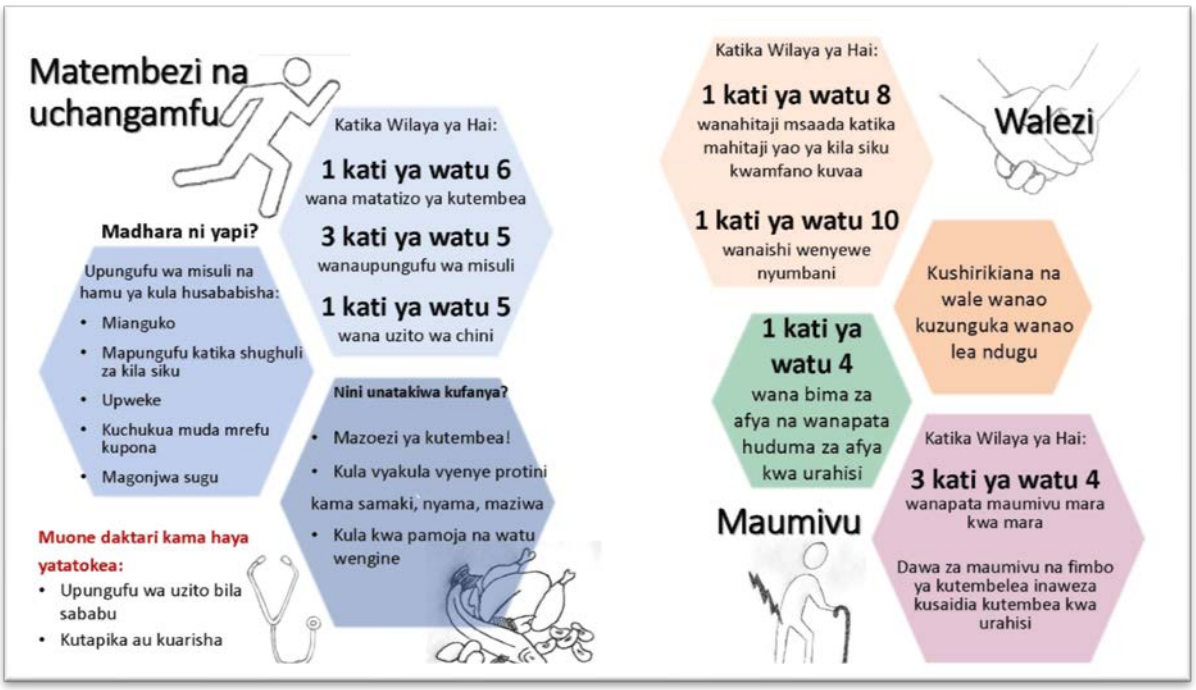
	In over 60 year olds in Hai district:	What is the impact	What to assess	Suggested actions
Mobility and Vitality	**1 in 5** people are underweight **3 in 5** have muscle loss **1 in 6** people have problems walking	Increase the risk of: ▪Falls ▪Reduced ability to do your daily work ▪Isolation ▪Slow healing ▪Chronic diseases	Walking speed Review the safety of them home environment eg move the bucket Do they need a walking aid? Do they have adequate protein in their diet?	▪Exercise for balance, strength and aerobic fitness ▪Treat other health problems ▪Increase protein intake ▪Social eating ▪Consider supplements
Falls	**1 in 7** have fallen twice or more in the last year	▪ Injury ▪ Fear of falling ▪ Hospitalisation ▪ Injury related death	▪ Lying and standing blood pressure for a postural drop ▪ Hazards at home ▪ Footwear quality ▪ Vision ▪ Review Medication	▪ Remove trip hazards at home ▪ Exercise for balance, strength and aerobic fitness ▪ Slow standing and increase hydration if postural blood pressure drop
Urinary Incontinence	Reported by **1 in 5** Urinary incontinence has multiple causes	▪Pressure Ulcers ▪Sepsis ▪Infection ▪Renal failure ▪Reduced social interaction	Reversible causes (Delirium, infection, atrophic vaginitis, meds, depression, high blood glucose, constipation, prostatic symptoms) Assess Fluid intake, meds, cognition, mobility, previous surgery.	Prompted voiding ▪ Follow a timed routine of bathroom visits Pelvic floor muscle training ▪ Develop a routine of repetitive contractions 2-3 times per week
Sensory Impairment	**1 in 2** report visual problems **1 in 3** report hearing problems **1 in 15** report cataracts, we suspect this is higher	▪ Depression ▪ Reduced physical performance/independence with daily activities ▪ Isolation	Evidence of cataracts Review medication for side effects Arrange routine eye screen if: Diabetes, severe myopia, family history of glaucoma Send to hospital if: acute visual or hearing loss, chronic otitis media	▪ Use simple language ▪ Reduce background noise ▪ Reduce hazards in the home ▪ Consider corrective glasses
Cognitive impairment and psychological wellbeing	**2 in 5** people have low mood in Hai **1 in 20** people have dementia	▪Can predict future dependency ▪Impacts on daily life ▪Carer strain	Orientation Ask your patient if they think there is a problem Assess social support Assess mobility and activity Ask if feelings of wanting to harm self?	▪Cognitive stimulation ▪Repeated orientation ▪Adapt language ▪Exercise ▪Avoid isolation ▪Social eating
Carers	**1 in 8** people need assistance with their daily needs eg dressing **1 in 10** people live alone	Impact to the carer: ▪Low mood ▪Stress and Anxiety ▪Financial strain ▪Change of identity	How is their mood? Acknowledge the frustration and stress of being a carer Encourage to continue caring, to avoid neglect	▪Being aware of those around you caring for relatives ▪Offer them practical support eg neighbours to sit with relative to give a break
High Blood Pressure	**1 in 2** people over 60 years have raised blood pressure Only **1 in 4** people knew it!	Increased risk of: Stroke Heart disease End organ damage (brain/kidney/eye)	Compliance with medication Diet Exercise End organ damage – urine dipstick for protein, headaches, vision	▪Explain the risks of hypertension eg stroke ▪Keep moving! ▪Reduced salt ▪Regular pressure checks ▪Take medication daily if diagnosed ▪Stop smoking

Reference: ICOPE Guidelines developed by the World Health Organisation https://www.who.int/ageing/publications/guidelines-icope/en

Affiliated bodies: Kilimanjaro Christian Medical Centre, Newcastle University, Northumbria University NHS Foundation Trust. Funding with thanks to the British Geriatrics Society

Swahili Leaflet





Matatizo ya kibofu cha mkojo

Katika Wilaya ya Hai:

Tumeambiwa na watu

1 katika 5

kua na matatizo ya kibofu cha mkojo. Yanasababishwa na mambo mengi

Madhara ni yapi?

- Vidonda vitokanavyo na kulala sana
- Maambukizi kwenye kibofu cha mkojo
- Kushindwa kwa figo
- Aibu ya kukaa na watu

Nini unatakiwa kufanya?

- Kwenda kujisaidia haja ndogo hata kama hajasikia kwenda chooni
- Mazoezi ya misuli ya njia ya mkojo

Muone daktari:

ili uweze kupima na kupata matibabu

Uwezo wa kuona na kusikia

Katika Wilaya ya Hai:

1 kati ya watu 2

wana matatizo ya kuona

1 kati ya watu 3

wana matatizo ya kusikia

Madhara ni yapi?

- Mawazo mengi
- Kuhitaji mtu katika kufanya shughuli za kila siku
- Upweke

Nini unatakiwa kufanya?

- Tumia lugha rahisi
- Punguza kelele katika eneo linalo kuzunguka
- Punguza vyanzo vya ajali nyumbani
- Zingatia matumizi ya miwani sahihi

Muone daktari ukiwa na:

- Kutokuona kwa macho ghafla
- Tatizo sugu la masikio
- Kutokusikia ghafla

Mawazo na kumbukumbu

Katika Wilaya ya Hai:

2 kati ya watu 5

wana mawazo mengi

1 kati ya watu 20

wanaugonjwa wa kusahau

Utaona nini?

Kumbukumbu:

- Kusahausahau
- Mabadiliko ya tabia
- Kupotea

Mawazo mengi:

- Kupunguza kufurahia watu na vitu fulani,

na uchangamfu

Nini unatakiwa kufanya?

- Kuchangamsha akili

kama kusikiliza radio au kuzungumza na watu

- Watumie lugha ya nyumbani na maneno marahisi
- Kuwakumbusha wakati na mahali alipo
- Usikae peke yako
- Kula kwa pamoja

Kuanguka

Katika Wilaya ya Hai:

1 kati ya watu 7

wameanguka mara mbili au zaidi ndani ya mwaka uliopita

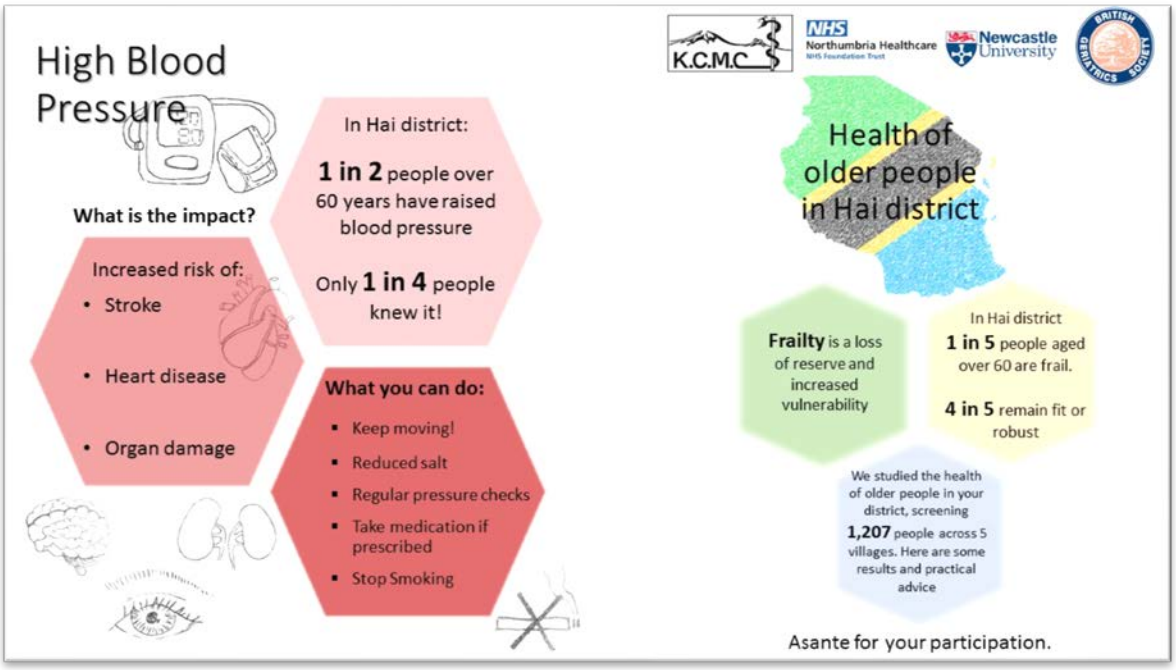
Madhara ni yapi?

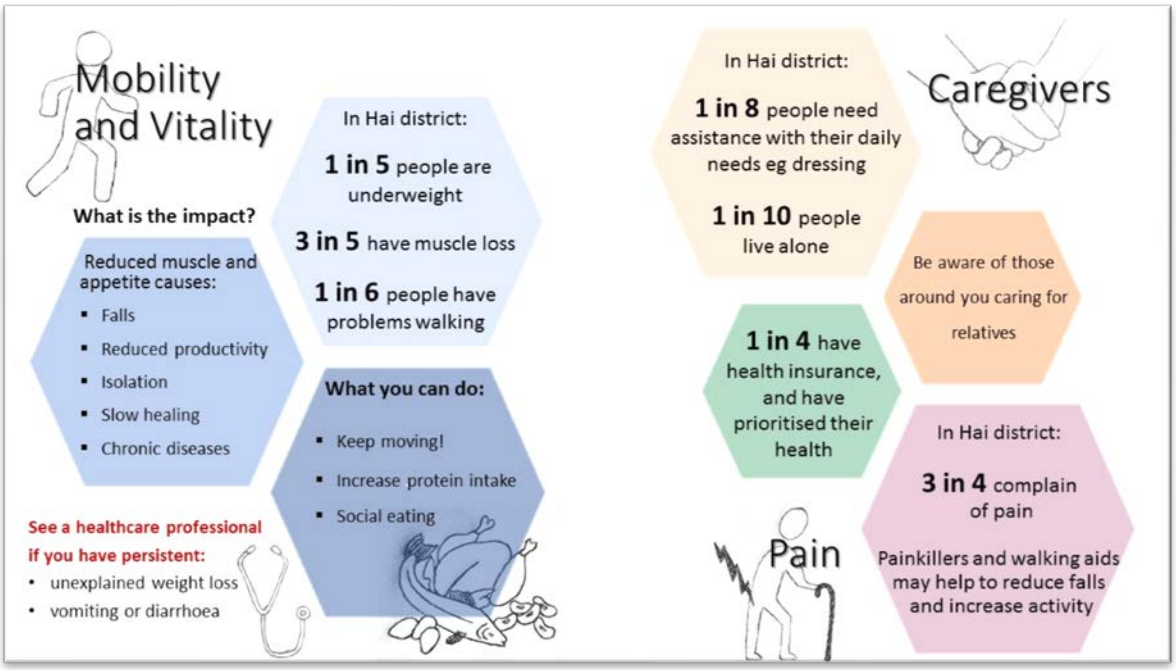
- Majeraha
- Uoga wakuanguka
- Kulazwa hospitalini
- Vifoo vinavyo sababishwa na majeraha

Nini unatakiwa kufanya?

- Mazoezi ya kutembea!
- Fanya mazingira ya nyumbani kua salama
- Pima macho na masikio hospitali
- Pima presha yako ya damu
- Kagua viatu kama vimeharibika

English information leaflet






Urinary Incontinence
In Hai district:
Reported by 1 in 5
Urinary incontinence has multiple causes.
What is the impact?
Ulcers
Sepsis
Infection
Renal failure
Reduced social interaction
What you can do:
Prompted voiding
Pelvic floor muscle training
See a healthcare professional to:
Assess for reversible causes
Sensory impairment
In Hai district:
1 in 2 report visual problems
1 in 3 report hearing problems
What is the impact?
Depression
Reduce physical performance
Isolation
What you can do:
Use simple language
Reduce background noise
Reduce hazards in the home
Consider corrective glasses
See a healthcare professional if you have:
Acute visual loss
Chronic ear infection
Acute hearing loss


Cognitive impairment and psychological wellbeing
In Hai district:
2 in 5 people have low mood in Hai
1 in 20 people have dementia
What to look out for:
Memory:
Forgetfulness
Personality change
Getting lost
Mood:
Reduced interest, energy and mood
What you can do:
Cognitive stimulation
Orientation
Adapt language
Exercise
Avoid isolation
Social eating
Falls
In Hai District:
1 in 7 have fallen twice or more in the last year
What is the impact?
Injury
Fear of falling
Hospitalisation
Injury related death
What you can do:
Exercise
Home modification
Review footwear
Blood pressure check on standing
Review sensory impairment

Appendix L The prevalence of frailty by CGA calculated by B-FIT category

	Frail by CGA and non-frail by B-FIT	Frail by CGA and pre-frail by B-FIT	Frail by CGA and B-FIT	Percentage frail by CGA (95% CI)
Total sample	7	49	35	19.1 (15.2-23.1)
Age- standardised all cases				15.8 (11.8-19.7)
60-69 years	2	7	1	6.9 (1.09-12.7)
70-79 years	4	8	10	19.9 (12.0-27.7)
≥80 years	1	34	24	44.7 (37.1-52.2)
Men	3	21	9	16.3 (10.8-21.7)
Women	4	28	26	21.8 (10.4-33.3)
Married	3	15	10	12.1 (6.0-18.2)
Widowed/divorced/single	4	34	25	27.3 (15.5-39.2)
Some education	3	29	15	12.4 (9.1-15.7)
No formal education	4	20	20	45.6 (20.1-71.0)
Able to read/write	3	24	13	11.2 (7.4-15.0)
Not able to read/write	4	25	22	52.0 (31.2-72.7)
Working for pay	4	6	1	14.0 (7.4-20.6)
Not working for pay	3	43	34	23.1 (17.3-29.0)
Low-land location	4	26	17	18.6 (11.8-25.4)
High-land location	3	23	18	19.8 (17.3-22.2)

Appendix M The frailty status and diagnoses of the 39 participants with missing Hai District FP data

Age and sex	CGA Frailty status	Missing FP parameters	Mobility status	Diagnoses
63 male	Not frail	Walking speed, (erroneous data deleted)	Walks independently	None
83 male	Not frail	HGS	Walks Independently	OA, BPH. Has a wrist brace on the left wrist following a motorbike accident.
85 male	Not frail	HGS	Walks Independently	HTN, OA, transient ischaemic event,
68 female	Frail	Walking speed	Wheelchair-Bound	Old polio, depression
71 female	Frail	Walking speed, HGS, Exhaustion	Immobile	Stroke, HTN,
61 male	Frail	Walking speed	Immobile	Old polio,
85 female	Frail	Walking speed, HGS, Exhaustion	Immobile	Dementia
80 male	Frail	Walking speed HGS	Immobile	Malnourished, cataracts,
87 male	Frail	Walking speed HGS	Wheelchair-bound	Rheumatoid arthritis with possible osteoarthritis, essential tremor, urge urinary incontinence, visual impairment right eye
84 male	Frail	Walking speed	Walks with Assistance	OA, palpitations, alcohol excess, multiple falls
84 male	Frail	Walking speed, HGS	Immobile	HTN, asthma, stroke, rheumatoid arthritis
89 female	Frail	Walking speed	Immobile	OA, HTN, chronic cough, incontinence of urine, peptic ulcer disease, cataracts
104 female	Frail	Walking speed	Walks with Assistance	OA, cataracts, gastro-oesophageal reflux disease,
81 male	Frail	Walking speed, HGS	Immobile	Type 2 Diabetes, bilateral above knee amputations for chronic infected foot

Age and sex	CGA Frailty status	Missing FP parameters	Mobility status	Diagnoses
				ulcers, supra-public catheter for BPH or neuropathy
70 male	Frail	Walking speed, HGS	Immobile	Pituitary macroadenoma, seizures, chronic hyponatraemia, cataracts
90 female	Frail	Walking speed, HGS	Immobile	Stroke, HTN, contractures,
103 female	Frail	Walking speed	Immobile	Peptic ulcer disease, asthma, osteoarthritis
80 male	Frail	Walking speed, HGS	Immobile	HTN, stroke, urinary incontinence catheterised
75 female	Frail	Walking speed	Immobile	Asthma/COPD, HTN, bilateral arthritis small joints of the hands
91 male	Frail	Walking speed	Walks with Assistance	Visual impairment, peptic ulcer disease
79 male	Frail	Walking speed, HGS	Immobile	HTN, stroke, chronic cough, bed sores,
75 male	Frail	Walking speed	Walks Independently	Cognitive impairment, cataracts
93 female	Frail	Walking speed, HGS	Immobile	Stroke, urinary incontinence, HTN
81 male	Frail	Walking speed	Immobile	Left above knee amputation for gangrene, peripheral vascular disease
93 female	Frail	Walking speed	Immobile	Dementia with visual hallucinations
90 female	Frail	Walking speed	Immobile	HTN, Type 2 diabetes, stroke
95 female	Frail	Walking speed, HGS	Immobile	Dementia, OA
88 female	Frail	Walking speed	Immobile	Osteoporosis, OA, disc problems
82 female	Frail	Walking speed	Immobile	OA, HIV, chronic cough
75 female	Frail	Walking speed	Immobile	HTN, stroke
90 female	Frail	Walking speed	Immobile	Lower limb paralysis ? TB of spine, urinary incontinence, constipation, chronic wheeze ? Post-TB bronchiectasis or COPD

Age and sex	CGA Frailty status	Missing FP parameters	Mobility status	Diagnoses
110 female	Frail	Walking speed, HGS	Immobile	Stroke, probable aspiration pneumonia, HTN, pressure sores, contractures
62 male	Frail	Walking speed, HGS	Immobile	Stroke, urinary incontinence, dementia, HTN, pedal oedema
104 female	Frail	Walking speed	Immobile	Cognitive impairment, visual impairment due to bilateral cataracts, immobility
90 female	Frail	Walking speed (erroneous data deleted)	Walks with Assistance	Visual impairment, goitre, COPD, OA
87 female	Frail	Walking speed, HGS	Immobile	Visual impairment, bowel and bladder incontinence
79 female	Frail	Walking speed	Walks with Assistance	COPD, haemorrhoids, #NOF following fall-not operated, lipoma, urinary and faecal incontinence, cataracts
77 female	Frail	Walking speed, HGS	Walks Independently	Dementia, visual impairment, OA
68 female	Frail	Walking speed	Wheelchair	Old polio, depression

OA=Osteoarthritis, HTN=Hypertension, COPD=Chronic Obstructive Pulmonary Disease, BPH= Benign Prostatic Hypertrophy, TB=Tuberculosis HIV=Human Immunodeficiency Virus

Appendix N The response frequencies for the variables included in the Frailty Index

Item number	Variable	Frequencies (%) or Mean (SD)
Assessment Domain: Function		
1.	In the past 30 days, how much difficulty did you have in standing for long periods such as 30 minutes?	None (no) 69 (29.5) Mild (a little) 24 (10.3) Moderate 39 (16.7) Severe (very much) 35 (15.0) Extreme or cannot do 66 (28.2) Missing 1 (0.4)
2.	Because of your health condition, in the past 30 days, how much difficulty did you have in taking care of your household responsibilities?	None (no) 78 (33.3) Mild (a little) 25 (10.7) Moderate 39 (16.7) Severe (very much) 34 (14.5) Extreme or cannot do 56 (23.9) Missing 2 (0.9)
3.	In the past 30 days, how much difficulty did you have in learning a new task, for example, learning how to get to a new place?	None (no) 85 (36.3) Mild (a little) 18 (7.7) Moderate 28 (12.0) Severe (very much) 45 (19.2) Extreme or cannot do 56 (23.9) Missing 2 (0.9)
4.	In the past 30 days, how much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	None (no) 93 (39.7) Mild (a little) 23 (9.8) Moderate 27 (11.5) Severe (very much) 24 (10.3) Extreme or cannot do 66 (28.2) Missing 1 (0.4)
5.	In the past 30 days, how much have you been emotionally affected by your health condition?	None (no) 88 (37.6) Mild (a little) 27 (11.5) Moderate 52 (22.6) Severe (very much) 43 (18.4) Extreme or cannot do 23 (9.8)
6.	In the past 30 days, how much difficulty did you have in concentrating on doing something for ten minutes?	None (no) 122 (52.1) Mild (a little) 25 (10.7) Moderate 33 (14.1) Severe (very much) 22 (9.4) Extreme or cannot do 32 (13.7)

Item number	Variable	Frequencies (%) or Mean (SD)
7.	In the past 30 days, how much difficulty did you have in walking a long distance such as a kilometre (or equivalent)?	None (no) 72 (30.8) Mild (a little) 26 (11.1) Moderate 38 (16.2) Severe (very much) 36 (15.4) Extreme or cannot do 62 (26.5)
8.	In the past 30 days, how much difficulty did you have in washing your whole body?	None (no) 138 (59.0) Mild (a little) 19 (8.1) Moderate 26 (11.1) Severe (very much) 15 (6.4) Extreme or cannot do 36 (15.4)
9.	In the past 30 days, how much difficulty did you have in getting dressed?	None (no) 152 (65.0) Mild (a little) 19 (8.1) Moderate 23 (9.8) Severe (very much) 13 (5.6) Extreme or cannot do 26 (11.1) Missing 1 (0.4)
10.	In the past 30 days, how much difficulty did you have in dealing with people you do not know?	None (no) 161 (68.8) Mild (a little) 24 (10.3) Moderate 21 (9.0) Severe (very much) 21 (9.0) Extreme or cannot do 17 (7.3)
11.	In the past 30 days, how much difficulty did you have in maintaining a friendship?	None (no)= 166 (70.9) Mild (a little)= 27 (11.5) Moderate= 14 (6.0) Severe (very much)= 10 (4.3) Extreme or cannot do= 17 (7.3)
12.	Because of your health condition, in the past 30 days how much difficulty did you have in your day-to-day work/school?	None (no)= 77 (32.9) Mild (a little)= 26 (11.1) Moderate= 38 (16.2) Severe (very much)= 34 (14.5) Extreme or cannot do= 53 (22.6) Missing= 6 (2.6)
Assessment Domain: Cognition and mood		
13.	IDEA cognitive screening tool (N=234)	Mean= 8.35 (3.46) 0-12
14.	Can the older person assist in small works of the house?	yes, no difficulty= 126 (53.8) yes, with assistance= 48 (20.5)

Item number	Variable	Frequencies (%) or Mean (SD)
		cannot do= 60 (25.6)
15.	Can the older person give advice?	yes, no difficulty= 174 (74.4) yes, with assistance= 31 (13.2) cannot do= 29 (12.4)
16.	Can the older person preside over feasts and ceremonies?	yes, no difficulty= 96 (41.0) yes, with assistance= 57 (24.4) cannot do= 81 (34.6)
17.	Depression EUROD score (N=233)	Mean 4.54 (SD 3.51) 0-12 Missing=1 (0.4)
18.	Overall in the last 30 days, how much of a problem did you have with worry or anxiety?	None= 102 (43.6) Mild=40 (17.1) Moderate= 58 (24.8) Extreme=33 (14.1) Missing=1 (0.4)
19.	Overall in the last 30 days, how much of a problem did you have due to not feeling rested and refreshed during the day (for example, feeling tired, not having energy)?	None= 74 (31.6) Mild= 40 (17.1) Moderate= 65 (27.8) Extreme= 54 (23.1) Missing= 1 (0.4)
Assessment Domain: Comorbidity		
Have you ever been told you have a diagnosis of any of the following?		
20.	Diabetes	No= 212 (90.6) Yes= 22 (9.4)
21.	Hypertension	No= 163 (69.7) Yes=71 (30.3)
22.	Cataracts (Have you been told you need an operation on your eyes?)	No=212 (90.6) Yes= 21 (9.0) Missing=1 (0.4)
23.	Stroke	No=214 (91.5) Yes= 19 (8.1) Missing= 1 (0.4)
24.	Heart disease/failure	No= 218 (93.2) Yes= 16 (6.8)
25.	Chronic respiratory condition, such as asthma or COPD	No= 217 (92.7) Yes= 17 (7.3)
26.	Arthritis or rheumatism	No= 179 (76.5)

Item number	Variable	Frequencies (%) or Mean (SD)
		Yes= 54 (23.1) Missing= 1 (0.4)
27.	Do you think you have a hearing problem?	No= 158 (67.5) Yes=76 (32.5)
28.	In the last 30 days, how much difficulty did you have in seeing and recognizing an object at arm's length or in reading?	No difficulty= 111 (47.4) Mild difficulty= 37 (15.8) Moderate difficulty= 60 (25.6) Extreme/cannot do= 26 (11.1)
29.	In the last 30 days, how much difficulty did you have in seeing and recognizing a person you know across the road (i.e. from a distance of about 20 meters)?	No difficulty= 105 (44.9) Mild difficulty= 48 (20.5) Moderate difficulty= 47 (20.1) Extreme/cannot do= 34 (14.5)
30.	Overall in the past 30 days, how much of a problem did you have with bodily aches and pains?	No difficulty= 44 (18.8) Mild difficulty =48 (20.5) Moderate difficulty= 91 (38.9) Extreme/cannot do= 50 (21.4) Missing 1 (0.4)
31.	Have you fallen down in the past year?	No= 170 (72.6) Once= 30 (12.8) Twice or more= 34 (14.5)
Assessment Domain: Health attitudes		
32.	In general, how would you rate your health?	Very good= 3 (1.3) Good= 43 (18.4) Neither good nor poor= 110 (47.0) Poor= 60 (25.6) Very poor= 16 (6.8) Missing 2 (0.9)
33.	Do you consider yourself currently ill?	No= 83 (35.5) Yes= 150 (64.1) Missing= 1 (0.4)
34.	Do you consider yourself to be living with frailty?	No= 85 (36.3) Yes= 148 (63.2) Missing= 1 (0.4)
Assessment Domain: Physical performance		
35.	High BP: Average BP ≥140 mmHg and/or diastolic BP ≥90 mmHg	High BP= 126 (53.8) Normal BP= 104 (44.4)

Item number	Variable	Frequencies (%) or Mean (SD)
		Missing= 4 (1.7)
36.	Mid-upper arm circumference (cm) (N=234)	Mean= 27.05 (SD 4.77) 16.70-51.00
37.	Calf circumference (cm) (N=230)	Mean= 31.81 (SD 4.07) 22.20-42.60 Missing= 4 (1.7)

Appendix O The prevalence of frailty by FI calculated by B-FIT category

	Frail by FI and non-frail by B-FIT	Frail by FI and pre-frail by B-FIT	Frail by FI and by B-FIT	Prevalence of frailty by FI (95% CI)
Fit	36	22	0	37.7 (32.48-42.91)
Mild frailty	28	29	1	31.77 (26.33-37.20)
Moderate frailty	13	41	4	20.53 (14.64-26.41)
Severe frailty	2	27	31	9.99 (7.48-12.49)
Prevalence by FI (0.38 cut-off)				
Total prevalence	7	44	35	18.35 (14.2-22.4)
Males	2	17	11	12.95 (6.55-19.34)
Females	5	27	24	23.65 (17.84-29.45)
60-69 years	1	5	1	4.23*
70-79 years	3	10	11	18.64 (8.82-28.45)
≥80 years	3	29	23	53.07 (45.91-60.22)
Education	5	27	15	14.33 (9.75-18.90)
No education	2	17	20	33.78 (22.45-45.10)
Married	1	13	10	8.10 (4.77-11.42)
Widowed, separated/divorced or single	6	31	25	30.41 (24.31-36.50)
Prevalence by FI (0.25 cut-off)				
Total prevalence	22	79	35	39.18 (30.41-47.94)
Males	11	26	11	33.05 (26.19-39.90)
Females	11	53	24	44.68 (31.76-57.59)
60-69 years	13	18	1	31.44*
70-79 years	6	21	11	35.24 (27.68-42.79)
≥80 years	3	40	23	62.15 (54.81-69.48)
Education	17	49	15	33.81 (23.89-43.72)
No education	5	30	20	59.92 (51.46-68.37)

	Frail by FI and non-frail by B-FIT	Frail by FI and pre-frail by B-FIT	Frail by FI and by B-FIT	Prevalence of frailty by FI (95% CI)
Married	11	31	10	31.77 (18.33-45.20)
Widowed, separated/divorced or single	11	48	25	47.87 (36.51-59.22)

*Unable to calculate standard error because of stratum with single sampling unit.

Appendix P Qualitative participants frailty status according to the B-FIT, and self-assessed frailty

Anonymised name (age)	B-FIT score	Self-identify as frail?	Illustrative quote
Bibi Lokeni (72)	0 = non-frail	Yes	*Her body has become frail because of diseases, the body has become weakened, and her backache bothers her a lot so she is unable to do her work well. (Mama Lataiyo, translating, daughter-in Law)*
Babu Laizer (85)	3 = pre-frail	No	*He says his body has become weak just due to diseases not because of old age. The diseases are what cause this yes eeh (Mama Lataiyo, translating daughter-in-law)*
Bibi Helena (90s)	2 = pre-frail	Yes	*Eeeh, (yeah) the body has no energy*
Bibi Zakia (70)	0 = non-frail	Yes	*Yeah, it's just like that, I tire but I go out to search and search and bring (something) to him (her husband)*
Babu Shuma (87)	-	Yes	*The body is starting to tire mother, especially these heels are painful*
Mama Pili (60)	0 = non-frail	No	*My health is ok, I have no problem, only I'm bothered by "presha" (high blood pressure) that really afflicts me a lot.*
Mama Kilala (62)	0 = non-frail	No	*Roles of elders is to take care, to look after the family then after the family has already established itself, the established family now looks after the elders again.*
Bibi Eliaika (109)	6 = frail	Yes	*It is because of these legs only, they don't work properly I feel like a weak person.*
Bibi Hosiana (85)	5 = frail	No	*No I have not yet become weakened*

Anonymised name (age)	B-FIT score	Self-identify as frail?	Illustrative quote
Bibi Martha (93)	2 = pre-frail	Yes	*For the weaknesses, I see there are (Mama Upendo, daughter-in-law)*
Baba Thomas (63)	4 = pre-frail	Yes	*I'm obliged to be a weak person, because I basically do not have a life, you know how people who have this disease are treated with discrimination.*
Babu Said (unknown)	-	Yes	*Frailty yes it is, when you do not have anything in the family you get frail*
Bibi Abraham (unknown)	-	Yes	*I have frailty, as I said my legs and hands are numb*
Mzee Massawe (95)	2 = pre-frail	Yes	*You find I am frail and I have a lot of thoughts.*
Baba Ayubu (74)	0 = non-frail	Yes	*Eeh! Yes, because as the age goes and so the strength, you may feel the body does not have strength, then you get sick often, sometimes you get a little better, sometimes it's just like that, but to rest, you can't rest meaning there's no one to help you.*
Mama Amina (70)	0 = non-frail	Yes	*Yes and frailty of the body, yes so it becomes frailty, we say maybe it's because of many diseases we often suffer and suffer from them.*

Anonymised name (age)	B-FIT score	Self-identify as frail?	Illustrative quote
Baba Munuo (70)	0=non-frail	No	*Frailty, a person is frail, first it's a state of failing to handle everyday life. Being able to handle everyday life and the ability to help one's self because in old age your strength is diminished, that is frailty.*
Babu Elirehema (80)	2= pre-frail	Yes	*Very much. The weaknesses are too many. The frailty is just severe, the frailty is severe because I get tired everywhere, it is refusing to work (the body), every part now refuses to work.*
Babu Materu (93)	0= non-frail	Yes	*My health is good, (but) due to old age yes, I have frailty, I feel frail but I do not have much disease.*
Bibi Ndumaeli (75)	4= pre-frail	Yes	*I feel the pain is increasing and frailty of the old age.*
Babu Obadia (82)	0= non-frail	Yes	*I have frailty of the elderly and I have aged. I have frailty of elders but I work although I cannot work as I could in youth.*
Bibi Felista (75)	3=pre-frail	Yes	*Yes, the body frailty is there, because I am sick, I am sick. I am sick in the stomach, I have pain in the legs. Ehee, If not for this one, I cannot go from somewhere, no, ehee. Frailty is there.*
Mzee Eliakimu (78)	-	Yes	*The challenges are many because here we are equal to children but elders have knowledge more than children.*

Anonymised name (age)	B-FIT score	Self-identify as frail?	Illustrative quote
Mzee Ali (50)	-	Yes	*(Yes I have those) problems of the elders is in missing their important needs. Firstly, there is no support of something called finance. Secondly, that when you are sick you defend yourself and your friend helps you. But waiting to be taken, you will have to die on the way because of no transport.*
Mzee Masana (76)	-	Yes	*The frailty of the elders here (in Tanzania) is very much. Unable, the government is unable! And maybe as we progress ahead with development, towards which we are heading, maybe we will have greater progress than our frailty.*

Appendix Q Illustrative Case Histories

Mama Josephine na Baba Thomas

'Baba Thomas' was interviewed on the 14th August 2017 with his wife 'Mama Josephine'. He is 63 years old, and a retired accountant and auditor who trained in Dar es Salaam. His wife, aged 45 years had completed primary school and was a subsistence farmer. This older couple, both of whom were living with HIV infection, had children who were free from infection.

The couple both had failing health by their own admission, describing themselves as *"patients"* and *"affected"*. 'Baba Thomas' told us he was first diagnosed in 1987, when unmarried and working in Dar es Salaam. However, initially he didn't believe the diagnosis was correct, *"I didn't agree that I had got this disease, because I was healthy and I was working properly"*. He married his wife in 1996, and after being re-tested he finally accepted the diagnosis in 2004, after having two children. 'Mama Josephine' started taking antiretrovirals (ARVs) in 2006, and 'Baba Thomas' in 2007, twenty years after his first diagnosis. When asked about his health, he quoted his most recent CD4 count, saying that he was grateful to have survived so long with the disease.

Baba Thomas: Most of my friends who lived with the same disease as me are now dead, I am thankful to God.

However, it transpired that they had recently been switched to second-line ARVs due to failure of the first-line medications, suggesting that the infection was not well controlled. They had previously received medications for prevention of opportunistic infections alongside their ARVs, however these had been stopped recently due to drug shortages, another cause for concern.

Baba Thomas: These tablets we are using are for the second stage and when these are over there are no more medicines, do you know? I don't know what you doctors can tell me about this?

Overall, 'Baba Thomas' described himself as living with frailty. He described unintentional weight loss and low physical activity. He was also blind, and used a stick or required assistance to move around. This put him in a particularly vulnerable situation, so that if he needed to use the toilet during the day when 'Mama Josephine' was out working, he relied on local children or passers-by to assist him. 'Baba Thomas' was assessed by the Brief Frailty Instrument for Tanzania (B-FIT) and was given a score of 4 from a maximum of 6 ("pre-frail" category).

Mama Josephine: Our life is not a good life that we live, because my husband lost his eyes he cannot see anymore, so I am the one who runs the family and I cannot do this without Jesus Christ.

They both faced a significant degree of stigma and social isolation. In field notes reflecting on the interview, it was noted that the usual family supports was lacking. 'Baba Thomas' had eight close family members living in the village, but they had refused to help them due to the shame of having HIV-infection in the family. 'Baba Thomas' faced this stigma most acutely, given that he was also living with the stigma of old-age frailty and dependency. Whereas, his younger wife, who was still able to work, faced less discrimination stating that she was included in a local women's co-operative group, and could attend church.

EGL: So how does he feel about that? Does he think perhaps he is becoming frail?

JR: And do you think because of these issues you are a worthless person[83]?

Baba Thomas: I'm obliged to be a worthless person, because I basically do not have a life, you know how people who have this disease are treated with discrimination.

From five children, two were living with them and helping their mother to earn enough money for their daily subsistence, all of them making small amounts by undertaking casual manual labour or cattle herding, as well as contributing to the domestic chores.

Baba Thomas: Those two are taking care of cattle for people just here.

Mama Josephine: They are taking care of other people's cattle so that we can get a means of living[84].

The conventional narrative of grandmothers in the context of HIV/AIDS was dissected critically by Chazan, (Chazan, 2008) where the author argues that women and grandmothers haven't changed their roles because of, or in response to the HIV/AIDS epidemic, rather they are *"doing what they have always done- caring for their families"* (Chazan, 2008, p954). This rings true in these data, where 'Mama Josephine' as a mother of five, struggles to support her family. This would be her role in the presence or absence of HIV-infection. Here this

[83] Mnyonge= noun meaning weak person or down-and-out. It is not the usual translation used for frailty, and holds an additional value judgement of worthlessness.

[84] JR's original translation was "so they can get money for survival." Which has been altered to a closer translation to the spoken Swahili, however JR may have chosen this translation to emphasise the extreme nature of the situation, that the family is reliant on two young boys who should be in primary school.

mother's pragmatism extends to employing all resources to hand, including three of her children.

The family faced significant financial hardship, which was evident in the description of a diet of limited variety and low in protein. In response to this, 'Baba Thomas' referred to waiting for a "sponsor" or a "good Samaritan" to help them by paying for another child to attend school, or by helping to finish build their house or toilet[85].

Baba Thomas: There is only one who is at school.

JR: So there is only one who is at school?

Mama Josephine: He was taken by sponsors[86] that one, due to the hardship of life that we are facing.

Interestingly, the impact of foreign sponsors was also felt on a wider scale. In the following quotation 'Baba Thomas' noticed that they were being required to pay for medications more frequently. He reflected that perhaps foreign "sponsors" were becoming less reliable;

Baba Thomas: We depend on ourselves, when you get sick and go to the see the doctor, the doctor will write (the prescription) and will tell you to buy them, so in the past, sponsors from Germany, Europe used to provide those medicines, I don't know if they were given, or sold, you know this country of ours, you can't understand it.

HIV-infected adults who primarily used government-run health services, were more dissatisfied with the quality of the service than older adults without HIV-infection in South Africa (Negin et al., 2017). A significantly lower proportion of HIV-infected patients felt they had been involved in their treatment, or felt able to talk to a health provider privately. In addition to the lack of medications, it is possible that 'Baba Thomas' also faced discrimination by healthcare providers based on his HIV-infected status. The quotation below refers nostalgically to the time when the health service was provided for free from between 1961 until the early 1990s when user fees were introduced (Maluka, 2013).

Baba Thomas: Someone who is a patient like me, how do I feel? If there is a pharmacy inside the hospital and am still asked to go buy those medicines outside in the shop,

[85] It is common in Tanzania to build your house in sections, as you have the means, as it is a secure means of storing wealth, and difficult to save up enough to build a house at once. Baba Thomas's house wasn't finished, and had sheets covering the windows instead of glass panes.
[86] Fadhili is the verb to help or to favour, so the term "wafadhili" means those who help or favour. It was a term used a lot and translated to "sponsors" by JR and LM.

how am I supposed to feel while I have nothing? Now I can go back to the leadership of Teacher Nyerere, everything was provided, when you get a prescription in the hospital...

This case was chosen to illustrate two main points. Firstly, to give an example of older people living with HIV-infection. This case exemplifies how HIV-infection in old age may exacerbate someone's frailty through chronic undernutrition and social isolation, and how frailty and HIV-infection intersect to exacerbate an older person's social vulnerability. Secondly, this is an interesting example of multi-generational inter-dependency, which is not desired, but is being forced through a pragmatic need to survive in the absence of more formal opportunities for financial support.

Mzee Massawe

'Mzee Massawe', interviewed was 95 years old when interviewed on the 11th of August 2017. He was the eldest of six siblings and came from the Mnyasa tribe of Malawi growing up herding cattle. After running away from home, he fought for the British during the Second World War (in the year 1941) as part of the East African counter-offensive on Ethiopia. He then spent a decade in road construction in Tanzania, building the road from Dar es Salaam to Nairobi, and from Marangu, Kilimanjaro region to Arusha. He also worked building a college in Kampala, Uganda, in his words; *"It was a college, not for Africans it was for the Whites*[87]*"*.

After we were done with those duties[88] *they told us those who stay near and far will be returned back to their homes, now with luck I didn't go back home. (Mzee Massawe)*

He then continued to work in different industries around Tanzania, becoming a mechanical specialist working in sugar and sisal plantations. Finally he moved to live in Hai District working as a farm labourer for wealthier Mchagga people[89], at the time that Julius Nyerere had started campaigning for Tanzanian independence. The following transcript extract illustrates how unusual and counter to cultural norms this lifestyle was, and still is considered to be.

JR: Now, Babu did you have the ability to marry?

[87] Wazungu (n)= Europeans. It has been translated as "Whites" by JR, and today it is generally used for any white foreigner. Mzee Malawi's use of the term here is a strong reminder that during his lifetime the wazungu were colonialists, while the term "wazungu" is now used to refer to "foreign tourists/development workers".
[88] shughuli=noun work, job, business, activity, but I have chosen to keep the original translation as it suggests that he was not free to choose and was under the control of the colonial British at this time.
[89] Mchagga=Chagga tribe's people, the dominant cultural and ethnic group in Kilimanjaro region.

Mzee Massawe: For sure to say the truth, myself, for bad luck I was moving around.

JR: Eeeeh?

Mzee Massawe: I was moving around.

JR: You were moving around, what does it mean?

Mzee Massawe: (while laughing) just a vagrant[90].

JR: You were just a vagrant?

Mzee Massawe: Mmh

JR: Aha but you didn't succeed to get a wife to stay with?

Mzee Massawe: For sure when I came here, I stayed here for five years, just right here.

JR: Yes?

Mzee Massawe: Then I married one woman.

JR: Yes?

Mzee Massawe: Then, when we both fell in love I married her, bad luck she came to die.

JR: (while she is surprised) Aaah!

Mzee Massawe: Eeeh, and she was buried there in the Church[91].

'Mzee Massawe' had one son during his four year marriage, who worked as a guide climbing Kilimanjaro *"with whites and tourists"*. Sadly, he died from altitude sickness on the mountain. At this time, 'Mzee Massawe' worked as a manual labourer farming on the land of a local Pastor. Unfortunately, as he aged, he became ill and unable to work. In 2010, he was admitted to hospital requiring an operation. Shortly after discharge the Pastor was forced to retire and to move away from the village due to fraud, leaving 'Mzee Massawe' living in a

[90] uhuni=noun vagrant or prostitute. This was originally translated as "hooligan" by JR, which perhaps conveys the antisocial nature of his lifestyle.

[91] This is significant because if he had owned any land, she would have been buried on her husband's land. The fact that his wife was buried at the church, against local custom, signifies that he was too poor and unsettled and didn't have his own plot where she could be buried.

dilapidated single-room shelter on the Pastor's land. When JR and I visited, we were shocked to see his poor condition. By his own admission, he recognised that he was very frail, however he scored 2 from 6 according to the B-FIT screening tool, ("pre-frail" category).

JR: Grandfather do you see that you are very frail?

Mzee Massawe: Very

JR: Very?

Mzee Massawe: You find I am frail and I have a lot of thoughts[92]*.*

He had fallen, most likely due to being dehydrated and hungry, and had burnt his hand in the open fire. We discovered that he was relying completely on the haphazard assistance of neighbours or local school children who sometimes offered to help him with chores, such as carrying water or fetching firewood.

Mzee Massawe: If I were a healthy person, wouldn't see things were so bad, but because this time I am lacking, I see it is bad because I don't have someone to greet me in the morning, I don't have someone to…it is just this way since morning I have stayed here till you have entered now.

There is much more implied in the expression *"I don't have someone to greet me in the morning"*. The deeper meaning is that he lacks the reliable daily care which a family would provide. This social isolation he describes is more than a loneliness and earning for company. Taking the framework of *Ubuntu*, not having someone to mutually greet, makes you less of a person. 'Mzee Massawe''s existence is challenging his personhood, and this is perhaps the biggest scarcity of all that he faces.

JR: And babu, do you think the neighbours around here help you?

Mzee Massawe: There was this one who used to help me but he has travelled, he said he will come back.

JR: When will he come?

Mzee Massawe: He will come tomorrow.

[92] Having "a lot of thoughts" is an expression of distress, common in African countries. KAISER, B. N., HAROZ, E. E., KOHRT, B. A., BOLTON, P. A., BASS, J. K. & HINTON, D. E. 2015. "Thinking too much": A systematic review of a common idiom of distress. *Soc Sci Med,* 147**,** 170-83..

JR: Tomorrow?

Mzee Massawe: Eeeh.

JR: And how frequently does the neighbour come to help you?

Mzee Massawe: It is not that he is really very far, every day he comes to help me, he comes from where he is and puts for me some vegetables to help me and places them there, eeh or green vegetables sometimes, he works far and he is an Mchagga but we do respect each other.

JR: How do you think you should be helped?

Mzee Massawe: Just vegetables, ugali and bananas, I don't eat.

JR: Just vegetables and ugali to eat?

Mzee Massawe: Mmh, just give me soup.

JR: Just soup?

Mzee Massawe: Mmh.

This case illustrates the dilemma of being from "outside", and how this socially vulnerable position can add to an older person's frailty. The outsider doesn't fully belong and isn't socially integrated within the village, and in death will have nowhere to be buried. His care is improvisational, not "close" and comes from neighbours and passing children. This form of care fits with the "functional-subsistence discourse", where opportunities for formal financial support (e.g. TASAF[93]) or healthcare waivers (e.g. the exemption policy) have been missed. The second point to draw from this case is the limitation of Sen's capability approach in extreme poverty. 'Mzee Massawe''s first and only request to us, when asked what would improve his situation, was soup with vegetables. Suggesting that hunger and thirst had become overwhelming priorities above all other needs, an example of frailty as "scarcity mindset". In field notes, I listed his many urgent needs:

"From my perspective 'Mzee Massawe' has so many urgent needs, for healthcare; a suprapubic catheter, wound care, antibiotics, nursing. Accommodation; a bed with a

[93] TASAF= Tanzanian Social Action Fund TANZANIA SOCIAL ACTION FUND. 2019 Available: http://www.tasaf.go.tz/ [Accessed 23rd July 2019 2019]. Conditional cash transfers were given through this scheme to the poorest village members, identified by the village committee.

mattress, windows with glass, even flooring, a safe place to cook, a toilet. Food; regular meals with a balanced diet, access to clean water to drink. Clothes; warm, fitting and clean."

After meeting 'Mzee Massawe', we discussed his terrible living situation with the village Chairman, who agreed he would co-operate with us to try to help his situation, but this would take sensitivity, in order not to offend the Pastor. This led to the Chairman contacting the Pastor confidentially, who wished not to be involved. Then the Chairman wrote a letter to the Moshi social work department, requesting an assessment, and to consider him for transfer to Amani Residential Home. Unfortunately, 'Mzee Massawe''s condition deteriorated during this process and he was taken to the regional hospital by a neighbour, where he died. He was buried at the Lutheran church hospital as he had no land and no family to organise a fitting burial, the final act of care (*"Hawana mahali pa kuzikwa"*: They have nowhere to be buried).

Appendix R The four types of discourse, the related themes/sub-themes and how these discourses relate to this study.

Discourse	Themes/sub-themes	What this study adds
Cultural-conformable;	*"Kutunza wazee ni wajibu"*: taking care of the elderly is a responsibility *"Wazee ni hazina"*: The elders are treasure *"Kwasababu wazee wamefanya kazi sana Tanzania"*: Because the elders have worked so much for Tanzania *"Wanaheshimu sana wazee"*: They very much respect elders *"Hawajiwezi"*: They cannot do for themselves/ they have no means of their own *"Najitahidi"*: I strive	Traditional ideals of reciprocity extended beyond the traditional family, to the "Tanzanian Nation". This nationalist and socialist political ideology has been hugely influential, particularly for this age-cohort who spent their younger adulthood under Julius Nyerere's presidency.
Structural-adaptive;	*"Maendeleo"*: Development *"Ninapenda serkali inisaidia"* : I would like the government to help me *"Wazee wakipatiwa mahali"*: The elders should be given a place *"Tunapata dawa"*: We get medicines, particularly *"Tunawaelemisha"*: We teach them	Participants asked for more formal avenues of care, to be provided through the government. The village health committee is a volunteer-led community entity with political origins in Tanzania's socialist past, but today they represent the community's agency for change. Using persuasion, education, advocacy and sometimes practical actions they provide support to frail older people, their households and the wider community.

Discourse	Themes/sub-themes	What this study adds
The calculating-innovative discourse;	*"Wazee wakipatiwa mahali"*: The elders should be given a place *"Wanaokuja na diagnosis zao kichwani"*: They come with their diagnosis in their heads	These data support a general Tanzanian rejection of paid-for institutionalised care for all except neglected "abandoned" older people, or displaced "outsiders", however adult children paying for full-time home-based for their frail parent was acceptable. Due to the poor quality and reliability of services at government health facilities, paying OOP for private healthcare was preferable to some.
The functional-subsistence discourse;	*"Kuna waliotelekezwa"*: There are those who have been abandoned *"Wanatoka nje"*: They come from outside *"Unatakiwe uwe na roho nguvu sana"*: You need to have a very strong heart *"Mzee Massawe"* (see illustrative case history Appendix Q) *"Majirani wakisaidia"*: The neighbours help	This was quite common in the context of family networks failing and in the absence of more formal opportunities for care. Often this constituted frailty as "being in scarcity". Frail older people relied on inadequate and unreliable forms of care, such as begging from neighbours, or simply went without (food, healthcare, and "close" care) in order to survive.

Appendix S Verbal Autopsy codes and corresponding ICD-10 codes by deceased participant

Age, sex, and CFS frailty category	VA code	VA title	ICD-10 code	ICD-10 title
82, male, Managing well	VA-11.10	Intentional self-harm	X83.8	Intentional self-harm by other specified means
80, female, Vulnerable	VA-02.08	Malignant neoplasm of breast	C509	Malignant neoplasm of breast, unspecified
75, male, Vulnerable	VA-01.03	Tuberculosis	A16.9	Respiratory tuberculosis unspecified, without mention of bacteriological or histological confirmation
99, female, Vulnerable	VA-04.05	Congestive heart failure	I500	Congestive heart failure
90, female, Mildly frail	VA-01.13	Acute lower respiratory infections (including pneumonia and acute bronchitis)	J189	Pneumonia, unspecified
89, male, Mildly frail	VA-03.03	Diabetes mellitus	E14	Unspecified diabetes mellitus
87, female, Mildly frail	VA-99	Unspecified causes of death	R99	Other ill-defined and unspecified causes of mortality
85, female, Moderately frail	VA-11.11	Assault	Y09	Assault by unspecified means
75, female, Moderately frail	VA-04.01	Hypertensive diseases	I13.9	Hypertensive heart and renal disease, unspecified
90, female, Moderately frail	VA-11.01	Pedestrian injured in traffic accident	V09	Pedestrian injured in other and unspecified transport accident

Age, sex, and CFS frailty category	VA code	VA title	ICD-10 code	ICD-10 title
95, male, Moderately frail	VA-08.01	Alzheimer disease	G30.9	Alzheimer disease, unspecified
72, female, Moderately frail	VA-04.03	Cerebrovascular disease	I679	Cerebrovascular disease, unspecified
98, male, Moderately frail	VA-02.98	Other specified neoplasms	C67.9	Malignant neoplasm of bladder, unspecified
80, female, Moderately frail	VA-02.03	Malignant neoplasm of stomach	C169	Malignant neoplasm: stomach, unspecified
95, male, Moderately frail	VA-04.01	Hypertensive diseases	I11.9	Hypertensive heart disease
81, male, Severely frail	VA-03.02	Severe malnutrition	E43	Unspecified severe protein-energy malnutrition
80, male, Severely frail	VA-01.99	Infectious diseases, unspecified	A41.9	Sepsis, unspecified organism
89, female, Severely frail	VA-03.03	Diabetes mellitus	E14	Unspecified diabetes mellitus
95, male, Severely frail	VA-98	Other specified causes of death	T83.5	Infection and inflammatory reaction due to prosthetic device, implant and graft in urinary system
95, female, Severely frail	VA-08.01	Alzheimer disease	G30.9	Alzheimer disease, unspecified
62, male, Severely frail	VA-04.99	Diseases of circulatory system, unspecified	I70.262	Atherosclerosis of native arteries of extremities with gangrene, left leg
75, female, Severely frail	VA-04.03	Cerebrovascular disease	I629	Intracranial haemorrhage (nontraumatic), unspecified

Age, sex, and CFS frailty category	VA code	VA title	ICD-10 code	ICD-10 title
79, Male, Very severely frail	VA-04.03	Cerebrovascular disease	I679	Cerebrovascular disease, unspecified
90, female, Very severely frail	VA-04.03	Cerebrovascular disease	I679	Cerebrovascular disease, unspecified
110, female, Very severely frail	VA-98	Other specified causes of death	A41.9	Sepsis, unspecified organism
87, female, Very severely frail	VA-99	Unspecified causes of death	R99	Other ill-defined and unspecified causes of mortality

Appendix T Medical certificate of Cause of Death assigned from VA questionnaire data

Age and sex	CFS score	Part Ia	Ib	Ic	Part II
82, male	3	Suicide by hanging			Likely gastrointestinal malignancy
80, female	4	Pneumonia	Malignant neoplasm of the breast		
75, male	4	Respiratory tuberculosis			
99, female	4	Congestive Cardiac failure (unknown aetiology)			
90, female	5	Pneumonia			Hypertension
89, male	5	Hyperglycaemic coma	Diabetes mellitus		Chronic Liver and kidney disease
87, female Unable to assign COD	5				
85, female	6	Brain injury	Assault		HIV-infection
75, female	6	Congestive heart failure	Hypertension		Chronic kidney disease, Chronic Obstructive Pulmonary Disease

Age and sex	CFS score	Part Ia	Ib	Ic	Part II
90, female	6	Congestive Cardiac failure	Lower respiratory tract infection	Road-traffic accident leading to fractured humerus	Frailty
95, male	6	Aspiration pneumonia	Alzheimer disease		BPH, frailty
72, female	6	Aspiration pneumonia	Stroke		Diabetes Mellitus, Dementia, Hypertension
98, male	6	Bladder cancer			frailty, Benign prostatic hypertrophy
80, female	6	Metastatic gastric cancer			Hypertension, Ischaemic heart disease
95, male	6	Congestive heart failure	Hypertension		
81, male	7	Malnutrition			Frailty
80, male	7	Septicaemia	Urinary tract infection		Chronic kidney disease, Dementia
89, female	7	Pneumonia	End-stage renal failure	Diabetes mellitus	
95, male	7	Septicaemia	Long-term catheter-associated infection	Prostatic hyperplasia	Frailty

Age and sex	CFS score	Part Ia	Ib	Ic	Part II
95, female	7	Alzheimer disease			Frailty
62, male	7	Gangrene	Acute ischaemic limb	Peripheral vascular disease	Hypertension, stroke
75, female	7	Intracranial haemorrhage	Hypertension		
79, Male	8	Aspiration pneumonia	Stroke		Frailty, pressure sore
90, female	8	Aspiration pneumonia	Stroke		Frailty, Hypertension
110, female	8	Septicaemia	Infected foot ulcer		Stroke, dementia, frailty
87, female Unable to assign COD	8				Frailty

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