

Values and Decision-making within an Acute Medicine Service

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Abstract

Theoretical frameworks of values in healthcare tend to come in one of two kinds: monism and pluralism. However, both value-monism and value-pluralism prove inconsistent and unrealistic when applied to controversial cases. The lack of clarity about values in healthcare contributes to the contentious nature of key concepts in decision-making, such as sickness and futility.

The prominent decision-making models considered in this thesis are substituted decision-making, supported decision-making, shared decision-making, dual process theory, values-based practice and values-based medicine. Whilst each has its strengths, each model fails to provide a compelling account of the role of values in decision-making, on the grounds of arbitrariness, incompleteness or ambiguity.

A lack of clarity about the role of values in decision-making is particularly problematic in busy and pressured clinical environments. An Acute Medicine Service (AMS) is a part of a hospital which is dedicated to the early management of medical emergencies. The workload of an AMS entails a heavy decision burden concerning a broad range of clinical problems under time pressure.

In this ethnographic study, I was participant-observer within an AMS over a period of 16 months. This involved numerous informal interviews and 27 formal interviews with staff, patients and relatives. A thematic analysis of empirical data, borrowing insights from the tradition of philosophical hermeneutics, provides a plausible interpretation of the role of values in decision-making within an AMS.

The data I present are organised around three main themes: *restoring order*, *working together* and *what's best*. Within an AMS, a course of action is appraised according to three values: *welfare*, *choice* and *effectiveness*. These values are interdependent in a manner distinct from monism and pluralism. The implications of these findings for the philosophy of medicine and clinical decision-making are discussed, with some suggestions for future prescriptive models and further research.

Dedication

To my wife, Ashleigh:

For, up on this, not giving

And, upon this, forgiving.

Acknowledgments

I could not have continued this journey, nor even started it, without the persistent support of others along the way. If I have reached a finish line, it is as much a sign of dependence as any competence.

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For the simplicity on this side of complexity, I wouldn't give you a fig. But for the simplicity on the other side of complexity, for that I would give you anything I have.

Oliver Wendell Holmes

Chapter 1. Introduction

What is the role of values in decision-making within an Acute Medicine Service (AMS)?

In some ways, this is not a new question. Value theory has an extensive history within philosophy. It features persistent areas of difficulty: What are values? How many values are there? How are evaluative judgments justified? In some ways, however, this *is* a new question. Whilst philosophical difficulties about values may be old, even ancient, the application of these questions to decision-making within the context of an AMS is a novelty.

However, I seek to address this question not in view of its mere novelty but in view of its importance for contemporary healthcare. Over the past 30 years, there has been a great deal of attention given to values within healthcare; organisations, professions and individuals are all said to have values. Likewise, a great deal of attention has been given to decision-making within healthcare, with new models of good clinical decision-making being proposed and promoted.

However, relatively little attention has been paid to the relation between these two areas: values *in* decision-making. Values within healthcare have been proclaimed more than studied and displayed more than scrutinised. Perhaps this is because values are seen to raise questions that cannot be answered, or raise answers that cannot be questioned.

Similarly, models of good decision-making within healthcare make assumptions about values in order to endorse the model as *good* decision-making. Such prescriptive models are reflected in professional and legal guidance, and are frequently intended to apply broadly across healthcare settings including an AMS. However, there has been relatively little literature relating to how decision-making within an AMS is actually done. As a result, decision-making models are expected to be enacted within an AMS without adequate consideration of the theoretical or practical context of their implementation.

This thesis consists of a circular journey in four stages¹. Firstly, I critically explore theoretical issues in the philosophy of medicine and clinical decision-making models. I demonstrate that what is problematic about these issues is an inadequate account of *values* (Chapters 2-3). Secondly, I contextualise these issues within the relatively new entity of an AMS (Chapter 4). Thirdly, I provide a plausible account of how values are involved in decision-making within an AMS, based on ethnographic and interview data (Chapter 5-7). Fourthly, I return to theoretical issues in the philosophy of medicine and clinical decision-making models in light of empirical findings (Chapters 8-9).

¹ This is articulated later in terms of a research question and 6 sub-ordinate questions (see: Chapter 5 *Aim and objectives*).

In Chapter 2, I identify two key concepts in healthcare decision-making: *sickness* and *futility*. A critical exploration of different concepts of sickness draws connections between epistemological approaches, ontological preconceptions and fundamental values. Turning to futility, I note that the concept of futility has been characterised to a very limited extent in current literature. This is related to frameworks of the goals and values of healthcare. A search for a consistent and realistic framework ends in disappointment.

In Chapter 3, I review prominent models of clinical decision-making, categorised by therapeutic relationship (paternalism and anti-paternalism), cognitive speed and values-consciousness. I argue that the tension between paternalism and anti-paternalism reflects an underlying tension between competing fundamental values, the selection of which is *arbitrary*. A prominent model of clinical decision-making adapted from research in cognitive psychology shows promise. However, its anthropology seems reductionistic and its account of values seems *incomplete*. Values-conscious clinical decision-making models are more philosophically sophisticated but nevertheless exhibit *ambiguity* in important respects.

In Chapter 4, I paint a picture of what an AMS is, according to contemporary literature. Simultaneously a medical specialty, an organisational unit and a place for healing, an AMS is difficult to define. The priorities of an AMS include managing patients urgently, in addition to other priorities that may pull in other directions. An AMS is thus an environment in which decision-making is both pressured and stretched. If a lack of understanding of the role of values in decision-making is problematic, this problem may be felt most exquisitely within an AMS.

In the methodology, Chapter 4, I describe the way in which I strive to provide a plausible account of how values are involved in decision-making within an AMS. My empirical methodology is an ethnography of an AMS with semi-structured interviews. My analytic methodology is a thematic analysis of interviews and field notes that borrows from the discipline of philosophical hermeneutics. In this chapter I also reflect on how I found being in the field.

In chapters 6, 7, and 8 I present my interpretive analysis of empirical data. Each chapter relates to one of three major themes: *restoring order*, *working together* and *what's best*. Each chapter features a triad.

In *Restoring order*, there is a triad of problems. The single aim of an AMS is to restore order but this involves addressing three kinds of problem. When one kind of problem is not helped, participants have a sense of futility. The nature of this futility depends on the kind of problem that goes unaddressed.

In *Working together*, there is a triad of needs. Within an AMS, people restore order by working together to alleviate needs. Although this is a single collaborative effort, there are different portrayals of what the need actually is: professional need, personal need and organisational need. Sometimes all three needs are

satisfied harmoniously. When one kind of need is overlooked, however, participants experience what I have termed 'cacophony'. The nature of this cacophony depends on the kind of need which remains unalleviated.

In *What's best*, there is a triad of values. Within an AMS, people work together to restore order by figuring out what course of action is best. A course of action is appraised according to three values simultaneously: *welfare*, *choice* and *effectiveness*. Sometimes a course of action is endorsed by all three evaluative standards. At other times, a decision involves value conflict, which is when things become more difficult.

In the discussion, chapter 9, I recapitulate the narrative of the data chapters by presenting a 'trivalent' approach to decision-making within an AMS. I then employ this trivalent framework as a tool by which to critically appraise the theoretical issues raised in Chapters 2 and 3.

Finally, Chapter 10 summarises the connections between this empirical study and the theoretical terrain in which it is situated. This interpretive account of the role of values in decision-making within an AMS proves fruitful ground for responding to some of the theoretical issues in the philosophy of medicine and clinical decision-making, whilst also raising new questions for the future.

Chapter 2. Philosophy of Medicine

In this chapter, I identify the lack of a framework of values in healthcare that is adequate to account for decision-making in times of conflict. In order to demonstrate this, I use two starting points. Firstly, an exploration of the concept of sickness draws connections between epistemological approaches and fundamental values. Fundamental values can endorse incompatible courses of action, manifesting as insoluble conflict in decision-making. Secondly, an extended exploration of the concept of futility shows the inadequacy of monist and pluralist accounts of the goals and values of healthcare in controversial cases.

This chapter lays the theoretical groundwork for Chapter 3, which considers the frameworks of values to which contemporary decision-making models are committed.

2.1 Two key concepts in healthcare decision-making

2.1.1 Sickness

There is a range of terminology which can be used to describe the opposite of being *well*. Such terms include *sickness*, *illness*, *disease* and *dysfunction*. There is an extensive body of literature on the history of such terms and their distinguishing features. For instance, 'illness' is typically portrayed as emphasising the lived reality of a medical condition in contrast to 'disease' or 'dysfunction', which emphasises the aberrant physiology of a body part (Boorse, 1999; Fulford, 2000). It is beyond the scope of this thesis to explore each of these terms in detail. Instead, I seek to characterise this cluster of non-health terms; namely, what it is to not be well. For this purpose, I use the broad notion of 'sickness' to represent this cluster of unhealthy terminology.

Susan Sontag famously contrasts being well with being sick in the poetic opening to *Illness as Metaphor*:

'Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place' (1983: 3).

Upon identification as 'citizens of that other place', people become patients: the sick. In general terms, the recognition of sickness is usually the motivation for clinical attention and the justification of clinical intervention.

More specifically, a recognition of sickness by a patient, relative or clinician marks the beginning of the process of healthcare decision-making. Some survey studies have shown that adults ordinarily experience symptoms on a regular, even daily, basis (Dunnell and Cartwright, 1972; Banks *et al.*, 1975). However, it is only once these symptoms are interpreted as a possible illness that a patient would seek medical attention, concerned that 'all is not well' (Armstrong, 2003: 3). Likewise, it is only once a patient's presentation resembles an illness that a clinician would typically intervene. A patient's experience and a clinician's

assessment are thus hermeneutic enterprises that assess whether the clinical information *means* the patient is sick (2003: 3–14).

However, it could be countered that there are instances when an intervention is administered prior to any recognition of sickness. For example, a general practitioner (GP) may prescribe statin medications to prevent a myocardial infarction even if the patient has never experienced any symptoms of cardiac ischaemia². Secondly, a child may be immunised against polio-myelitis despite not showing any signs of contracting this disease. Thirdly, a patient on an Acute Medicine ward in a comatose state could be administered steroids in the absence of a diagnosis.

The decision to initiate even such treatments as these, though, is still prompted by the recognition of a significant *risk* of sickness³. In the first example, a GP may prescribe statin medication if the *risk* of cardiovascular disease is sufficiently high to warrant it. In the second example, a child may be immunized against polio-myelitis because the *risk* of contracting the serious disease in the future is sufficient to warrant the extremely low harm of the intervention⁴. In the third example, the woman in a coma has a greatly increased *risk* of steroid-responsive sickness (and a near-certain risk of sickness of some kind, given that healthy people do not come in comatose states.)

There are undoubtedly exceptions to the rule that a recognition of sickness, or risk of sickness, represents the start of healthcare decision-making. Sometimes healthcare decisions are made on the basis of resource limitations and personal demands which, arguably, are not necessarily related to a recognition of sickness. Nevertheless, recognising (risk of) sickness is an important early step in healthcare decision-making. As a result, how 'sickness' is conceived is an influential part of this process.

Sontag's metaphor of 'dual citizenship' (1983: 3) is a caution against posing a false dichotomy between well-being and sickness. Bearing this warning in mind, I offer a brief taxonomy of well-being and a brief taxonomy of sickness. These taxonomies are epistemological rather than ontological. Rather than describing different *states* of well-being and sickness (such as getting a pay rise or breaking a leg), I intend to describe their different *conceptualisation*.

² 'Cardiac ischaemia' refers to a lack of blood flow to the heart. This tends to be caused by coronary artery disease and is a risk factor for subsequent myocardial infarction.

³ In some instances, an increased risk of illness is itself considered an illness. This is the case in asymptomatic essential hypertension, for example, which is recognised as a predisposition to acute cardiovascular events such as stroke or myocardial infarction.

⁴ There is also an additional benefit of achieving herd immunity, if there is widespread uptake of immunisation across a population.

2.1.1.1 Two kinds of well-being

In an appendix to his influential book *Reasons and Persons*, Derek Parfit proposed a categorisation of theories of well-being: hedonism, desire-fulfilment theories and objective list theories (1984: 493ff.). Philosophers of medicine have subsequently followed Parfit's division into subjectivist theories of well-being (such as hedonism and desire-fulfilment) and objectivist theories (such as objective list theories). Subjectivist theories have been described as models of 'taste' and objectivist theories as models of 'perception' (Griffin, 1996: 20 ff.). As philosopher of medicine Thomas Schramme puts it: 'Either something [such as well-being] is valuable because it is desired (taste model) or something is desired because it is valuable (perception model)'⁵ (Schramme, 2017: 161).

According to this categorisation, both a subjectivist approach and an objectivist approach could deem the same person to be *well* for different reasons. The two kinds of reasons are described by Parfit's colleague, James Griffin, as 'states of mind' reasons and 'states of the world' reasons. The former improve the amount of pleasure experienced in the world and the latter improve the conditions in the world (1986: 7–20). The two kinds of reason are inevitably linked: improving people's states of mind constitutes a change in the world, and improving the world may bring about a change in people's states of mind. Nevertheless, the two approaches could be said to deal in a slightly different utilitarian currency.

Griffin transposes Parfit's subjectivist - objectivist framework into a binary taxonomy of his own. According to Griffin, there are two main conceptualisations of well-being, the first of which is a *desire* account. A desire account conceives of well-being as the fulfilment of what people want (*actual-desire*) (1986: 10); a narrower desire account might improve on this by restricting well-being to the fulfilment of only what is *rationaly* wanted (*informed-desire*) (1986: 11). Despite this amendment, Griffin acknowledges a weakness of this approach once other people are introduced into the picture:

'Why should I accept that your mere desires make a claim on me? You may, when informed, want champagne, but if you do not need it, why should my obligations to you be at all engaged?' (1986: 40).

Hence Griffin supplements the desire account with a second conceptualisation: the *need* account of well-being. He draws a contrast between the two as follows:

'Desires have to do with how a subject of experience looks out on the world; needs have to do with whether one thing is in fact a necessary condition of another' (1986: 41).

⁵ Schramme goes on to introduce a second way in which objectivist and subjectivist theories can be categorised, according to a value-laden or value-free dimension (2017).

Griffin endeavours to loosely distinguish between ‘instrumental needs’ and, morally weightier ‘basic needs’, defining the latter as ‘what we need to survive, to be healthy, to avoid harm, to function properly’ (1986: 42). Without using the word, Griffin’s depiction of human need entails a vision of human *flourishing*, a vision of the good life which is beyond mere opinion.

Despite carving his binary taxonomy of well-being along the subjectivist-objectivist axis inherited from Parfit, Griffin comments that this need not be a strict dichotomy; there is scope for an ‘eclectic concept’ that borrows from both sides of the debate (1986: 42). It is not my interest here to take sides in this debate; rather, I wish to identify what the debating sides are. As Schramme notes, ‘the philosophical debate on well-being is mainly concerned with the problem of whether it is subjective or objective’ (2017b: 168), namely, whether being well is a ‘mode of consciousness or of existence’ (2017b: 159). Proponents of the latter tend to presuppose a vision of perspective-independent human flourishing⁶ (2017b: 163).

In summary, the way well-being is conceptualised can be grouped into two broad approaches. A *subjectivist* approach conceives of well-being in terms of pleasure, taste, states of mind, desires and modes of consciousness. An *objectivist* approach, in contrast, conceives of well-being in terms of an objective list, perception, need and perspective-independent human flourishing.

2.1.1.2 Two kinds of sickness

Having sketched two ways of conceptualising well-being, I turn to do the same for one of well-being’s antonyms, sickness. As with well-being, one approach approximates to an objectivist approach and the other to a subjectivist approach.

2.1.1.2.1 Biomedical model

The biomedical model of sickness is associated with the object-oriented and laboratory-oriented cosmologies in the history of medicine (Jewson, 1976). Nevertheless, it continues to be a prominent theoretical approach today, and its proponents can be broadly grouped into two camps: *naturalists* and *normativists*. The former consider sickness to be a value-free category whereas the latter acknowledge medical categories such as sickness to be inevitably value-laden (Kingma, 2017). According to normativists, to have a disease or illness is to have something which is *bad* or *harmful* in some way (Margolis, 1976; Agich, 1983; Cooper, 2002). What both camps agree on, however, is that having a disease (defined as biological dysfunction) is a necessary condition of being sick.

For instance, Christopher Boorse is a biological naturalist who equates health with normality. An organism is healthy ‘insofar as its mode of functioning conforms to the natural design of that kind of organism’ (1999,:

⁶ Some authors might seek a basis for objective standards of human living by appeal to John Rawls’ primary social goods (1971). This, I contend, is simply another preconception of human flourishing, albeit one which is minimally characterised.

20). Boorse intentionally builds on C. Daly King's early attempts to define health and normality 'objectively... as that which functions in accordance with its design' (1945). As one author summarises it, a biostatistical account 'defines health as normal function and normal function as the statistically typical contribution to survival and reproduction in a reference class' (Kingma, 2017: 52). To be sick, on this account, is to function abnormally.

Normativists also construe sickness as biological dysfunction but are more explicit about the value-laden nature of the proper function: sickness is dysfunction-plus-harm. For example, neo-Aristotelians evaluate a condition as healthy or ill with reference to a presupposed view of flourishing: 'to be a good entity of some sort is to do the kind of things that that sort does' (Kingma, 2017: 59). On a neo-Aristotelian account, then, an eye that fails to see is not flourishing because seeing is what eyes do (and are supposed to do).

I do not intend to provide a full critique of the biomedical model of sickness. For the purposes of this thesis, what is significant is that the biomedical model endeavours to conceptualise sickness in *objective* terms. To be sick is to fail to flourish in some way. For the naturalist, this failure to flourish takes the form of statistical abnormality associated with an impediment to evolutionary progress. For the normativist, it takes the form of failing to function as something *should* function. Whilst a biomedical model does not exclude the lived reality of sickness⁷, *feeling* sick is not a necessary condition of sickness; what sickness requires is biological abnormality compared to a vision of proper function. In this sense, the biomedical model is an objectivist approach to defining sickness.

2.1.1.2.2 Social constructionism

2.1.1.2.2.1 Biographical disruption

However, some authors find the biomedical model of sickness unsatisfactory. Biological approaches, including biostatistical as well as neo-Aristotelian models, draw lines around what is proper and what is not. As biologist-turned-bioethicist Jackie Leach Scully comments, 'the lines drawn around normality, abnormality and disability are not self-evident. These lines determine many moral choices in research and healthcare, and they shift according to experience and perspective' (2004: 652). Biological functionalist models appeal to science for their legitimacy. However, as Scully continues, 'science does not stand above the culture in which it operates, and the influences flow both ways' (2004: 652).

The biomedical model of sickness tends to overlook the socially constructed aspect of the concept of sickness. Instead of simply contrasting someone's physiology with a biological norm, some social

⁷ Biological naturalist Thomas Szasz arguably comes close to this in his provocative work *The Myth of Mental Illness* (1962). However, Szasz is not here denying the *reality* of psychological and social phenomena; rather, he is challenging the *diagnostic sufficiency* of such phenomena.

constructionist approaches to sickness portray it as a culturally-embedded disruption in personal identity: a biographical disruption⁸ (Bury, 1982; Mattingly, 1991). Havi Carel writes:

‘Becoming ill creates a need to find meaning for a new narrative: the narrative of health that has now been disrupted by illness’ (2013: 98).

As well as biographical disruption, sociological accounts of sickness feature the related notions of ‘symbolic transformation’ (Fleischman, 1999), ‘loss of self’ (Charmaz, 1983) and perhaps most famously ‘narrative reconstruction’ (Williams, 1984), which is ‘the key process ill patients need to go through as they try to make sense of their own life stories and the place of illness within them’ (Armstrong, 2003: 76). According to a social constructionist approach, the patient who breaks a collar bone suffers more than a fractured clavicle; she experiences a fracture in her experience of life. A wounded organ is accompanied by a wounded life. There may conceivably be occasions when there is in fact no evident biological dysfunction but nevertheless the patient is sick, suffering an interrupted life story.

If sickness is socially constructed in this way, to *feel* unwell is to *be* unwell⁹. There is no necessary appeal to biological dysfunction or statistical norms; what counts is the patient’s experience of the world. Sickness is not just something in the world, it is something in the *life-world*. The recognition of sickness is not measured by any scientific, objective, circumstantial yardstick; rather, sickness is recognised by its intrusion into the story of someone’s authentic being-in-the-world (Carel, 2017). In this way, a social constructionist model could be described as a subjectivist approach to defining sickness.

In summary, the two prominent models of sickness that I have presented are reflective of the two kinds of well-being described above. There is an objectivist (need-based) approach to well-being and an objectivist (biomedical) approach to sickness, both of which make appeal to a vision of human flourishing. There is a subjectivist (desire-based) approach to well-being and a subjectivist (social constructionist) approach to sickness, both of which make appeal to aspects of personal experience.

However, this does not exhaust the range of conceptualisations of well-being and sickness. In what follows, I present a third theoretical approach that could be considered another kind of social constructionism, albeit one that is not defined by personal experience in the same way.

⁸ In this sense social constructionism could more accurately be termed *psychosocial* constructionism.

⁹ This subjectivity need not be construed individualistically. On a social constructionist model, it is not merely the sick person’s subjectivity that counts but also the *inter-subjectivity* of the community in which the sick person is situated; the sick person identifies as, and is identified by others as, unwell.

2.1.1.2.2.2 Genealogy

In *The Genealogy of Morals* (2003) and *Beyond Good and Evil* (1990), philologist Friedrich Nietzsche characterises the history of moral philosophy as a power play which is merely disguised as the logical deliberation of ethical ideals; rather than the desire for truth, evaluative judgments are reflective of the ubiquitous 'will to power' (1990, 2003). Appeals to authority, such as result from belief in God, supposedly function as a psychological means of soothing the *ressentiment* of the impoverished and powerless. A change in authority, such as a conviction that 'God is dead and we have killed him' (1974) would result in a revolution in evaluative standards, and an acknowledgement of *perspectivism* – 'the doctrine that any belief is just an interpretation of the world from a particular point of view, there being no objective authority for values' (Hicks, 2003: 77).

The Nietzschean themes of power and the 'revaluation of all values' (Hicks, 2003: 72) were picked up by Foucault and applied to contemporary institutions such as the prison, the asylum and the clinic (1975, 1984). Foucault identified several means by which the medical profession has historically maintained its powerful posture in society, such as by 'hierarchical observation, normalizing judgment, and examination' (May, 1992: 42–43). Authoritative evaluations within a clinical context are not simply the product of neutral, rational professionals; rather, they are the product of those in charge procuring their agenda through 'anatomopolitics of the human body' and 'bio-politics of the population' (Foucault in May, 1992: 40). In Foucauldian terms, the professional's evaluation of a patient's situation is not merely the result of the clinician's position of power but also constitutive of it. As Hicks summarises:

'Foucault shows that... what is made manifest by these hidden power relations are the disciplinary practices and institutions whose aim is to 'normalize' and 'standardize' human life' (2003: 98).

The perspectivism that Nietzsche and Foucault so fervently preached does not deny the reality of diagnosis or the knowledge of illness. Rather, they recognise that such knowing has an overlooked primary function:

'Knowledge is not made for understanding; it is made for cutting' (Foucault in May, 1992: 154).

On this account, a diagnosis of sickness is not primarily a truth claim about a state of affairs; it is a tool with the power to bring about an effect. It is architectural or, to return to Nietzsche's terminology, genealogical.

Feminist critic, Susan Sherwin, also characterises the role of the medical tradition in genealogical terms:

'With its authority to define what is normal and what is pathological and to coerce compliance to its norms, medicine tends to strengthen patterns of stereotyping and reinforce existing power inequalities' (Sherwin, 1992: 22).

On this view, the controlling influence of the medical tradition is not limited to dramatic controversies. Rather, it extends into the everyday process of diagnosing illness, by way of regulating what is normal; 'exactly what constitutes disease, degeneration, defect or deficit... is decided by reference to a biomedical norm' (Scully, 2004: 651), over which the profession is sovereign¹⁰.

According to a genealogical approach, then, sickness is a concept which is used to procure the agenda of those in charge. Like biographical disruption, genealogy could be described as a social constructionist approach that defines sickness in experiential terms. However, rather than being rooted in the experience of a person's challenged identity, genealogy is rooted in the experience of humanity's 'will to power' (1990, 2003).

I have presented one objectivist account of sickness and two subjectivist accounts. To conclude, I illustrate these with an imaginary case.

Winston Glover is admitted to an Acute Medicine ward with swollen legs and feeling breathless on minimal exertion. On the ward, he is assessed by three doctors, all of whom agree that Winston is sick.

Dr Biomedicine looks across at Winston's ECG and notes an abnormally fast heart rate; he looks at Winston's chest X-ray and notes an abnormally wide heart shadow with abnormal amounts of fluid present in the pleura either side: "yes, heart failure", Dr Biomedicine concludes.

Dr Biography sits at the bedside and listens as Winston tells how he has been lately, compared to how active he usually is. Winston describes his regular hobby of gardening, and his friends down at the vegetable plot. "I see, so this this just isn't you at all!", exclaims Dr Biography before sighing "oh dear, heart failure."

Dr Genealogy has just written the hospital's heart failure protocol, which defines what level of breathlessness is acceptable and what is not. This protocol helps prevent over-treating with expensive medications. "I think it's my heart that's playing up, doctor", says Winston. "I'll be the judge of that", says Dr Genealogy, gazing down alternately between Winston and the proforma boxes she is ticking in front of her, which determine whether Winston meets the criteria for treatment according to the new protocol: "okay, heart failure", she concludes.

¹⁰ A cynical perspective on the medical profession's power was expressed lucidly by Ivan Illich, who noted the toxic societal effects of 'iatrogenesis' and put forward the pejorative notion of 'medicalisation' (1974). The over-reach of medical categories and institutions into ordinary life, which Illich famously described, is a theme which contemporary authors have continued to develop (Conrad, 2005).

Sickness is a key concept in healthcare decision-making. Like its counterpart, well-being, it can be conceptualised in objectivist and subjectivist terms. The objectivist biomedical model is typically defined in functional terms, in relation to human flourishing. The subjectivist social constructionist models are typically defined in experiential terms, in relation to narrative identity or the will to power.

2.1.2 Futility

If the recognition of sickness is the approximate starting point of decision-making in healthcare, futility could be said to represent the end point. Intuitively, death may seem to mark the end of healthcare decision-making. After all, death is the point at which there is no more health to care for. However, drawing this line is problematic, as the following four scenarios illustrate. Firstly, cardio-pulmonary resuscitation (CPR) entails decision-making, yet it is enacted in a physiologically grey area between life and death. Secondly, organ transplantation preparation entails decision-making, where even in death there remains some health to care for: the health of another. Thirdly, a holistic approach to palliative care may deem patient care to continue after death. This may take the form of respecting the deceased's body and providing bereavement support. Fourthly, there are instances when a patient is discharged from a healthcare service not because of death but because there is no more that can usefully be done.

In view of this, it may be more precise to say that clinical care, which may start at the recognition of sickness, ends not necessarily with death but with the recognition of *futility*: when further clinical attention of a certain kind is not worthwhile. Should a treatment be deemed futile by the responsible clinical team, they are under no obligation to provide it (Ardagh, 2000: 398; Biggs, 2007); should a treatment be deemed futile by a patient with capacity who withdraws her consent, she is at liberty to decline it (Herring, 2012: 149). How futility is conceived is therefore very important in healthcare decision-making in general, and the refusal or withdrawal of treatment in particular.

2.1.2.1 Futility in theory

The extent to which the concept of futility has been characterised in medical literature is surprisingly limited, given the influential nature of such an 'ethical trump card' (Weijer and Elliott, 1995: 683). Schneiderman *et al* highlighted the potency of the concept of futility in decision-making:

'Futility is a professional judgment that takes precedence over patient autonomy and permits physicians to withhold or withdraw care deemed to be inappropriate without subjecting such a decision to patient approval' (1990).

Schneiderman *et al* proceeded to provide one of the most well-known depictions of futility, which rests on two criteria. A treatment is futile if it either lacks *impact* or if the impact lacks *benefit* (1990). However, 'benefit' is arguably just as difficult to define: by what standard is benefit to be assessed? To define benefit

in terms of conferring some good is to simply kick the semantic can down the road; 'good' is notoriously difficult to define, as its colourful history in ethics literature demonstrates (MacIntyre, 2002). Yet without further characterisation, futility risks being used as a tool to sidestep proper ethical deliberation, repealing the 'hard gained advances in patient autonomy' (Schneiderman *et al*, 1996).

Some efforts have been made to characterise futility further. Schneiderman *et al* endeavoured to delineate two different kinds of futility. A course of action is *quantitatively* futile if it was useless in the last 100 similar cases; it is *qualitatively* futile if it merely extends unconsciousness or ventilator-dependence (1990). Five years later, Brody and Halevy proposed a four-fold categorisation of futility: physiologic, imminent demise, lethal condition and qualitative futility (1995). Ardagh considers such conceptualisations to have merely "muddied the waters" of decision-making', introducing a new term for the age-old notion of balancing benefits and harms (2000: 399). Others are tempted to give up on the quest of defining futility, instead embracing an attitude of 'while it cannot be defined, we certainly know it when we see it' (Halevy and Brody, 1996: 571).

A more forceful criticism of these conceptualisations is that they fail to address the main philosophical difficulty behind the notion of futility:

'In the most controversial cases in which futility is invoked the disagreement between doctors and families is not about the probability that an intervention will work but about the goals that it will serve' (Weijer and Elliott, 1995: 684).

A therapeutic intervention is futile, then, 'when it cannot alter the likelihood of [a] defined goal emerging into reality' (Mohindra, 2007: 75). However, in practice, the difficulty with the concept of futility is not what it means but what the *goal* of treatment is (Chwang, 2009: 491).

2.1.2.2 Futility, goals and values

Chwang considers previous literature defining futility to have been wrong-headed: 'The concept of futility is univocal and easy to grasp; there is nothing complex or murky about it' (2009: 489). For Chwang, ascertaining what the *goals* of treatment are is the difficulty; defining futility is easy: 'futility is uselessness' (2009: 487).

The concept of futility is difficult to apply because there is often a lack of clarity about the fundamental *goals* of treatment. According to Gillon, this can also be expressed as a lack of clarity about the *values* involved in treatment decisions. Assessing futility involves asking the following question:

'how valuable or otherwise are the outcomes, and according to whose values— patients' or their surrogates', doctors', and other health professionals', managers' or societies' values?' (1997: 339)

In summary, futility is a key concept in healthcare decision-making. There is no consensus on how best to define it. According to Chwang and Gillon, applying the concept of futility requires clarity regarding the *goals* of healthcare treatment and the *values* involved in healthcare decision-making.

2.2 Goals of healthcare

‘It is a simple fact but almost universally ignored in modern thought that when one loses sight of the end of one’s thought and action, the thought and action waver between fanaticism and futility’ (Buchanan in Pellegrino and Thomasma, 1981: 151). If this be the case, then a consideration of medicine’s goals will not just help define futility *in* medicine, but help prevent the futility *of* medicine.

Thomas Schramme, in his study of the goals of medicine, recognises two main approaches to this subject: a *consensual* approach and a *teleological* approach (2017a). A consensual approach tends to yield a plurality of goals (which I refer to as goal-pluralism) whereas a teleological approach tends to yield a single ultimate goal (which I refer to as goal-monism).

2.2.1 Goal-pluralism

It is not a new claim to say that medicine pursues multiple goals. Implicit within the Hippocratic Oath is a range of both positive and negative obligations (Holm, 2017: 396–397). However, The Oath is arguably more explicit about what is *excluded* from the proper scope of medicine than what is *included*. From its wording, it is difficult to characterise the positive goals of medicine beyond the ‘benefit’ of the sick and the prevention of ‘harm and injustice’ to patients (U.S. National Library of Medicine, 2012).

In 1979, Thomas McKeown formulated four core goals of medicine as follows:

1. To assist us to come safely into the world
2. To support us comfortably out of the world
3. To protect the healthy
4. To care for the sick and disabled (in Armstrong, 2003: 130).

Whilst the multiplicity of goals avoids simplistic reduction to a single principle, this strength can also be a weakness. What if goal 1 conflicts with goal 3, such as in the case of an unborn baby coming ‘into the world’ and a mother whose health is threatened by the baby’s safe arrival? The doctor’s duty to ‘assist’ and to ‘protect’ are then in unavoidable conflict. In this way, the goals are potentially incoherent. Putting it more mildly, adjudicating between goals in times of goal-conflict (in the absence of an overarching meta-goal) is *arbitrary*.

When there is competition between multiple goals, decision-makers must use clinical judgment in order to commit to the best course of action. For example, a GP may decide that the sanctity of the baby’s life renders

goal 1 more important than goal 3 and thus express a conscientious objection to abortion (if it were requested). A different GP may decide that the mother's well-being is the primary concern, which may render goal 3 more important than goal 1.

I am not intending here to endorse one goal over the other¹¹. Rather, I am illustrating that it *is* one over the other. In this way, goal pluralism collapses into goal monism. When decision-makers commit to a course of action during times of unavoidable goal-conflict, one goal trumps another. Without an overarching meta-goal to appeal to, such adjudication between competing goals is arbitrary.

In 1996, the Hastings Center published a more precise list of the goals of medicine. Whilst not exhaustive, the list was intended to be a philosophically scrutinised statement of international consensus. Like the earlier 'McKeown thesis' (Bynum, 2008), it features four core goals:

1. The prevention of disease and injury and promotion and maintenance of health
2. The relief of pain and suffering caused by maladies
3. The care and cure of those with a malady and the care of those who cannot be cured
4. The avoidance of premature death and the pursuit of a peaceful death (Hastings Center in Schramme, 2017a: 125)

Whilst the plain reading of each goal may sound commonsensical, there are nevertheless contentious elements in this list. However, my interest here is not so much in problems *within* a single goal but the problems *between* multiple goals. Again, there are occasions when multiple goals come into conflict. Like McKeown's earlier list, then, the Hastings Center's list of goals of medicine also suffers from potential inter-goal conflict, leaving the decision-maker to adjudicate between competing goals. Such adjudication is arbitrary and collapses goal-pluralism (in theory) into goal-monism (in practice).

Other pluralist accounts of the goals of medicine present dualisms such as both caring and curing (Stegenga, 2018), or curing and healing (Szawarska, 2017). My aim is not to provide a thorough investigation of each one. Instead, I wish to illustrate the shortcomings of goal-pluralism in general. No matter how many goals there are, it seems that goal-pluralism in theory collapses to goal-monism in practice. If the goals never conflict, they are arguably the same goal and thus a form of goal-monism from the start. If the goals do in fact come into conflict, then the process of operationalising such a framework collapses into arbitrary goal-monism.

¹¹ This brief description of the case omits contextual details and anthropological considerations, which may be essential for an adequately nuanced ethical evaluation of the situation.

If a course of action is futile insofar as it fails to serve the goals of medicine, and if the ‘most controversial cases in which futility is invoked’ (Weijer and Elliott, 1995: 684) are cases of disagreement about the goals of medicine, then models of goal-pluralism do not contribute much useful ground to the futility debate. The most controversial cases are characterised by unavoidable goal conflict. During unavoidable goal conflict, goal-pluralism collapses into an arbitrary goal-monism in practice. Thus, in the most controversial cases, a goal-pluralist model deems a treatment to be futile insofar as it fails to serve a single goal, the selection of which is arbitrary. This is surely an intolerable conclusion for all but the most hardened of genealogists! Perhaps goal-pluralism’s alternative, goal-monism, will avoid such an ethical *reductio ad absurdum*.

2.2.2 Goal-monism

Goal-monist frameworks tends to be the product of a teleological approach to medicine. A teleological approach is one which ‘sees medicine as a practice with an inherent telos’ (Schramme, 2017a: 121). What kind of ‘practice’ is medicine? I summarise three authors’ responses to this question.

Stanley Hauerwas describes medicine as a *moral* practice ‘constituted by intrinsic moral convictions that are operative even if not explicitly acknowledged’ (1986: 4). Hauerwas notes a false *telos* that is cherished by the modernist narrative of technical mastery, which fosters the illusion that we can overcome our limitations and ‘get out of life alive’ (in Sloane, 2016: 83). Instead, medicine as ‘profession’ must ‘[carry] the wisdom of our finitude’ (1986: 13). Recognising both the inevitability and meaningfulness of vulnerability and mortality, Hauerwas construes medicine’s goal as for ‘patient and physician alike to be present to one another in times of suffering’ in the context of a caring community (1986: 6).

Whilst Hauerwas’ depiction of medicine’s ultimate goal can be summarised in a single sentence, what it entails cannot. What does it mean to be ‘present to one another’? What is a ‘[time] of suffering’ and is it synonymous with an episode of illness? What is a community and what does it mean for it to be caring? What is the role of other healthcare professionals in this portrayal? Whilst Hauerwas offers insightful commentary on the technological-redemption narrative of modern medicine, the theological story in which his own theory is embedded requires much more clarification in order to afford a coherent theological philosophy of medicine (Sloane, 2016: 87). Until such a time, Hauerwas’ goal-monism (in theory) permits such varied interpretations as to function as goal-pluralism (in practice).

Andrew Sloane describes medicine as a *social* practice, according to MacIntyre’s famous (and lengthy) definition:

‘any coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity, with the result

that human powers to achieve excellence, and human conceptions of the ends and goods involved, are systematically extended' (1984: 187)

Sloane acknowledges that, as a socially situated and socially established enterprise, medicine's *telos* is thus intertwined with broader anthropological concerns:

'the nature and justification of medicine as a practice depends on an underlying understanding of humanity and the goods proper to our existence as humans' (2016: 146).

Portraying the central unit of medical practice as the clinical encounter, a central feature of being human as vulnerability, and the central *ethos* of medicine as communitarian care, Sloane is ready to present his goal-monist conclusion:

'[Medicine's] goal is to care for vulnerable people in such a way as to enable them to function as members of their community as well as can reasonably be expected' (2016: 147).

This fundamental *telos* of medicine Sloane paraphrases as 'caring for this frail flesh' (2016: 150).

A strength of Sloane's account is that, as a former clinician, he is alert to the complexity of medicine as a social practice. He acknowledges the political factors shaping healthcare delivery, the phenomenology of illness, the limitations of biomedical science and broader societal influences on the priorities of healthcare.

A weakness of Sloane's account is that, like Hauerwas' account, its goal-monism becomes goal-pluralism when operationalised. What does it mean to 'care'? What are people and how is their vulnerability to be assessed? What does good community-functioning entail? By what standard are expectations appraised as reasonable? The range of answers with which any one of these questions can be met demonstrates that multiple versions of 'caring for this frail flesh' are born as soon as this model is applied. As with Hauerwas, any proclaimed *telos* is only as useful as the clarity, comprehensiveness and consensus of the presupposed narrative in which it is contextualised. In the absence of such *doxa*¹², Sloane's goal-monism (in theory) disintegrates into goal-pluralism (in practice).

By far the most prominent account of goal-monism is the teleological account of physician-philosopher Edmund Pellegrino¹³. Like Hauerwas, Pellegrino construes medicine as a moral practice 'because its end, making right decisions about patients with those patients, involves values' (1981: 151). Like Sloane, Pellegrino also construes medicine as a social practice, whose philosophy emerges from the experience of

¹² 'Doxa' is a Husserlian concept adopted by sociologist Pierre Bourdieu, which the latter used to refer to the subconscious, shared epistemic commitments of members of a social field (Deer, 2008): 'a set of fundamental beliefs which does not even need to be asserted in the form of an explicit, self-conscious dogma' (Bourdieu, 2000: 16).

¹³ Much of Pellegrino's work in the philosophy of medicine was published in conjunction with David C. Thomasma.

the clinical encounter (Sloane, 2016: 90) and 'relates to the more general issues of the good life, the good man [sic], and the nature of man and the cosmos' (Pellegrino and Thomasma, 1981: 281). Unlike both, however, Pellegrino also considers medicine to have a culturally-independent *essence* that 'sets it apart from other activities as an enterprise of a special kind' (in Sloane, 2016: 90).

Pellegrino sees the patient's trust in the physician and healthcare provider as the 'moral center [sic]' of medical practice, 'the moment of clinical truth, that which makes medicine what it is' (Pellegrino and Thomasma, 1981: 270). In view of this moral centre, medicine is charged with making decisions with a particular therapeutic orientation: 'what is best for *this* patient?' (1981: 178). Such decision-making is complex, however, requiring experiential judgement to bridge the gap between 'medicine as assistance and medicine as explanation' (1981: 67).

Characterising the *telos* of medicine is a major focus of Pellegrino's work in the philosophy of medicine. As he puts it, medicine 'suffers from an abundance of means and a poverty of ends' and 'cannot be successful until it knows exactly what it is trying to achieve' (1981: viii). Although aware of the divergence of opinion on this subject, Pellegrino emphasises the 'curative intention' of medicine as its ultimate goal:

'This curative intention is an end-in-view. It is immediate enough in most cases so that it can function as the objective of the physician-patient relationship. In this way, it acts as a definer of the relationship and a source of judgment about whether or not a good medical decision has been made' (1981: 67).

The curative inclination of medicine entails an instrumental value, healing, and an intrinsic value, health (1981: 282). Thus, on this teleological account, *promoting health* is the ultimate goal of medicine. In *Helping and Healing*, health is defined subjectively as 'that state in which we feel able to do the things that we wish to do with a minimum of pain and discomfort' (1997: 15). However, elsewhere Pellegrino states that promoting health also must minimally involve 'organic restoration' (1981: 72).

Despite Pellegrino's painstaking efforts to characterise medicine cautiously, with due attention given to philosophical considerations, practical realities and clinical experience, his goal-monism nevertheless succumbs to the same instability as the previous two examples.

Medicine is a hermeneutic enterprise (Svenaeus, 2010). As a result it is possible, even inevitable, that its major doctrines afford a range of interpretations. For example, it is disputable whether curing and healing are as synonymous as Pellegrino supposes (Szawarska, 2017). Pellegrino's subjectivist definition of health, combined with a vague notion of organic restoration, leaves this *telos* very difficult to circumscribe. For example, is someone who is addicted to narcotics made healthier by a heroine injection, after which she

feels able to do the things she wishes to do with minimal pain and discomfort? One interpretation of Pellegrino might say “yes”, another interpretation might say “no”. Such hermeneutic conflict could be considered conflict *within* a goal: *intra*-goal conflict. Insofar as this is the case, Pellegrino’s goal-monism (in theory) disintegrates into goal-pluralism (in practice).

2.2.3 Unity and diversity

This brief exploration of goal-pluralism and goal-monism leads to a curious conclusion. The theoretical diversity of goal-pluralism collapses into goal-monism in times of inter-goal conflict. The theoretical unity of goal-monism disintegrates into goal-pluralism in times of intra-goal conflict. Diversity unifies and unity diversifies. Either way, theory does not translate to practice. Both goal-pluralism and goal-monism, then, are inconsistent and unrealistic frameworks by which to conceive the *telos* of medicine.

As a reminder, this exploration of goal-pluralism and goal-monism was prompted by an analysis of the concept of futility. Whether or not a course of action is futile depends on the *telos* of healthcare. It is futile if it fails to serve this teleological goal (or set of goals). In the most controversial cases of invoking ‘futility’, there is dispute as to what exactly the *telos* of clinical efforts actually is. This could take the form of inter-goal or intra-goal conflict. A consideration of goal-pluralism and goal-monism has not resolved this problem. Whether a goal-pluralist or goal-monist theory is employed, such a teleological framework is inconsistent and unrealistic when applied to cases of controversy.

An exploration of the concept of futility has led to a critical appraisal of the goals of medicine. I have failed to find a framework of goals that can be consistently and realistically applied to cases of controversy in clinical practice. Instead of ‘goals’, I now turn to an alternative normative category, one which is of central importance to this thesis: *values*. After exploring what values are and how many there are, I will return to consider how values relate to the concepts of sickness and futility.

2.3 Values of healthcare

2.3.1 What are values?

2.3.1.1 In philosophy

The theory of values has been a prominent theme in philosophy since David Hume drew a distinction between ‘is’ statements and ‘ought’ statements in his 1740 book *A Treatise on Human Nature* (Hume, 1978). Hume described a *non sequitur* which results from confusing ontological and ethical categories, which came to be known as the naturalistic fallacy. Seeking to avoid this error, subsequent thinkers adopted a ‘facts-and-values’ paradigm, in which the categories of description and prescription were neatly unmixed (Davydova and Sharrock, 2003; Hughes, 2011, pp. 3–28); facts related to matters of *truth*, values related to matters of *goodness*.

The facts-and-values paradigm continued to exercise influence in moral philosophy. This is evident in the model of prescriptivism presented by R.M. Hare in *The Language of Morals*, in which descriptive utterances are sharply distinguished from prescriptive ones (1963). However, this dichotomy has received fierce criticism within philosophy and sociology.

Within philosophy, John Searle showed that certain facts that he called 'institutional facts' already entail evaluative notions such as 'obligations, commitments and responsibilities' (1969: 190). Others remarked that categorising human judgment by way of descriptive and prescriptive utterances is an absurd reduction in the first place. One author paraphrases Iris Murdoch on this topic (1970) by describing valuation as 'a more or less continuous part of our waking experience' (Sayer, 2011, p. 26).

Within sociology, Alfred Schutz pointed out that the facts-and-values paradigm overlooks some of the complexities of human nature, confusing people for empirical 'puppets' (Davydova & Sharrock 2003: 363). One such complexity is that description and evaluation are inextricably intertwined. Alfred Louch explains:

'There are not two stages, an identification of properties and qualities in nature and then an assessment of them... There is only one stage: the delineation and description of occurrences in value terms' (1966: 85).

Hume's problem, that an 'ought' cannot be derived from an 'is', sent much of modernist moral philosophy on an epistemological wild goose chase. As one author summarises it, 'this way of framing this question comprehensively misses the point' (Sayer, 2011: 19). In contrast to Hume and his modernist followers, an approach which acknowledges the inherently integrated nature of facts and values has come to be known as the 'facts-plus-values' paradigm¹⁴ (Fulford, 1999).

However, discussion of the *relationship* between values and facts does not provide a workable *characterisation* of what values are. The term 'values' has such a broad and nebulous semantic range that George Orwell listed it as one of the most useless words in the English language (2013: 5–8)! For the purposes of this study, I will characterise what I mean by values by drawing on two sources: one ancient and one contemporary.

Aristotle opens his *Nicomachean Ethics* with a discussion of what 'good' is. In this account, some goods are subordinate to other goods. *The good* is 'that at which all things aim' (1941: 935). The chief good must be something 'which we desire for its own sake' (1941: 935). Having commended the political life and the

¹⁴ This bears many similarities to the 'values within reason' paradigm described by social scientist Andrew Sayer (2011).

contemplative life in passing, Aristotle eventually identifies the chief good as happiness¹⁵, which is ‘the best, noblest, and most pleasant thing in the world’ (1941: 945); it is ‘final and self-sufficient, and is the end of action’ (1941: 942). For the purposes of this thesis, however, what is of interest is not so much Aristotle’s nomination of happiness as chief good but the characterisation that he offers next.

Is happiness ‘among the things that are *praised* or rather among the things that are *prized*’ (1941: 949, emphasis added)? This is the question to which Aristotle turns. Things which are praised are commended with reference to some standard which is presupposed as good. For instance, Aristotle says that a strong man and a good runner are praised because they are ‘related in a certain way to something good and important’ such as strength and speed (1941: 949). In contrast, things which are prized are not praised with reference to some other standard. Prized things are ‘more divine and better’ (1941: 949). Rather, it is ‘by reference to these all other things are judged’ (1941: 949–950). To Aristotle, happiness is not something praised but prized; it is with reference to happiness that other things are esteemed as praiseworthy.

I now rephrase Aristotle in the language of values. Things which are praised are things which are *valued*. This may include things that people prefer and wish for (Fulford, 2014). Things which are prized are *values*; they are the standards by which other things are deemed praiseworthy. They are the ‘end-points of iterative enquiry’ (Little, 2014b: 172)¹⁶. However, a degree of nuance must be added to this Aristotelian dichotomy of praised things (which are valued) and prized things (which are values). To express this, I refer to a more contemporary source.

Andrew Sayer is a social and political theorist who explores the nature of values in *Why Things Matter to People* (2011). He notes that ‘values are not merely *a priori*... they are to some extent the product of interactions and experiences’ (2011: 27). Whereas Aristotle professed happiness to be the perfect prize through a process of contemplation, Sayer cautions that our ‘professed values’ could be different to our ‘values in use’, given that we acquire values ‘between the two extremes of passive osmosis and extended reflection on experience’ (2011: 26).

In a manner that could arguably be harmonised with Aristotelian *phronesis*, Sayer suggests that we ‘think of values as “sedimented” valuations that have become attitudes or dispositions, which we come to regard as justified’ (2011: 25). Sayer sees values as ‘more abstract than the particular concrete evaluations from which

¹⁵ Aristotelian happiness has also been translated as ‘flourishing’ in order to avoid confusion with momentary pleasures: ‘for one swallow does not make a summer, nor does one day; and so too one day, or a short time, does not make a man blessed and happy’ (1941: 943).

¹⁶ The *Nicomachean Ethics* thus features an adumbration of Ronald Dworkin’s taxonomy of goods: things which are praised approximate to *instrumental* goods and *subjective* goods, and things which are prized approximate to *intrinsic* and *inviolable* goods (1993). However, Dworkin is less explicit about intrinsic and inviolable goods functioning as evaluative standards. I return to consider Dworkin’s taxonomy in the Discussion (see: Chapter 9 *Trivalent framework*).

they derive and which they in turn influence' (2011: 25–26). Rather than a strict binary of praised things and prized things (values), 'the relation between values and particular valuations is... recursive' (2011: 26).

In this thesis, I employ a facts-plus-values paradigm which adopts a qualified Aristotelian schema: *values are the standards by which things are judged good or bad, which are in turn shaped and sustained by such judgments.*

2.3.1.2 In healthcare

I now turn to briefly summarise what the values are, or are said to be, of UK healthcare.

The Care Quality Commission (CQC) sets the standards by which UK healthcare organisations are monitored. Organisations which are deemed to be high-performing according to CQC standards are 'allowed greater spending freedoms and... subject to less close performance managing' (Newdick and Smith in Francis, 2013: 1742). Thus, healthcare organisations are in the paradoxical situation of being free to act insofar as their actions are compliant with CQC standards; they are free to do what they *have to do*¹⁷.

The CQC regulates according to five values nationwide:

'We ask the same five questions of every service – Is it safe? Is it effective? Is it caring? Is it responsive? Is it well-led?' (2016: 3).

Such standardisation is no embarrassment to the CQC, who explicitly promote the development of a 'shared vision of high-quality care' (2016: 3).

This sentiment is shared by Lord Darzi in his report *High Quality Care for All: NHS next stage final review* (Department of Health, 2008). In this report, he laments the lack of shared vision for the NHS. To address this, he recommends the establishment of an NHS Constitution, which will 'set out the purpose, principles and values for the NHS'. Such a statement of values would apply to the entirety of NHS organisations and have a regulatory function: 'it must have bite, with means for enforcement and redress, not just warm words or aspirations' (2016: 78).

Lord Darzi's efforts came to fruition in 2012, when the first version of the NHS Constitution was published. All NHS bodies, including foundation trusts, are subject to its statutory authority (Francis, 2013b: 1412). Whilst its general guidance is open to 10-yearly review, the seven core guiding principles which feature in the constitution may not. Referring to the Health Act 2009, Francis notes that the NHS Constitution's core principles are unchanging (2013b: 1412). These principles are listed in table 2.1 (Department of Health, 2015: 3–4).

¹⁷ The expression is borrowed from Aldous Huxley's *Brave New World* (2007).

<i>The NHS provides a comprehensive service, available to all</i>
<i>Access to NHS services is based on clinical need, not an individual's ability to pay</i>
<i>The NHS aspires to the highest standards of excellence and professionalism</i>
<i>The patient will be at the heart of everything the NHS does</i>
<i>The NHS works across organisational boundaries and in partnership with other organisations in the interest of patients, local communities and the wider population</i>
<i>The NHS is committed to providing best value for taxpayers' money and the most effective, fair and sustainable use of finite resources</i>
<i>The NHS is accountable to the public, communities and patients that it serves</i>

Table 2.1: Core principles of the NHS

In addition to the seven guiding principles, six NHS values are articulated in the NHS Constitution. These values 'provide common ground for co-operation to achieve shared aspirations, at all levels of the NHS' and are listed in table 2.2 (2015: 5).

<i>Working together for patients</i>
<i>Respect and dignity</i>
<i>Commitment to quality of care</i>
<i>Compassion</i>
<i>Improving lives</i>
<i>Everyone counts</i>

Table 2.2: Values of the NHS

The following year, Lord Francis QC published his *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* (2013b). One key message of volume 3 of this report suggests that the healthcare system 'identify a means of ensuring a common culture of positive values... prevailing over, and driving out, negative values' (2013b: 1357). Whilst pleased with the arrival of the NHS Constitution and accompanying NHS values, Francis considers it to have under-penetrated day-to-day NHS work. Despite a vast array of bureaucratic 'checks and balances', Mid Staffordshire Foundation Trust exhibited a culture which is 'focused on doing the system's business – not that of the patients' (2013a: 4).

In reaction to this, Francis suggests that compliance with NHS Constitution standards should be incorporated into CQC monitoring, reflected in NICE guidance and 'owned' more by patients and professional staff (2013b: 1399). This has given rise to values-based recruitment (VBR), which is currently used in England 'to select healthcare staff, trainees and students on the basis that their values align with those stated in the Constitution' (Groothuizen et al., 2018: 1).

2.3.2 How many values are there?

2.3.2.1 In healthcare

2.3.2.1.1 Grey literature

Lord Francis QC did not simply appropriate the NHS values in order to bolster and re-assert them. He suggested an amendment that identifies one value as more fundamental than the others: ‘the overriding value of the NHS should be that *patients are put first* in everything done’ (2013b: 1416, emphasis added). Francis diligently shows that this overriding meta-value is reflected in the professional guidance of the full range of healthcare professions.

Francis points out that the General Medical Council identifies the first duty of a doctor as to ‘make the care of your patient your first concern’, which is followed by the duties to treat patients ‘as individuals and respect their dignity’ (General Medical Council, 2013). He observes that such a patient-first principle is echoed in nursing literature; the code of conduct for registered nurses, published by the Nursing and Midwifery Council, asserts that all nurses must ‘make the care of people [their] first concern, treating them as individuals and respecting their dignity’ (Nursing and Midwifery Council, 2008: 3). The Health and Care Professions Council (HCPC) regulates 15 professions, from physiotherapists to social workers. Francis analyses the HCPC’s code of conduct document and notes the requirement to put service users first, treating them with respect and dignity (2013b: 1407). Finally, Francis summarises managerial guidance which also endorses the primacy of patients, which he refers to as a ‘patient-centred approach’ (2013b: 1408).

In the eyes of Lord Francis QC, then, the NHS operates according to multiple values of which one is the fundamental value: being patient-centred. The quality of healthcare, including decision-making, can be ultimately appraised by the single evaluative standard of *patient-centredness*. The Francis Report is thus extremely significant in terms of values. Where Lord Darzi proposed a form of value-pluralism, Lord Francis QC adds a qualification which renders this framework to be, fundamentally, a form of value-monism.

2.3.2.1.2 Bioethics literature

An alternative perspective is voiced by feminist ethicist Sara Fry, in *The Role of Caring in a Theory of Nursing Ethics* (1992). Although preceding the Francis Report by some 24 years, her critique of the value-base of healthcare somewhat undermines Lord Francis’ survey of professional guidance by challenging the supposed consensus on which his value-monism depends. She argues that the voice of non-medical healthcare professions has been stifled by the presumption that their ethics is merely a ‘subset of contemporary medical ethics’ (1992: 93). Fry describes a Procrustean tendency to interpret nursing ethics according to ready-made models of medical ethics. Such models include bioethical principlism, contract theory, human rights theory and Rawlsian justice theories. The effect of this tendency is to ‘espouse a masculine approach to decision-

making and ethical analysis' (1992: 93). If this is the case, then Francis' survey of the ethic of all major healthcare professions is in fact only a survey of medical ethics in all its major guises.

Fry proceeds to divide bioethical literature on the value foundations of healthcare into two groups. Firstly, there are theories which prize the principle of respect for autonomy (Engelhart, 1986), whose fundamental value is *choice*. Secondly, there are theories which prize the principle of beneficence (Pellegrino and Thomasma, 1988), whose fundamental value is *welfare*. Fry sees the problem with this as one of scope: 'there is no good reason to assume that autonomy and producing good are, de facto, the appropriate value foundations for the practice of nursing simply because they are accepted for the practice of medicine' (1992: 95–96).

Some authors look for an alternative value basis for healthcare work in the notion of *caring*. The first major step in this direction came from developmental psychologist Carol Gilligan's *In a Different Voice*, in which she cautiously posited that men's moral evaluations tend to be justice-oriented whereas women's tend to be care-oriented (1982). Nel Noddings builds on Gilligan's work, intending to maintain a consciously 'feminine' approach and a focus on care, which she defines as the attitude which accompanies being 'charged with the protection, welfare, or maintenance of something or someone' (1984: 9). On Noddings' relational model, good healthcare depends on 'the maintenance of conditions that will permit caring to flourish' (1984: 5)¹⁸.

With regard to the value-foundation of healthcare, I have presented a sample of models in bioethical literature. Some of these are consciously subversive of traditional theorising in healthcare ethics and none of them holds *patient-centredness* to be their fundamental value. Traditional models tend to portray a foundational value of *choice* or *welfare*; anti-traditionalist models appeal to an alternative value foundation, such as the value of *caring*.

There are exceptions to this rule. For example, Boyer and Lindemann Nelson take a closer look at Gilligan's work and note that 'the major differences between the women and men she describes can be characterized as much in terms of *process* as in terms of what is valued' (1992: 110, emphasis added). Accordingly, they suggest that caring is not simply a substitute value to replace autonomy or welfare; instead, caring is 'an alternative way of responding toward that which is of value' (1992: 107). More recent research in feminist

¹⁸ William Frankena also reacts to the medico-centrism of traditional healthcare ethics and looks to *caring* as the foundation for a new approach. Frankena is the main spokesperson of moral point-of-view (MPV) theory, which consists of an agent taking two steps:

1. 'Subscribing to a particular substantive moral principle (or value)
2. Taking a general approach, perspective, stance or vantage point from which to proceed' (1983: 101)

Frankena endorses caring as the 'basis of human normative judgments', which he characterises as similar to Kantian respect-for-persons or Christian love (1983: 71–72).

ethics has responded to this call for an alternative evaluative paradigm. One of the most prominent of these is Eva Feder Kittay's 'nested relationality' paradigm, in which the ubiquity of needs is the moral basis of caring (1999). Annelies van Heijst expands on Kittay's model, highlighting that 'mutual dependency' entails the neediness of both staff and patients, as well as 'the need of a relational web of human life for mere survival and for a meaningful life' (2011: 145).

Whilst these alternatives from feminist ethicists do represent genuine alternatives to the *choice-* and *welfare-*based models of traditional medical ethics, what they offer is still a model with a base. Rather than stipulating a *substantive* value as the foundation for healthcare ethics, such feminist accounts present a *procedural* value (couched in relational terms) as the foundation of healthcare ethics. In this way, they are alternatives to traditional medical ethics but they are not alternatives to traditional medical *foundationalism*. Instead, they are further examples of the predominance of value-*monism* in contemporary healthcare literature.

Nevertheless, the anti-traditionalist flavour of such accounts does highlight a space for more radical alternative models of healthcare values; a truly anti-traditionalist alternative might also presuppose an alternative mode of ethical justification. Philosophically speaking, perhaps value-foundationalism could be replaced with a form of *coherentism* or *pragmatism* or something else altogether. Suffice it to say that the vast majority of models of values in healthcare, including healthcare decision-making, are foundationalist. Whether such models originate from grey literature or bioethics literature, such foundationalist accounts are predominantly value-monist.

2.3.2.2 *In philosophy*

This exploration of values in healthcare was prompted by frustrated attempts to define futility. In order to provide further characterization of futility, greater clarity on the goal(s) of medicine is required. Frustrated by the lack of clarity (at least in controversial cases) offered by goal-pluralist and goal-monist accounts, I turned attention to values to see if they fare any better.

So far, I have shown that models of the values of healthcare are typically foundationalist. Whilst the NHS Constitution was penned as value-pluralist by Lord Darzi, Lord Francis QC's commentary seeks to modify it to a value-monist framework. Models of healthcare values in bioethical literature dispute the nature of the foundational value but not value *foundationalism* itself. Each model presented in healthcare or bioethics literature can be categorised as value-pluralist or value-monist. In what follows, I describe the problematic nature of both value-pluralism and value-monism. As with goal-pluralism and goal-monism, values are caught on the horns of a dilemma; pluralism and monism seem to be the only options yet neither provides the theoretical clarity by which to characterise futility.

2.3.2.3 Value pluralism

I start with the problem with value-pluralism:

‘If one state of affairs is better than another just in case it contains more value than the other, and there are two or more basic intrinsic values, then it is not clear how two states of affairs can be compared, if one contains more of the first value, but the other contains more of the second’ (Schroeder, 2016).

Value-pluralism can be problematic because different values can endorse different states of affairs. For example, consider two of the five regulatory values of the CQC: *caring* and *effective* (2016). A certain course of action may be caring but not effective. This may be the case if, for example, a consultant were to sit and discuss treatment options extensively for one hour with each patient during a ward round. An alternative course of action may be effective but not caring. This may be the case if, for example, the same consultant spends 4 minutes with each individual patient in order to come up with an approximately safe plan without compromising ward round speed. Which of the two course of action is better? Intuition may yield a response to this question, but the CQC framework itself is unable to provide answers.

To adjudicate between the two courses of action requires one value to trump the other, such as by asserting “it’s simply more important to be caring than to be effective”. However, any such assertion simultaneously reduces the pluralist framework to a form of monism in which the triumphant value functions as *the* value.

The problem¹⁹ with value-pluralism is that of unavoidable inter-value conflict. Healthcare ethicist David Seedhouse summarises the ‘five conceivable routes towards the resolution of value conflict’ (1988: 85) as follows:

1. Finding some ultimate value or ultimate ordering of values
2. Finding a set of rules
3. Appealing to the law
4. Settling for relativism
5. An appeal to the facts

Where route 1 successfully overcomes value conflict but fails to remain pluralist, routes 2-5 successfully remain pluralist but fail to overcome value conflict. Value-pluralism is only action-guiding in times of inter-value conflict when one value trumps another; value-pluralism plus controversy yields value-monism.

¹⁹ Value-pluralism suffers additional problems which are not directly relevant to this thesis. These include the inexplicability and incommensurability of values (Schroeder, 2016).

In conclusion, value-pluralism falls where goal-pluralism fell; when implemented so as to guide action in times of inter-value conflict, value-pluralism (in theory) collapses into value-monism (in practice).

2.3.2.4 Value monism

Next, I turn to the problem with value-monism. A famous example of value-monism is the utilitarianism promoted by Jeremy Bentham, in which ‘happiness’ is *the* fundamental good which ought to be maximised absolutely²⁰. However, all forms of value-monism (including Bentham’s) face the problem of hermeneutic diversity. That is to say, any one value or principle affords a range of interpretations and applications.

For example, take monism endorsed by the Francis Report, whose ‘overriding value’ approximates to patient-centredness (2013b: 1416). What exactly is a ‘patient-centred approach’ (Francis, 2013b: 1408)? What does it mean for a patient to be central or ‘put first’ (2013b: 1416)? Does being patient-centred entail promoting a patient’s *welfare* or respecting a patient’s *choice*? Or perhaps both and, if so, how? Despite its political endorsement, what remains ‘lost in many of the discussions of patient-centered [sic] care... is the essential and revolutionary meaning of what it means to be patient centered’ (Epstein and Street, 2011: 100).

Insofar as a single fundamental value, like patient-centredness, is open to various interpretations, it functions as various values. In conclusion, value-monism falls where goal-monism fell: when implemented in times of *intra*-value conflict, value-monism (in theory) disintegrates into value-pluralism (in practice).

In this way, an exploration of values in healthcare gains no further ground than the exploration of the goals of healthcare. Like goal-pluralism and goal-monism, value-pluralism and value-monism prove inconsistent and unrealistic frameworks by which to conceive of the values of healthcare. As a result, they fail to provide the theoretical clarity and stability necessary to further characterise the concept of medical futility. More significantly for our purposes, both pluralism and monism are inadequate frameworks by which to account for the role of values in clinical decision-making.

2.3.3 Values and key concepts in healthcare decision-making

This review of literature relating to the goals and values of healthcare was prompted by difficulty characterising the slippery concepts of sickness and futility.

²⁰ Bentham’s friend and utilitarian successor, John Stuart Mill, proved a little more ambiguous. Mill hinted at additional values beyond happiness (or at least different kinds of happiness) in his famous line: ‘it is better to be a human being dissatisfied than a pig satisfied’ (Oxford Reference, 2019). Thus, it remains contentious as to whether Mill was a monist or pluralist about value (Schroeder, 2016: 7).

2.3.3.1 Futility and values

It is unclear how to characterise futility beyond lack of 'benefit' (Schneiderman, Jecker and Jonsen, 1990) or 'uselessness' (Chwang, 2009: 487) and how to apply the concept in controversial cases. This is because in controversial cases the goals and values of healthcare are often unclear or contested (Weijer and Elliott, 1995). A search for a clear and realistic framework of the goal(s) and value(s) of healthcare decision-making proved relatively fruitless; pluralist frameworks collapse and monist frameworks disintegrate. A clearer and more realistic understanding of the goals and values of healthcare decision-making is required to enable the concept of futility to be applied in controversial cases.

2.3.3.2 Sickness and values

I now turn to the other key concept in healthcare decision-making with which this chapter started: sickness. What goals and values are implicit in the two kinds of sickness I presented above (see: *Two kinds of sickness*)?²¹

According to an objectivist conception of sickness such as the biomedical model, sickness is a state of abnormal biological function. Thus the goal of a clinical course of action is to correct the abnormality or at least reduce its harmful effects. To return to the imaginary case of Winston Glover (see: *Two kinds of sickness*), Dr Biomedicine's goal in treating Winston's heart failure is to improve his heart function so as to get it as close to normal as possible. Whether Winston realises it or not, whether he wishes for it or not, re-normalisation is what he needs for his well-being. The objectivist notions of *normality* and *need* are determined by a preconception of human flourishing. What is valued on this account is proper functioning, which I refer to as *welfare*²²; more than that, welfare is the standard by which a healthcare intervention is judged good or bad. In shorthand, an objectivist conception of sickness such as the biomedical model implicitly endorses welfare as its fundamental value.

I turn now to a subjectivist conceptualisation of sickness. What goals and values are implicit in conceiving sickness as biographical disruption? On this model, the goal of a clinical course of action is to enable continuity in life narrative. In the imaginary scenario of Winston Glover and his gardening, Dr Biography is concerned that Winston 'isn't himself' as a result of heart failure. Winston's social identity is largely constituted by his life choices, such as being a keen gardener who is well-known at the vegetable plot. The aim of treating his heart failure is to enable Winston to reconstruct his life narrative in accordance with his identity. This involves valuing his unique priorities, preferences and wishes. I refer to these collectively as

²¹ For the purposes of this thesis I take values to be *the standards by which things are judged good or bad, which are in turn shaped and sustained by such judgments* (see: *What are values?*)

²² I recognise that 'welfare' has a broad semantic range, including different kinds of welfare such as the material view, the wish-based mental view and the state-dependent mental view (Hansson and Grüne-Yanoff, 2018). For the purposes of this thesis, I restrict its meaning to proper function according to a vision of flourishing.

Winston's *choice*. More than that, Winston's choice becomes the standard by which a clinical course of action is judged good or bad. A subjectivist conception of sickness such as the biographical disruption model implicitly endorses choice as its fundamental value.

2.3.3.3 *Welfare and choice*

The question of which value (welfare or choice) is fundamental has implications for bioethics. In terms of Beauchamp and Childress' bioethical principles (2009), to prize welfare as the fundamental value in healthcare decision-making is to prioritise the bioethical principle of *beneficence*²³; to prize choice is to prioritise the bioethical principle of *respect for autonomy*.

Sarah Fry, whom I mentioned above (see: *Bioethics literature*), divides prominent bioethics theories into two groups: those that prize the principle of *beneficence* and those that prize the principle of *respect for autonomy* (1992: 95–96). Thus the contrast between the two groups of bioethics theories may have something in common with the contrast between the two ways of conceiving sickness: both contrasts reflect a difference in fundamental values, namely, welfare or choice.

Likewise, the question of which value is fundamental has implications for clinical practice. As mentioned above (see: *Grey literature* and *Value monism*), *patient-centredness* is currently heralded as the fundamental value of the healthcare professions. Yet the meaning of 'putting patients first' is profoundly unclear (Epstein and Street, 2011) and can be interpreted in terms of welfare or in terms of choice.

2.3.3.4 *What about genealogy?*

Before bringing the chapter to a close, it must be noted that the genealogical conceptualisation of sickness has been overlooked in terms of its fundamental value. Like biographical disruption, genealogy could also be categorised as a subjectivist approach to defining sickness, according to cultural power structures and interpersonal power plays. However, the implicit goal(s) and value(s) of genealogy are not easy to identify. The goals of restoring proper function or biographical continuity do not pay adequate attention to the dynamics of control that are essential to genealogy. Where a biomedical model prizes *welfare* and a biographical disruption model prizes *choice*, perhaps a genealogical model prizes *something else*.

This chapter has covered a lot of ground since identifying some of the most prominent models of sickness. Each model of sickness can be characterised epistemologically (by its objectivist or subjectivist approach), ontologically (by its complementary account of well-being) and ethically (by its fundamental value). This is summarised in table 2.3.

²³ Arguably, the other consequentialist principle of *non-maleficence* is prioritised in equal measure.

	Epistemological approach	Complementary account of well-being	Fundamental value
Biomedical model	Objectivist	Need	Welfare
Social constructionism: <ul style="list-style-type: none"> • Biographical disruption 	Subjectivist	Desire	Choice
Social constructionism: <ul style="list-style-type: none"> • Genealogy 	Subjectivist	?	?

Table 2.3: Concepts of sickness

2.4 Conclusion

I opened this chapter by introducing two concepts which are effectively the starting point and end point of healthcare decision-making: sickness and futility.

A review of literature relating to the concept of sickness identified two approaches: an objectivist approach and a subjectivist approach. The most prominent example of an objectivist approach is the biomedical model, which complements a need account of well-being. The most prominent example of a subjectivist approach is social constructionism, which can be sub-divided as focussing on biographical disruption or genealogy.

Each conceptualisation of sickness features an implicit goal and fundamental value. The biomedical model and the biographical disruption model prize the values of *welfare* and *choice*, respectively. These are different values which may endorse incompatible courses of action in a given situation. This conflict is not resolved by grey literature promoting patient-centredness. This is of great significance to clinical practice because decision-makers who presuppose a different concept of sickness may espouse a different fundamental value and thus be committed to incompatible courses of action. In such instances, decisions must be made amidst insoluble value conflict. How clinical decision-making models manage value conflict will be explored in Chapter 3.

A review of literature relating to the concept of futility identified various attempts to define the term, with limited success. None has achieved widespread acceptance. The frustration of attempts to characterise futility is a result of ambiguity in the goals and values of healthcare. A survey of frameworks of the goals and values of healthcare identified two kinds: monist and pluralist. Whether of goals or values, the application of such frameworks proved inconsistent and unrealistic in controversial cases. The lack of an adequate account of the values of healthcare is problematic for two reasons. Firstly, attempts to characterise futility

will continue to be frustrated. Secondly, it remains unclear what values are actually involved (and what their role is) in decision-making. The second problem is taken up in the following chapter, in which I consider the values inherent in a range of prominent clinical decision-making models.

Chapter 3. Clinical Decision-making Models

In Chapter 2, I presented two key concepts in healthcare decision-making. A critical exploration of the concept of sickness showed the potential for conflict between the values which are implicit in different models of well-being and sickness. A critical exploration of the concept of futility identified a lack of any clear and realistic framework of values in healthcare decision-making.

In this chapter, the problematic nature of values in healthcare decision-making comes into sharper focus. My aim here is to show that conflict in values accompanies clinical decision-making models. To this end, I critically explore a broad range of decision-making models in contemporary literature. I have categorised these models along different axes: by therapeutic relationship (paternalism and anti-paternalism), by cognitive speed (dual process theory) and by values-consciousness (values-based models).

The conclusions of the previous chapter and this current chapter will be accentuated when they are contextualised within an Acute Medical Service (AMS) in Chapter 4.

3.1 Therapeutic relationship: Paternalism and anti-paternalism

The location of a decision-making model on a spectrum from paternalism to anti-paternalism is determined by how it conceives of 'who holds the property rights over which decisions' (Jensen and Mooney, 1990: 14)²⁴. The paternalism – anti-paternalism spectrum could also be conceived as a dichotomy, depending on which decision-maker is deemed to be the majority shareholder.

At one end of the spectrum, paternalism holds the informed doctor, as expert in their trade, to hold the property rights of clinical decisions: 'doctor knows best'. On this theoretical basis, paternalism in practice enacts a model of *substituted* decision-making. According to this model, the patient is informer (and informative) but it is the doctor who is informed; the patient-as-agent assists the responsible clinician.

At the other end of the spectrum, anti-paternalism holds the informed patient, as expert on their own life, to hold the property rights of clinical decisions: 'patient knows best'. On this theoretical basis, anti-paternalism tends to enact a model of *supported* decision-making. According to this model, the doctor is informer (and informative) but it is the patient who makes the informed choice; the clinician-as-agent is responsible for assisting the particular patient.

²⁴ Whilst sociological literature has highlighted the distributed nature of clinical decision-making (Rapley, 2008) and the role of non-medical healthcare professionals, the consultation between the doctor and the patient is still deemed 'the essential unit of medical practice' (Morgan, 2003: 55). As such, I focus here on the so-called 'doctor-patient relationship' but do not limit any reflections to this encounter alone.

3.1.1 Substituted decision-making

The substituted decision-making of traditional paternalism, accompanied by deferential attitudes towards the doctor and medical thinking, has historically been the *modus operandi* of clinical practice; it has 'endured from antiquity almost until today and... only recently has come under fire' (Jensen and Mooney, 1990: 3). I will present an ancient argument and a contemporary argument for paternalism and then an exploration of its theoretical underpinnings.

3.1.1.1 Arguments for paternalism

The Hippocratic tradition has exerted a longstanding influence on modern medicine. The adoption, adaption and recitation of 'the Oath' over many centuries epitomised what it is that the medical professional *professes* (Lyons and Petrucelli, 1987: 215). Embedded within the Oath is a decision-making ethic with a paternalist ethos. For example, 'I will use dietetic measures for the benefit of the sick according to *my* ability and judgment' (Edelstein, 1967: 6, emphasis added). As Edelstein puts it, the Hippocratic physician 'promises to guard his patient against the evil which they may suffer through themselves' (1967: 23). This protectionism is an indication that the Hippocratic physician prioritised the welfare of his patient over the autonomy of his patient. As such, he practised substituted decision-making for the good of his patient and the guard of his art. This ethic is reminiscent of the Pythagorean philosophy which so influenced the Hippocratic tradition, which held knowledge to be 'too potent and dangerous to be in the hands of ordinary lay people' (Veatch and Mason Spicer, 1994: 411). Patients fare better by trusting the physician's judgment rather than trying to work it out themselves; such is the ancient argument for paternalism.

However, paternalism need not be equated with Hippocratic traditionalism. Some authors deny any ongoing place for the Oath but nevertheless endorse a qualified form of paternalism under certain circumstances (Culver and Gert, 1982, pp. 148–150; Veatch and Mason Spicer, 1994). Still others consider the for-or-against debate too simplistic with regard to paternalism, given it has various aspects and various definitions (Shinebourne and Bush, 1994). Before turning to another argument for paternalism, then, it is worth pausing, to consider what paternalism actually is in contemporary terms.

Within healthcare, Lockwood defines medical paternalism as:

'behaving towards someone in a way that does not respect his or her autonomy, for that person's own (supposed) good' (1985).

More recently, medical paternalism has been defined as follows:

'deciding to act in an autonomous person's best interests without taking that person's will decisively into account (or deciding expressly against it)' (Groll, 2012, in Specker Sullivan, 2016: 439).

Whilst no consensus exists regarding its precise definition, the normative composition of paternalism can be broadly traced from such preliminary definitions. In terms of the bioethical principles of Beauchamp and Childress (2009), a paternalist approach to decision-making could be summarised as a prioritisation of (supposed) beneficence over respect for autonomy. In shorthand, paternalism puts the value of *welfare* before the value of *choice*.

I turn now to a relatively recent argument for paternalism. Clinicians Shinebourne and Bush make a case for substituted decision-making in *For Paternalism in the Doctor-Patient Relationship* (1994). Interestingly, they observe the inevitability of paternalist decision-making in situations of clinical urgency:

‘When the heart has stopped beating, just as when the child runs in front of a car, the place for reasoned discussion is nil, the place for immediate, decisive action is central’ (1994: 401).

In the next chapter, I show urgency to be a major priority of decision-making within an Acute Medical Service (AMS) (see: Chapter 4 *Urgency*). Thus, if ever there were a place for paternalist decision-making, an AMS may be it.

Shinebourne and Bush question the pejorative connotations of paternalism: ‘why should acting like a father be construed as bad for the patient or in some way morally wrong?’ (1994: 401) and conclude that paternalism is desirable for patients when the stakes are high:

‘The sicker the patient, the more vulnerable, the more regressed because of pain and anxiety, age, infirmity or debilitation, then in our view the more some patients will wish for an element of the sort of care a father may give his child’ (1994: 406).

Shinebourne and Bush thus articulate one of the main arguments for paternalist decision-making such as substituted decision-making: *patients want it*. In times of clinical urgency and severity, patients often do not want information about a decision, let alone participation in it, let alone responsibility for it (Ende, Kazis and Ash, 1989; Beisecker and Beisecker, 1990; Ryan, 1992; Charles, Gafni and Whelan, 1997: 683). Herein lies one of the ironies of paternalism: it is an approach to decision-making which prioritises what a patient needs over what a patient wants, yet the need for paternalism is justified in terms of what patients want. Sometimes the urgency of the situation requires it and sometimes patients prefer it; such is the contemporary argument for paternalism.

3.1.1.2 Theoretical underpinnings

Philosopher John Kleinig explores the theoretical commitments of paternalism in general in his book *Paternalism* (1983). Alluding to John Locke, Kleinig notes the emergence of liberal society as the cultural moment in which paternalism became noticed and criticised:

‘The old idea of a natural hierarchy, presided over by the monarch as patriarch, was challenged in the name of an individual no longer under tutelage, but endowed with reason and natural rights, able to be accounted the overseer of his own life-plans’ (1983: 3).

The contemporary contestation of paternalism is in many ways the momentum of a ball which J.S. Mill started rolling in his account of the sovereign individual and harm (to others) principle (1859: 223–224). By challenging paternalism, Mill provided the intellectual tools for subsequent writers to define and characterise the concept of paternalism more sharply.

One of the most influential definitions of paternalism (in general) is that of Gerald Dworkin, who depicts it as ‘the interference with a person’s liberty of action justified by reason referring exclusively to the welfare, good, happiness, needs, interests or values of the person being coerced’ (1971: 108) As Kleinig summarises it, there is a hierarchy of values inherent in this definition: ‘individual freedom is abrogated in the name of benevolence’ (1983: 5).

Dworkin also provides a narrower second definition in which paternalism ‘might be thought of as the use of coercion to achieve a good *which is not recognized as such by those persons for whom the good is intended*’ (1971: 112, emphasis added). The additional criterion (that the good not be recognised as such) renders this conception a kind of *strong* paternalism. In strong paternalism, X imposes on Y in order to procure some good whilst disregarding Y’s ‘capacity to choose that good for him- or herself’ (Kleinig, 1983: 14). In *weak* paternalism, however, X imposes on Y only in order to protect Y from ‘harm caused to the individual by conditions beyond his control’ (Beauchamp, 1978: 1197). Mill’s famous example of forcibly preventing an unsuspecting man from crossing an unsafe bridge (1859: 294) is thus an example of weak paternalism.

Kleinig notes additional classifications of paternalism, such as *positive* or *negative*, *active* or *passive*, and *direct* or *indirect* (1983: 14). The common themes in all such depictions is that an individual’s freedom of choice is in some way curtailed (by way of imposition, interference or coercion) in order that some good might be procured (benefit or protection from harm). It seems essential to paternalism in general, then, that it be accompanied by normative content. Namely, a paternalist decision is one in which the duty to do good trumps the duty to respect autonomy. In terms of values, *welfare* trumps *choice*.

Having established that paternalism (in general) entails a values hierarchy (*welfare* before *choice*) and is influenced by cultural shifts, I now turn to consider how cultural shifts might influence paternalism in healthcare specifically.

3.1.1.3 Shifting values

Jensen and Mooney describe the shift away from paternalism in healthcare to reflect a change in values in Western societies (1990). Where traditional medicine deferred to the medical expert's welfare assessment, 'now autonomy is espoused as the basic value for the modern health care system' (1990: 3). To cherish autonomy over welfare is to endorse a form of anti-paternalism.

However, the term anti-paternalism may be misleading. This is not a case of neo-Marxist revolt, the diseased under-class against the clinical ruling class. Rather, 'such espousal [with autonomy] appears almost universal: doctors, other professional groups, patients and politicians – all are apparently advocating autonomy as the ethical basis of modern health care' (1990: 3). It is simplistic, therefore, to construe the tension between paternalism and anti-paternalism solely in terms of a power struggle between groups. Anti-paternalism is not simply *anti* the powerful clinician; it is *anti* the primacy of welfare as more foundational than autonomy. The tension between paternalism and anti-paternalism is not merely political; it is *ethical*.

Just as the broad brush-strokes of 'paternalism' can be refined in various ways, so Jensen and Mooney note that 'autonomy' can be characterised in at least three ways: *deontological* autonomy, *relativistic* autonomy and *social* autonomy (1990). Deontological autonomy is 'when an individual, presented with adequate information about his or her situation, makes his or her own personal choice, free from any external coercion or interference' (1990: 5). This is a definition in keeping with other bioethical literature (Engelhardt, 1986, 1988; Beauchamp and Childress, 2009). Relativistic autonomy is 'when differences in human attitudes and values are respected' (Jensen and Mooney, 1990: 6).

Social autonomy is distinct from the first two categorisations in that it 'is not a power or resource... nor is it just a claim... Rather autonomy is conceived as an end' (1990: 6). According to Jensen and Mooney, social autonomy is an ideal situation in which 'we act as responsible persons in relation to our own lives and to those of others' (1990: 6). Social autonomy is thus reminiscent of the depiction given in the World Health Organisation's programme *Health for all by the year 2000* (WHO, 1983) and some forms of relational autonomy in feminist sociological literature (Kittay, 1999; van Nistelrooij *et al.*, 2017).

Jensen and Mooney use this taxonomy of autonomy to explain shifts along the spectrum from paternalism to anti-paternalism: 'as the mix of the different forms of autonomy changes over time so, in our view, does the distribution of these [decision-making] property rights. Who decides what?' (1990: 14). One manifestation of this is a shift towards anti-paternalism in the form of *supported* decision-making as a preferable model to substituted decision-making.

3.1.2 Supported decision-making

The case for supported decision-making is typically made by appeal to the bioethical principle of ‘respect for autonomy’ (Beauchamp and Childress, 2009). Davidson *et al* consider autonomy to be supported decision-making’s ‘central principle’ (2015: 61) and quote the following maxim with approval: ‘no person should have another person appointed to make a decision on their behalf, if they could make the decision themselves with assistance and support’ (Chartres and Brayley, 2010: 1). The more autonomous a patient can be, then, the better. Rather than use the term ‘autonomous decision-making’, proponents of supported decision-making prefer its more nuanced terminology in order to avoid a false dichotomy²⁵:

‘Law, policy and practice have... sometimes approached decision making as if people are either globally capable or incapable, but most people require some level of support with decision making’ (Davidson *et al.*, 2015: 61).

In 2006, the United Nations Convention for the Rights of Persons with Disabilities (UNCRPD) gave approval to supported decision-making in order that people with disabilities would be helped towards ‘full and effective participation in society on an equal basis with others’ (United Nations, 2006: 2). Specifically, the UNCRPD requires States to ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’ (Article 12(3)) (2006: 10). This duty is claimed to be incumbent upon States as a matter of ultimate values:

‘A basic tenet of liberal–democratic philosophy is that the state has a primary role in protecting autonomy or the right of individuals to choose and pursue their own life path, and all the decisions that entail along the way’ (Bach and Kerzner, 2010: 6).

This rights-based argument in favour of supported decision-making depends on a political philosophy which heralds autonomy as a primary value, if not *the* primary value, of liberal democracies.

It is noteworthy that UNCRPD occurred in the short intervening period between the authorisation and the implementation of the Mental Capacity Act (MCA) (2005) in England and Wales, which came into force in 2007 (Department of Health, 2007: 1). The MCA is the primary legislation relating to healthcare decision-making (Beadle-Brown, 2015: 17). It is largely compatible with UNCRPD and articulates principles which were intended to make supported decision-making the standard for healthcare decision-making (Beadle-Brown, 2015). As the MCA Code of Practice says, the statutory principles ‘aim to assist and support people who may lack capacity... not to restrict or control their lives’ (Department of Health, 2007: 20). The MCA intended to

²⁵ I have spoken of supported decision-making as the opposite end of the spectrum to substitute decision-making. However, it may be more accurate to place ‘autonomous decision-making’ as the truly opposite pole, with supported decision-making functioning as a catalyst towards it.

move healthcare decision-making away from paternalist substituted decision-making towards anti-paternalist supported decision-making (Essex Autonomy Project, 2012; Beadle-Brown, 2015).

However, in practice this has reportedly not been the case. The House of Lords Select Committee in 2014 raised concerns about how the principles of the MCA were being implemented (2014). This report considered the culture within healthcare organisations to be an obstacle to supported decision-making's success. The committee suggested a change in professional attitudes from 'protection and paternalism to enablement and empowerment' (2014, para. 108). In terms of values, what the MCA 2005, UNCRPD and the House of Lords Select Committee are all promoting is a revolution; not a revolution in class hierarchy but a revolution in *values* hierarchy. Supported decision-making proponents endorse *choice* (not welfare) as the foundational value of liberal democracies in general and healthcare decision-making in particular.

In conclusion, the tension between paternalism and anti-paternalism, between substituted decision-making and supported decision-making, is a tension between fundamental values: *welfare* versus *choice*. However, must decision-making be construed in such adversarial terms? Could it not be possible to transcend this dialectic by eliminating its mutual exclusivity? Rather than decisions being either substituted or supported, could they not be in some way *shared*?

3.1.3 Shared decision-making

I will dedicate a little more space to the consideration of shared decision-making because it has achieved remarkable prominence in UK healthcare literature to date. I explore the background to it, its content and the values it expresses.

3.1.3.1 Background

The National Institute for Health and Care Excellence (NICE) is an extremely influential organisation in the UK which publishes evidence-based guidance on best clinical practice. NICE's intention to '[ensure] that shared decision making becomes an essential part of medical practice' (Haslam, 2016) is soon to be translated into the publication of national guidelines on shared decision-making (NICE, 2018b). The incorporation of shared decision-making into everyday clinical practice will require more than guidelines, however. In recognition of this, NICE is one of 40 organisations who have formed a 'shared decision-making collaborative' (2019). This collaborative includes NHS England, the General Medical Council (GMC) and the Academy of Medical Royal Colleges, and has produced an action plan to promote shared decision-making in areas such as healthcare leadership, education, and training (NICE, 2016). Once 'instruments for measuring shared decision-making' are established, NICE suggests that 'these could then feed inspection regimes', such as the Care Quality Commission, and 'incentive schemes', such as the Quality Outcomes Framework (2016).

The principles of the shared decision-making collaborative are echoed by the Coalition for Collaborative Care network (C4CC), which was established in 2014 (Coalition for Collaborative Care, 2019a). C4CC emphasises the importance of shared decision-making in the context of long-term conditions, where patients are 'fully engaged as partners in decisions and planning of their care' (2019b). C4CC features partner organisations from a broad range of fields. These include authoritative organisations such as Health Education England and Public Health England as well as charitable advocacy organisations such as Age UK, Alzheimer's Society, Diabetes UK, Hospice UK and Mind. In contrast to the shared decision-making collaborative, C4CC is notably multidisciplinary, featuring such partners as the Royal College of Nursing, the Royal College of Occupational Therapists, the Royal Pharmaceutical Society and the Chartered Society of Physiotherapists (2019a).

It is evident, then, that shared decision-making is a model which has been firmly endorsed by an extremely wide range of healthcare organisations. The collaboration of such organisations is serving to secure its implementation in the future of UK healthcare, by means of education, training, culture change and governance. Even this, however, is only half the story. The rise to fame of shared decision-making was facilitated by a complex of various other factors, which I now sketch.

In the UK, the last 50 years has seen a shift from the prominence of acute care to chronic care (Charles, Gafni and Whelan, 1997: 682; Fitzpatrick, 2008: 5). The majority of healthcare aims to *manage* illness in the community rather than cure it (Charles, Gafni and Whelan, 1997: 682). Managing chronic illnesses typically depends on factors such as patient education and patient compliance, and is most effective if both physician and patient have an active role to play in decision-making (Charles, Gafni and Whelan, 1997: 682). Over the same period of time, the internet has enabled widespread access to healthcare information, which (in conjunction with the consumer rights movement) has nurtured an environment in which a patient can more naturally challenge a physician's authority (Charles, Gafni and Whelan, 1997: 682).

In addition to these demographic and technological changes, shared decision-making has been supported by ethical, legal, cultural and political factors. Ethically, patient involvement in decisions is considered essential to quality of life considerations (Mueller, Hook and Fleming, 2004). Legally, informed consent requirements have evolved to demand increased involvement and tailoring of the decision-making process to the particular patient (Braddock *et al.*, 1997; *Montgomery v Lanarkshire Health Board*, 2015; Herring *et al.*, 2017). Culturally, there is increased respect for diversity, including diversity in patients' wishes (Richardson and Carryer, 2005). Politically, 40% of health complaints are attributed to poor communication in some Western countries (NSW Health Care Complaints Commission, 2005), prompting communication to be seen as equal in importance to the delivery of care itself (Department of Health and Ageing, 2000). What is more, shared decision-making was explicitly promoted in the UK Department of Health's 2010 White

Paper, boldly entitled 'liberating the NHS' (2010). In this document, the Secretary of State for Health gave a statement on decision-making which packs a punch: 'Shared decision-making will become the norm: no decision about me without me' (2010: 3). And with that, the stage was set for a new model of decision-making, a collaborative model which could be more readily incorporated into today's healthcare climate.

3.1.3.2 Content

According to medical sociologist Myfanwy Morgan, shared decision-making is intended to be a means of transcending the paternalism – anti-paternalism dualism, replacing unilateral empowerment with a 'relationship of mutuality'; in such a model, patient and doctor function as 'equal partners in the... consultation' (2003: 62). In sharing the decision-making process, both patient and doctor supposedly retain a high level of control in decision-making (Stewart and Roter, 1989). Whilst there is 'great fluidity' regarding the definition of shared decision-making (Trede and Higgs, 2008: 45) the following key characteristics were articulated in the 1997 landmark publication by Charles *et al* (1997: 681):

- At least two participants, physician and patient, are involved
- Both parties share information
- Both parties take steps to build a consensus about the preferred treatment
- An agreement is reached on the treatment to implement

Like Morgan, Charles *et al* also depict shared decision-making as an alternative to the polarity of (paternalist) substituted decision-making and (anti-paternalist) supported decision-making²⁶; in these two extremes, control and responsibility 'are clearly vested with the physician or the patient respectively, and whether the opposite party accepts the decision is not relevant' (1997: 688).

Given the surge in interest in the model, what more can be said of the content of shared decision-making? NICE offers a cursory definition:

'Shared decision making is when health professionals and patients work together. This puts people at the centre of decisions about their own treatment and care. During shared decision making, it's important that:

- care or treatment options are fully explored, along with their risks and benefits
- different choices available to the patient are discussed
- a decision is reached together with a health and social care professional' (2019).

²⁶ Charles *et al* do not use the terms 'substituted decision-making' and 'supported decision-making' in their 1997 article, as these terms were established subsequently. Their descriptions of existent decision-making models can be approximated to these frameworks, however.

This definition arguably raises more questions than it answers: What does it mean to ‘work together’? (Substituting a decision and supporting a decision could both be considered forms of collaboration.) What does it mean to be ‘at the centre’ of decisions? Is it just the individual patient in their present state who is centralised? How can options (and their accompanying risk-benefit analysis) possibly be ‘fully explored’? In whose eyes are the ‘available’ options to be determined? What if a decision cannot be reached consensually? What if a patient does not want to be involved in this way? Perhaps the forthcoming NICE guidelines will address such questions. In the meantime, I turn to already-published guidance from the GMC in order to further characterise the model of shared decision-making.

3.1.3.2.1 GMC guidance on shared decision-making

According to the GMC, all doctors have a duty to ‘respect patients’ right to reach decisions with [doctors] about their treatment and care’ (2013). This responsibility to work ‘in partnership’ with patients is expanded in the GMC’s 2008 guidance, intended to promote shared decision-making, entitled *Consent: patients and doctors making decisions together* (2008). This document outlines what the GMC considers good practice in decision-making, and relates to ‘all decisions about care’ (2008: 6). The underlying aim of this guidance is to foster a doctor-patient relationship of ‘partnership’, based on ‘openness, trust and good communication’ (2008: 9).

Doctors are to give patients information that patients ‘want or need in order to make decisions’ (2008: 6). The content and form of this information is to be tailored according to the ‘needs, wishes and priorities’ of the patient (2008: 11). As in the supported decision-making model, the patient is in control of the decision outcome:

‘The patient weighs up the potential benefits, risks and burdens of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which one’ (2008: 8).

This is the GMC’s guidance for making a decision when the patient is deemed to have capacity. If the patient is deemed to lack capacity for the decision, the clinical team is charged to make a *best interests* decision in keeping with MCA 2005.

3.1.3.2.2 Best interests and shared decision-making

Nowhere in MCA 2005 is the notion of best interests actually defined (Department of Health, 2007). Instead there is procedural advice as to what tasks and considerations are involved in establishing what is in a patient’s best interests. This is where ambiguity is introduced into the equation. Whilst a patient’s ‘wishes and feelings, beliefs and values should be taken fully into account’, these may not always be decisive because they ought to be considered ‘alongside all other factors’ (Department of Health, 2007: 81).

In the MCA Code of Practice, an example is given to illustrate this. The scenario is of a man with learning difficulties called André who is unable to understand the risk of infection following a leg injury. Despite his resistance, the doctor can legitimately restrain him in order to administer a tetanus injection because she has 'objective reasons' for believing this course of action is in André's best interests (Department of Health, 2007: 81). A best interests decision leaves a door open for assessments of what is objectively good for someone. Some consider the preservation of life to be what enters this open door and others the continuity of life narrative (EWHC, 2011; Johnston, 2013).

A best interests decision, then, combines the patient's wishes with other factors. Putting it crudely, the illustration of André portrays this as an integration of the patient's subjective intentions with the doctor's 'objective reasons'. In this way, making a best interests decision is not quite synonymous with doing what the patient would have wanted, nor with doing what the doctor thinks is best.

I now consider the values expressed by GMC guidance on shared decision-making.

3.1.3.3 Values

At first glance, shared decision-making seems to be a poorly disguised form of anti-paternalism. If a patient has capacity to make a decision, she makes the decision. The responsibility of the doctor is reduced to information provider, laying out the relative strengths of each item on the clinical menu.

Despite the egalitarian connotations of 'sharing' and 'partnership', this model prioritises the judgment of the patient over that of the clinician. As the GMC summarises it: 'the patient decides whether to accept any of the options and, if so, which one' (2008: 8). A clinician is not authorised to over-rule a competent patient's wishes or invalidate their capacity status on the grounds that the patient's choice is unwise in welfare terms (Department of Health, 2007). If the patient has capacity, the door is not open to the doctor's so-called objective reasons. Speaking of bioethical principles, respect for autonomy trumps beneficence. Speaking of values, *choice* trumps *welfare*.

At second glance, however, there also remains a paternalist element within this model of shared decision-making. The patient weighs up the 'various options', but it is the clinician who determines the variety of options from which to choose. A clinician is not obliged to offer treatment which they consider to be of no benefit to the patient, nor is the patient entitled to demand it (Ardagh, 2000: 398; Biggs, 2007). In this way, beneficence trumps respect for autonomy. *Welfare* trumps *choice*.

Thus, in a sense, there are two phases to the shared decision-making model. There is a preparatory phase, during which the informing clinician lays out the appropriate options, and there is an executive phase, during which the now-informed patient selects a course of action (table 3.1). These phases are not necessarily clean-

cut in temporal sequence. Rather, they are a *logical* sequence: only what the clinician avails is available; only what first passes the professional's *welfare* assessment is considered in the patient's *choice*.

	Preparatory phase	Executive phase
Judgment	Clinician decides which treatment options are <i>available</i> .	Patient decides which available treatment option is most <i>preferable</i> .
Fundamental value	Welfare	Choice
Therapeutic relationship	Paternalism	Anti-paternalism

Table 3.1: Phases of shared decision-making

During the preparatory phase, the clinician is the dominant agent and welfare is the dominant value. During the executive phase, the tables are turned: the patient is the dominant agent and choice is the dominant value. As such, shared decision-making does not transcend the paternalism – versus – anti-paternalism dialectic but instead intensifies it by condensing it into a biphasic model. Rather than sailing through the Scylla and Charybdis of paternalism and anti-paternalism, shared decision-making offers a ferry service between the two.

What about if the patient is deemed to lack capacity for the decision? Does a best interests decision fare any better than an informed choice at offering an alternative to paternalism and anti-paternalism?

In terms of values, a best interests decision functions in the same way as an informed choice decision. Where a patient lacks the capacity to make the decision, the doctor is obliged to take into account the patient's wishes, feelings, beliefs and values (Department of Health, 2007). Thus the doctor is duty-bound to respect even the incompetent patient's autonomy. This remains the case even if the patient's wishes, feelings, beliefs and values would align with a course of action which the doctor considers second-best. Autonomy trumps beneficence; *choice* trumps *welfare*.

However, the doctor is not duty-bound to initiate a course of action which is out of bounds according to their welfare assessment, justified by so-called objective reasons. In best interests decisions too, a course of action is only available if it is within the confines of what the doctor thinks is good for the patient, *really*. Beneficence trumps autonomy; *welfare* trumps *choice*.

Even in instances when the patient lacks capacity for the decision, then, shared decision-making exhibits the same biphasic features as otherwise. Firstly, the clinician circumscribes which options are available: the *welfare* assessment. Secondly, the patient's wishes, feelings, beliefs and values are to be used to evaluate which of the available courses of action is preferable: the *choice* assessment.

Whether or not a patient is competent, shared decision-making features a paternalist substituted decision which is logically followed by an anti-paternalist supported decision. The informed doctor sets the menu, beneficently; the informed patient selects the course, autonomously.

Shared decision-making has not transcended the conflict between paternalism and anti-paternalism, nor the corresponding value conflict between welfare and choice. Instead, the model offers an exercise in evaluative diplomacy, where each approach enjoys its own phase in the decision-making process and neither is to step over the halfway line. Thus, shared decision-making's strength is also its weakness. Its strength is to present a model which does not clearly take either side in the paternalism - versus - anti-paternalism debate but seeks to embrace the values of both. Its weakness, however, is that it draws a line between welfare (preparatory phase) and choice (executive phase) *arbitrarily*.

A shared decision-making model takes it for granted that there are a set number of options available. However, a radical paternalist approach could feel justified in presenting only one option: the best one (in the doctor's welfare assessment). A radical anti-paternalist approach to the same scenario could never feel justified in presenting only one option, as all possibilities are equal until the patient's wishes are expressed. Similarly, the manner in which treatment options are communicated is itself not a hermeneutically neutral enterprise; it may be influenced by the doctor's paternalist or anti-paternalist leanings (Shinebourne and Bush, 1994: 400–401).

Shared decision-making, as described by NICE and the GMC, fails to provide an alternative that transcends the dualism between paternalism and anti-paternalism. Furthermore, it does not justify the delineation between the paternalist preparatory phase and the anti-paternalist executive phase of clinical decision-making. As a result, decision-makers are left either vacillating between the two in the hopes of an agreement or drawing a line arbitrarily. After all, if there were any justification for delimiting welfare and choice, such an action would require appeal to a third value. In the absence of a third value, a peculiar antinomy remains: choice trumps welfare, and vice versa.

3.1.4 Alternative models in bioethics

I have so far presented and explored models of decision-making in healthcare which have been influential in clinical practice or endorsed by influential clinical organisations. Whether decision-making be portrayed as substituted, supported or shared, each model is either paternalist, anti-paternalist or an arbitrary mixture of both. However, perhaps a fruitful means of transcending the paternalist – anti-paternalist dialectic could arise from overlooked ground. I now consider clinical decision-making models published in non-clinical sources.

Bioethicist Robert Veatch suggests that a patient and a doctor be paired up on the basis of shared “‘deep” value systems’ (1995: 11). He considers this pairing to be an improvement because ‘if a clinician is skilled and passionately committed to maximizing the patient’s welfare, and knows the belief and value structure and socioeconomic and cultural position of the patient quite well, there would be some more reason to hope for a good guess’ (1995: 11).

Whilst introducing a new notion of pairing, Veatch’s account can nevertheless be categorised as an example of the physician-as-agent model, in which the only preferences that count are those of the patient (Charles, Gafni and Whelan, 1997: 684). In a physician-as-agent model, the patient’s (perceived) wishes remain in the decision-making driving seat. It is therefore the ‘flip side of the informed patient model’ (Charles, Gafni and Whelan, 1997: 684), which together form two sides of the anti-paternalist coin. One might even categorise Veatch’s perspective as consumerist; the patient merely needs to shop for the right doctor. More specifically, Veatch’s paired decision-making model is a form of supported decision-making, in which the doctor supports the patient’s autonomous decision by way of representative advocacy. In terms of values, autonomy is implicitly more fundamental than welfare; the goodness of the doctor’s ‘guess’ is measured by its relation to the patient’s ‘belief and value structure’. According to Veatch, *choice* trumps *welfare*.

Julian Savulescu is a bioethicist who contrasts the subjectivist ‘consumerist reaction’ (1997: 129) of Veatch’s account with a more objectivist account: ‘if objectivism about value is true – that there really are states which are good for people regardless of whether they desire to be in them – then we should accept a more rationalist liberal alternative’ (1997: 115). Savulescu summarises his position as influenced by the overall aim of healthcare: ‘if the practice of medicine is... in part a search for what is objectively good for individuals, then we should promote rational dialogue between doctors and patients’ (1997: 129). Savulescu’s account of an ethical approach to decision-making is thus founded upon an epistemology which assumes the objectivism of values and the universality of a conception of rationality.

However, it is not self-evident what rationality means in this instance. In the persistently incisive words of Foucault: ‘The main problem when people try to rationalise something is not to investigate whether or not they conform to principles of rationality, but to discover which kind of rationality they are using’ (in May, 1992: 97). Whilst Savulescu’s account serves to highlight the role of values in the decision-making relationship, it nevertheless fails to transcend the paternalism – anti-paternalism dialectic. This is because to smuggle a particular view of rationality in as *the* view of rationality simultaneously smuggles a form of soft paternalism into the decision-making relationship, one-sidedly determining the rules of the decision-making process (Specker Sullivan, 2016).

Savulescu's model does make an original contribution by highlighting the interconnectedness of ethics and epistemology. However, in terms of values, Savulescu's model is simply a *welfare*-based approach. Savulescu posits some 'states' which are 'objectively good for people', which can be pursued in conformity with a rational process which is *the* form of rationality. In other words, he believes in *the* good way of being (ontologically) and *the* good way of deliberating (epistemologically) as a basis for *the* good way of decision-making (ethically). This is a remarkably illiberal 'liberal alternative', in which the situated and embodied nature of individual human agency (Hughes, 2011) is expected to cede to the hegemony of a bioethicist's absolutist rationalism.

In short, the pursuit of what is objectively good for people on the grounds of what is the objectively good way to go about it is a type, if not a stereotype, of welfare-based decision-making. What is atypical, however, is that both patient and doctor submit to a higher authority: the laws of good reasoning. Savulescu's model is thus a form of paternalism in which the rationalist bioethicist is the *pater*. Nevertheless, it is not without its strengths. For example, Savulescu's model seeks to put the brakes on what he sees as the rise of ethical relativism and clinical consumerism, and the model is easily employed to reinforce the traditionalist status quo in paternalist corners of UK healthcare, of which some may approve. The weakness of his 'liberal' welfare-based approach is that, as well as not being liberal, its beneficent objectivism is arguably not, well, fair. According to Savulescu's paternalism, *welfare* trumps *choice*.

Annemarie Mol is a sociologist and political philosopher who calls for a new movement in healthcare, 'patientism', which resists the currents of both patriarchal traditionalism and liberal egalitarianism (2008: 36). She calls for a new logic in decision-making, a logic of *care*. Without succumbing to paternalism by 'allowing [clinicians] to do whatever they like', and without succumbing to anti-paternalism by 'pushing professionals back into their cage' (2008: 9), Mol calls for a third way that reconfigures standards of *good* decision-making. This involves opposing what has been referred to as the 'tyranny of autonomy' (Foster, 2009). However, Mol stops short of depicting a workable decision-making model for practice. Thus, the dichotomy remains; it is still unclear how to avoid absolutizing the value of *choice* without absolutizing the value of *welfare* instead.

3.1.5 Welfare and choice

There are, undoubtedly, numerous other iterations of how decisions should be made within healthcare. It is beyond the scope of this thesis to address them all. This survey attempts only to present some of the major players in the debate and to illustrate that none have successfully transcended the paternalist – anti-paternalist dualism. The closest contender, perhaps, is shared decision-making because this model contains

elements of both. Even this model, however, requires appeal to an unnamed third value to justify its arbitration between paternalist and anti-paternalist elements.

In conclusion, the conflict between decision-making models reflects a conflict in values. Some models appeal to *welfare* as their fundamental value; the resultant paternalist approach to decision-making is justified by the bioethical principle of beneficence. Some models appeal to *choice* as their fundamental value; the resultant anti-paternalist approach to decision-making is justified by the bioethical principle of respect for autonomy. It is noteworthy that paternalism and anti-paternalism both make *appeal* to a fundamental value rather than arguing for their fundamental values²⁷; it is taken as *given*. In the battle over fundamental values, then, all models take sides and do so arbitrarily.

However, shared decision-making is an exception. It appeals to *both welfare and choice* as its fundamental values; its biphasic structure is justified by both bioethical principles but is left unprincipled in its delineation between the two; it lacks a third value. In terms of values, where other models are arbitrarily one-sided, shared decision-making is arbitrarily two-sided. It remains to be seen how this theoretical tension between paternalism and anti-paternalism, between welfare and choice, is enacted and experienced in general, and within an Acute Medicine Service (AMS) in particular.

3.2 Cognitive speed: fast and slow

A second axis along which clinical decision-making can be categorised is the axis of cognitive speed. This may seem like a peculiar change of subject because speed of cognition is not something which features readily in clinically-oriented literature on decision-making. However, the speed of processing is a theme which has enjoyed prominence in recent research in cognitive psychology and is starting to be applied to clinical contexts. I raise it here in view of the fact that it is likely to gain traction within clinical literature in the near future. As such, the section that follows is as much a literature 'pre-view' as re-view. I start by surveying three dominant research paradigms in the psychology of decision-making. I then focus on one paradigm in particular (cognitivism), one theory in particular (dual process theory) and one model in particular (universal model of clinical reasoning).

3.2.1 Psychological paradigms

The scientific study of decision-making depends in part on the pre-empirical commitments of the researcher and research community; what 'decision-making' is depends on the paradigm through which it is studied

²⁷ Arguably, any justification of a fundamental value makes appeal to a more foundational value or to the same value and is therefore either self-undermining or circular.

(Kuhn, 1962, 2005). Broadly speaking, research into decision-making can be grouped into three scientific paradigms: *behaviourism*, *cognitivism* and *interpretivism*.

3.2.1.1 Behaviourism

The first studies into clinical decision-making stemmed from behaviourist psychology, according to which 'internal states of consciousness are excluded... as being beyond scientific study' (Loftus and Smith, 2008: 206). This paradigm can be broadly located within the empirico-analytical tradition, given that 'behavioural laws that link stimuli to behaviour are assumed to be similar in kind to the laws of physics and chemistry' (Loftus and Smith, 2008: 205–206). However, despite its initial promise, behaviourism was soon considered an inadequate conceptualisation of the complexities of decision-making due to its relative neglect of contextual detail and interpersonal interaction (Loftus and Smith, 2008). The more powerful conceptual framework that many adopted in place of behaviourism, which was heralded as paying due attention to the subtlety of mental phenomena, is the cognitivist paradigm (Patel and Arocha, 2000).

3.2.1.2 Cognitivism

Where behaviourism envisioned cognition as a scientifically impenetrable black box with 'environmental inputs and behavioural outputs', cognitivism employs the metaphor of cognition as 'information processing, similar in kind to that carried out by computers' (Loftus and Smith, 2008: 206). Cognitivism proposes there are mental structures, such as categories, prototypes, instances, schemas, scripts and networks (Gruppen and Frohna, 2002) which function in relation to three key core concepts: information processing, memory representation and problem solving (Case and Bereiter, 1984).

Within cognitivist psychology, a subspecialty of decision theory was quick to develop. The so-called first generation of the psychology of decision making imagined a decision-maker to be a self-interested gambler, who was engaged in a mathematical game: 'it is assumed that the player should select the option that has the greatest expected value' (Beach 2005: 7). This was an approach that came to be known as the 'expected utility model' (Ubel and Loewenstein, 1999: 82).

Despite the allure of simplicity and mathematical precision, a second generation of decision theory arose out of frustration with the first. The gamble analogy and expected utility model are unrealistic in their neglect of people's limitations; decision makers are frequently dependent on simplifying strategies, which lead to information distortions such as the 'availability heuristic' and 'representativeness heuristic' (Tversky and Kahnemann, 1974, 1981). There are now over 50 known forms of cognitive bias (Baron, 2000). Furthermore, decision makers are typically unable to estimate the probabilities of unique events (Gigerenzer, 1991).

These observations prompted a second generation of decision theory, which 'abandons the gamble analogy and views decision making as a form of problem solving' (Beach, 2005: 9). I will return to the cognitivist

construal of decision-making as problem solving in a moment, after summarising the contribution of a third paradigm: interpretivism.

3.2.1.3 Interpretivism

From an interpretivist perspective, decision-making within a healthcare context is considered to be ‘socially, historically and culturally constructed’ (Loftus and Smith 2008: 209). Interpretivism seeks to understand phenomena, particularly human phenomena, within their social context (Holman, 1993), presupposing that ‘multiple interpretations of reality can exist’ (Loftus and Smith 2008: 209). In contrast to behaviourist and cognitivist approaches, an interpretivist approach to decision-making seeks to understand the phenomenon without isolating it from its social context. As Leonard explains, ‘to understand a person’s behaviour or expressions, one has to study the person in context, for it is only there that what an individual values and finds significant is visible’ (1989: 46).

Within healthcare, research into decision-making within an interpretivist paradigm has largely arisen out of the non-medical professions. This is perhaps unsurprising, given the medical profession’s affinity to the empirico-analytical tradition, wedded as it is to ‘a positivist philosophical stance where objectivity is the key issue’ (Higgs and Loftus 2008: 215). Since the 1950s, interpretivist research has made major contributions to understanding decision-making in nursing, physiotherapy and occupational therapy (Benner, 1984; Benner and Tanner, 1987; Crepeau, 1991; Benner *et al*, 1992; Jensen *et al*, 2007).

3.2.2 Dual process theory

I return now to the cognitivist paradigm. Specifically, I draw attention to second-generation research into decision-making as problem-solving, which has made a significant impact on the understanding of clinical decision-making.

In 1978, Elstein *et al* explored how diagnostic problems are resolved by medical professionals and posited a process of limited hypothesis generation, which then guides subsequent data collection and interpretation (1978). This method of ‘backward reasoning’ has been termed ‘hypothetico-deductivism’. It has been described as Bayesian in its probability estimation and Popperian in its hypothesis falsification, but orientates these epistemic tools in a problem-solving direction (Croskerry, 2009: 1022).

However, whilst a hypothetico-deductivist approach to problem-solving is characteristic of novices, it does not equally reflect the approach of clinical experts. Ericsson and Simon reported that a ‘forward reasoning’ approach to problem solving distinguishes experts from novices, and that this is ‘one of the most robust findings’ in the field of clinical reasoning (Ericsson & Simon 1993: 132). Experts tend to use if-then production rules (Patel and Groen, 1986) and intuitive pattern recognition (Loftus and Smith, 2008).

Elstein anticipated a ‘clinical-statistical polarization’ between those cognitivists who valued the intuition of the experienced practitioner and those who valued the rationale of the quantifying theoretician (1976). In response, some have proposed a cognitive continuum between intuitive and analytic approaches, along which decision-makers take their place guided by cues and experience: *cognitive continuum theory* (Hamm, 1988). Others have proposed two processes: the fast, intuitive ‘system 1’ and the slow, analytical ‘system 2’ (Evans, 2008; Croskerry, 2009). This *dual process theory* has been popularised in Daniel Kahnemann’s best-selling book *Thinking, Fast and Slow* (2012) and is well corroborated by neuroscientific evidence (Mills-Finnerty *et al*, 2014; van den Bos and Flik, 2015; Broche-Perez *et al*, 2016; Foxall, 2016).

3.2.3 Universal model of clinical reasoning

3.2.3.1 Summary

Clinician in Emergency Medicine, Pat Croskerry, appreciates the workable nature of dual process theory, which allows for cognitive flexibility according to the specific circumstances of the clinical scenario:

‘Many clinical situations are often characterized by too many variables or unknowns, too many ethical and financial restrictions, or too many other resource limitations to ever allow a simple quantitative approach to guide a particular clinical decision, and actuarial models simply cannot be applied in many clinical situations. This is the clinical reality that medical decision makers face daily’ (2009: 1026).

Observing the lack of any ‘unifying approach’ to medical decision making, Croskerry incorporates cognitivist dual process theory into a clinical context to propose a ‘universal model for clinical reasoning’ (2009: 1022). System 1 processing is fast and intuitive but prone to diagnostic error; system 2 processing is analytical and less prone to diagnostic error but slower (2009: 1023–1024).

In this proposal, he is careful to emphasise the interdependence of the two arms of the model. For example, when a clinician observes a familiar-looking rash, she may diagnose shingles by way of recognition-primed processing (system 1). However, upon encountering atypical, unexpected features, she may switch to system 2 reasoning (‘rational override’). Likewise, the clinician may switch back to system 1 decision-making through ‘inattentiveness, distraction, fatigue, and cognitive indolence’, what he terms a ‘dysrationalia override’ (2009: 1024–1025).

3.2.3.2 Critique

There seem to me to be three main limitations of Croskerry’s model, adapted as it is from dual process theory. Firstly, it is limited in its scope. It is an approach to decision-making that intends to solve a problem and, specifically, a diagnostic problem. Secondly, it is limited in its professional perspective. Within the cognitivist paradigm there is comparatively little attention given to the decision-making process of other

healthcare professionals, patients or relatives. Thirdly, it is limited by the shortcomings of the computation metaphor presupposed by the cognitivist paradigm. Dual process theory can be firmly located within the empirico-analytical tradition, as evidenced by its emphasis on the rational processing of accurate information. However, decision-making in a clinical setting does not deal simply with informational 'brute facts' that need processing; it deals with personal problems, interpreted as meaningful by persons and reliant on persons for their amelioration.

Empirico-analytical approaches 'work best when the context is defined, limited and perpetual' (Holman, 1993: 30) but arguably lack appreciation for the ill-defined, relationally extended, unique context of clinical decision-making. For such a 'complex, multidimensional, integrated, task- and context- dependent process' as clinical decision-making (Loftus and Smith, 2008: 209) an expanded model which abandons the reductionist and individualist computation metaphor of cognitivism may prove insightful.

Croskerry considers his clinical adaptation of cognitivist dual process theory to be of use to healthcare professionals. His 'comprehensive approach' allows clinicians to 'gain insight and understanding into their own decision making' (2009: 1026). What spurs Croskerry on to promote this model is more than the appeasement of clinicians' intellectual curiosity, however. As he puts it, 'it is difficult to imagine anything of greater importance or relevance to patient outcomes and to patient *safety*' (2009: 1026, emphasis added). Ultimately, Croskerry urges clinicians to engage with his decision-making model on ethical grounds: 'For the *safety* of patients, the imperative to think critically, reason, decide, and diagnose well always remains' (2009: 1026, emphasis added). In terms of values, Croskerry is concerned for patient welfare and views the need for clinicians to gain decision-making insight as a means to that end. A strength of this clinical adaptation of cognitivist dual process theory, then, is its positive impact on clinical practice according to the value of *welfare*.

However, a weakness may be its construal of positive impact *only* according to the value of welfare. What if there were other values according to which impact could be appraised, such as *choice*? The individualist reduction inherent in cognitivism renders Croskerry's model located exclusively within a single cranium, namely, the clinician's. However, clinical problems look different from different perspectives (Higgs and Jones, 2008). There is minimal appreciation within Croskerry's model of clinical reasoning for the *meaning* of an illness in the life-world of a particular patient and, in this way, it could be said to lack respect for autonomy. By adopting a cognitivist paradigm, Croskerry's model is blinkered from the outset; it only sees people as individual information-processors. However, as feminist bioethicist Jackie Leach Scully puts it, the 'model of the moral self as a disembodied, rational decision maker functioning independently at the bargaining table overlooks important aspects of moral life' (2008: 24).

Furthermore, it may be that producing the correct diagnosis is not the only problem (or even the main problem) with which the clinician ought to be concerned. Likewise, it may be that the doctor is not the only (or even the main) problem-solver around.

Croskerry refers to some limited quantitative research to provide empirical warrant for his appropriation of dual process theory (Landrigan *et al*, 2004; Berner and Graber, 2007). However, in order to show whether clinical reasoning does indeed proceed according to this model, *qualitative* research is required into the experience of decision-makers within their social context. In short, cognitivism here needs interpretivism; the ethnographic study of an AMS, which I am soon to present, may serve to address this scientific shortfall. It remains to be seen how well Croskerry's cognitivist model maps onto decision-making in clinical practice, such as within an AMS. In particular, it remains to be seen whether welfare considerations alone are sufficient to characterise what deciding *well* is.

3.3 Values-conscious decision-making

Clinical decision-making models which have been considered thus far involve values implicitly. However, some decision-making models are more explicit about the role of values in making a decision in healthcare. I will explore two prominent examples of such values-conscious decision-making models: values based practice (VBP) and values-based medicine (VBM).

3.3.1 Values-based practice

3.3.1.1 Summary

KWM Fulford is the main proponent of VBP, having provided theoretical grounding for it in *Moral Theory and Medical Practice* (1989). Drawing on the insights of ordinary language philosophy, Fulford establishes that person-centred care is synonymous with personal-values-centred care (Fulford *et al*, 2012) and argues that good clinical care equates to good handling of the various values which are in play. He considers VBP to be a timely complement to the evidence-based medicine (EBM) movement, which is well-established in UK healthcare. David Sackett, an early proponent of EBM, describes it as an integration of best research evidence, clinical expertise and patients' values (Sackett *et al.*, 2000: 1). Fulford sees VBP as supplementing EBM in its values-conscious task and thus enabling clinical decisions to stand on 'two feet: evidence *plus* values' (2014: 11).

How does VBP lead to a decision? Fulford *et al* draw an analogy with democracy, in which decisions can be made and accepted without first requiring unanimity (2012). A similar process of balancing of values can result in fair decision-making even in the midst of values conflict, a circumstance Fulford describes as 'dissensus' (1998).

To characterise the process by which decisions should be made, Fulford proceeds to articulate ten principles, five theoretical and five practical, as a framework for values-conscious decision-making. These include the ‘squeaky wheel principle’, that values tend to be noticed in times of value conflict, and the ‘patient-first principle’, that the preferences and wishes of the patient are the clinician’s first port of call (2004: 206). Once all stakeholders have expressed their preferences, the responsible clinician is enabled to proceed with a decision according to a ‘balance of legitimately different value perspectives’ (2004: 216).

3.3.1.2 Critique

The model of VBP is endorsed across a wide range of healthcare professionals, as reflected in its Oxford-based network of individual and organisational partners (The Collaborating Centre for Values-Based Practice in Health and Social Care, 2020). Furthermore, VBP is self-consciously aligned with legal and professional guidance, such as the Mental Health Act 2007 and the ‘National Framework of Values’ (2004) of the National Institute for Mental Health in England (Fulford, 2014: 12). Its reception amongst scholars, however, has been a little more mixed. I will present three problems of VBP: one ontological, one epistemological and one evaluative.

3.3.1.2.1 Ontological problem

Many critics of VBP level their complaint at the basic unit of the model: values. According to VBP, what actually is a value? In Fulford’s own words, values extend to ‘needs, wishes, preferences, indeed to any and all of the many and diverse ways in which people express, directly or indirectly, negative or positive evaluations and value judgments’ (2011: 976)²⁸.

One of VBP’s fiercest critics, Bob Brecher, notes both the tautologous nature of this definition as well as its impractical vagueness:

‘What I do call for, and what I do not find anywhere in Fulford’s account of what he takes “value” to mean, is some minimal characterisation of what he has in mind’ (2014: 63).

Likewise, Kingma and Banner note that, across his writings on VBP, Fulford considers values to be ‘anything that people take to be important to illness *tout court*’ (2014: 41), rendering the concept of values ‘so broad as to become useless’ (2014: 43).

Whilst the individual patient is the ‘first call’ for information (Fulford, 2004: 213), Fulford suggests that the expressed values of *all* stakeholders need to be taken into account. Given the democratic process that ensues, it makes a great deal of difference who counts as a stakeholder and is thereby entitled to a vote in this decision-making process. Surprisingly, Fulford fails to articulate how the group of stakeholders is to be

²⁸ KWM Fulford’s sense of ‘values’ is thus much broader than the sense I use in this thesis (see: Chapter 2 *What are values?*).

determined, other than hinting it involves at least the patient and an ‘extended’ multidisciplinary team (2014: 8).

VBP’s ontological problem is that it is unrealistic about what values are and who stakeholders are. To continue his own metaphor, the clarity of Fulford’s democratic process is undermined by striking ambiguity about what counts as a vote and who counts as an electorate.

3.3.1.2.2 *Epistemological problem*

Whilst Fulford preserves deliberative space for the ‘clinical judgment’ that Sackett identified as an accompaniment to evidence and values, he nowhere characterises the nature of this judgment. For example, Fulford recognises that not all persons involved in a clinical decision are equal; hence the so-called ‘patient perspective principle’ (2004: 206). However, this principle merely prescribes the order of communication, not the relative weighting of different people’s evaluations.

In order to come to a decision, value-expressions must be more than listened to; there needs to be reason for action, a justification for a course of action. Appeal to a vague notion of balancing does not help the practitioner know how to do balancing *well*. Critic Tim Thornton sees this omission as transforming VBP from liberal-in-theory to authoritarian-in-practice; as he puts it:

‘Surely not just any balance would do? For example, a “balance” imposed through undue force or influence by powerful parties to a clinical decision would not be a good outcome. So “balance” is to be understood as something like the right or a good balance, which seems to presuppose the kind of innocent authoritarianism in question’ (2014: 60–61).

The development of VBP seems to be epistemologically stunted²⁹, leaving it an insufficient guide for a clinical decision-maker, especially during times of dissensus.

3.3.1.2.3 *Evaluative problem*

The ontological and epistemological problems of VBP could also be described as normative problems: VBP does not adequately present what *ought* to be considered a value, whose values *ought* to be considered, nor how clinical judgment *ought* to be performed. The latter could be expressed in terms of values: Is a good balance to be measured by the evaluative standard of patient *welfare*? Or perhaps a good balance is one which best reflects the perspectives of the stakeholders, according to the evaluative standard of *choice*? Or perhaps another evaluative standard altogether?

²⁹ KWM Fulford conceded that VBP’s epistemological notion of balancing remains a work-in-progress in personal dialogue with me on 11/04/19.

I raise one final limitation of VBP. VBP, inspired by the procedural justice of a liberal democracy, involves a balancing of value-perspectives. Not any perspectives, however: only 'legitimately different perspectives' (2004: 206). Fulford deems values to be legitimate so long as they do not contravene the fundamental 'values-based premise of mutual respect'; disrespectful, discriminatory values such as racism are thus excluded from the VBP decision-making process (2004: 12).

Despite Fulford's construal of VBP as a *pluralist* framework of ten principles, it turns out that the ten are based on one. The foundational premise, *respect for persons*, acts as a meta-value by which all other value expressions gain their legitimacy. In philosophical terms, VBP is thus a value *monist* ethical system. In political terms, it is an ideology, espousing a liberal conception of the good society (Brecher, 2014: 65). In theological terms, it is a creed: there is no value but respect for persons, and VBP is its prophet.

Whilst 'respect for persons' has an intuitive resonance to it, it affords a vast array of interpretations. Firstly, what counts as a person? Secondly, what does it mean to 'respect' persons? Does respecting a person entail doing what promotes objective flourishing (*welfare*), or does it entail doing what appreciates subjective wishes and preferences (*choice*)? Or perhaps something else altogether?

The structure of VBP is only as strong as its foundation. The foundation of VBP is a meta-value which is arbitrary and ambiguous, leaving it unclear what the role of values *ought* to be in clinical decision-making.

3.3.2 Values-based medicine

3.3.2.1 Summary

Values based medicine (VBM) is a model proposed by Miles Little that has a lot in common with VBP. Both share a 'V'; they seek to address the value-laden aspect of clinical work. Both share a 'B'; they presuppose a values foundation as a basis for ethical justification. They are thus both forms of *foundationalism* about values. Whilst both abbreviations differ in their final letter, they nevertheless share a focus on 'medicine' and 'practice': the models are intended to be incorporated into day-to-day clinical decision-making.

However, they differ in their philosophical underpinnings; where Fulford depends on ordinary language philosophy to elucidate the nature of values, Little leans on a David Hume's account of ultimate ends beyond which 'it is an absurdity to ask for a reason' (2004 (1777): 293). Little rejects Fulford's loose definition of values which includes preferences, drawing a contrast as follows:

[Values] are not the same as preferences. Preferences may express values, but preferences are not values *per se*. Values for me are the end-points of iterative enquiry, a series of questions that keep asking for justifications until there is no answer except something like 'Because that is the way humans are', or 'Because societies cannot function any other way' (2014b: 172).

Little's account of values is thus reminiscent of the phrasing of the Warnock report, which noted that 'matters of ultimate value are not susceptible of proof' (Department of Health and Social Security, 1984: 2).

Little's depiction of values is unashamedly foundationalist: 'A society without foundational values is an incoherent concept' (2014b: 174). Despite this foundationalist conception, Little only considers some values to be truly fundamental:

'It is quite possible to talk about values anywhere along a continuum. At one end, we have the set of foundational values... at the other, we have the systems that give practical expression to these values in culturally appropriate ways' (2014b: 174).

Foundational 'F' values, according to Little, are universal across human cultures and 'pre-normative'; they form the basis of justifying normative claims, whether generalised axioms ('A' values) or specific practical expressions ('P' values) (2014b: 174).

Little identifies three foundational values: *survival*, *security* and *flourishing*. He holds these to be 'descriptive categories' and '*a priori* necessities for a culture or society to continue and to evolve – but [this] does not say how they must play out in each culture or society' (2014b: 173). As with Fulford's VBP, it could be argued that VBM is then also a disguised form of monism. An implied meta-value here is 'culture or society continuing and evolving (is good)'; or rather 'enabling culture or society to continue and evolve (is the standard of goodness)'. However, I think this would be a hasty inference; Little does not suggest that humanity's evolutionary propagation renders these values *good* but rather it renders these values *existent* (and vice versa).

In *Values, Foundations and Being Human*, Little illustrates how his F-A-P system of values could usefully operate as a framework for clinical decision-making. He narrates a scenario in which patients with a haematological disorder could be treated with a medication known as recombinant Factor VII. However, the benefit of this medication has not been conclusively shown and it is extremely expensive. Physicians can prescribe it off-licence but risk litigation by doing so (2014b: 179–180).

Little shows how decision-making could start with the three foundational values and work its way upwards. 'From the doctor's point of view, the patient's survival is paramount... From society's point of view as well, every possible step should be taken, because life is precious, and the use of Factor VII is still within the means of most Western societies' (2014b: 180). Little goes on to describe how the doctor would wish to protect her own security and flourishing by being able to 'say with conviction "I did everything I could"' (2014b: 180). Similarly, society at large expresses concerns related to security and flourishing:

‘Faith in our own security implies that all reasonable means will be used by medicine when death threatens. Death is the end of flourishing. We want to feel secure that medicine does what it can to rescue us from vulnerability’ (2014b: 180).

Little then turns to draw attention to the more superficial A and P values in play, noting that there is no conflict on the level of foundational values; ‘substantive disagreement begins at the A level’ (2014b: 180). He concludes this chapter by alluding to one of Immanuel Kant’s more poetic moments:

”...out of wood so crooked and perverse as that which man is made of, nothing absolutely straight can ever be wrought”(Kant, 1824) The wonder is that the species, warlike, spiteful, inconstant and capricious, has survived at all’ (2014b: 181).

In view of such capricious inconstancy, it is also remarkable that Little deems humanity to be so unshakeably constant in its tenancy of foundational values. I now turn to consider in what ways Little’s presentation of foundational values is problematic.

3.3.2.2 Critique

3.3.2.2.1 Pre-normativity

According to Little, ‘survival’, ‘security’ and ‘flourishing’ are descriptive categories that provide a basis for normative content without containing such normativity themselves. Is this a coherent thing to say?

Upshur does not find this notion of pre-normativity persuasive, seeing the three foundational values instead to be ‘regulative ideals that we strive, collectively, to ensure’ (2014: 216). He notes that Little’s account of foundational values is lacking an anthropology:

‘Do the values of survival, security and flourishing apply to all humans and societies equally? That is, ought persons, qua persons, qualify for or share these values? If so, then they must be regarded as normative in some sense, otherwise they can be countered as non-necessary and therefore non-foundational’ (2014: 217).

In Little’s defence, he seeks to present F values as foundational to humanity’s way of propagating and evolving. As such, foundational values are a basis for a structure of society rather than a structure of knowledge (2014a: 256). Little arrived at these three foundational values through empirical qualitative investigations and notes he could have named them ‘primordial factors’ in order to emphasise their descriptive, pre-normativity (2014a: 257). He adds: ‘consider the F-values as something essentially human like opposable thumbs. They are a given. We are stuck with them’ (2014a: 257).

Whilst Little’s F-values are evaluative in the sense that they function as standards by which persons evaluate a situation, they are merely descriptive in that ‘they offer partial understanding of the ways in which humans

respond to all kinds of experience... they are clearly stated to underpin evolutionary social processes, not knowledge' (2014a: 256). Thus Little does not claim that it is by these F-values that humans *should* respond to experience, ideally; he claims that it is by these F-values that humans *do* respond, in fact. As such, VBM does not tell us what the role of values in clinical decision-making *ought* to be but what it *tends* to be.

3.3.2.2.2 Universality

It could be argued, however, that VBM is not justified in claiming to be even a descriptive model, for two reasons.

Firstly, Little's account is caught on the horns of a dilemma. Whether or not Little's F-values are conceived within a form of social life, either conception leads to an intolerable conclusion. Within a form of social life, F-values would be meaningful but not universal; divested from a form of social life, F-values would be universal but not meaningful³⁰. To assert that such values are both meaningful (to be applied) and universal (applied by everyone) is for Little to have his theoretical cake and eat it.

Secondly, Little's attempt to justify the existence of F-values, by appeal to evolutionary necessity, is purely theoretical³¹. Whilst alluding in passing to qualitative data in support of VBM (2014a: 257), he sooner reaches for (the empiricist) David Hume's moral epistemology than any contemporary empirical data in support of his foundationalist claims. It remains to be seen whether *survival*, *security* and *flourishing* really are values involved in decision-making within healthcare generally and an AMS in particular.

3.4 Conclusion: values and decisions

In this survey, I have endeavoured to present a critical account of major decision-making models. The limitations of each model can be portrayed as an inadequate account of the role of *values* in healthcare decision-making, on the grounds of arbitrariness, incompleteness or ambiguity.

Some models exhibit *arbitrariness*, such as paternalist and anti-paternalist decision-making. These approaches take it as given that the fundamental value of healthcare decision-making is *welfare* or *choice*, respectively. Arbitrariness is also evident in shared decision-making's conjunction of paternalist and anti-paternalist phases, which lacks a third value by which to justify any delineation between the two phases.

³⁰ In contrast, the model of the role of values in decision-making that I present in this thesis is derived from an interpretive analysis of rich qualitative data. As a result, the applicability of this model to other settings relies on a context-dependent 'fusing of horizons' (Gadamer, 2013) rather than a context-free universalising of terms (See Chapter 5: *Trustworthiness*).

³¹ Arguably, research in social psychology provides some empirical support for Little's claims, given the similarity between F-values and the hierarchy of needs described by Abraham Maslow (1943). However, where Little's values are necessary for propagation for the human species, Maslow's needs are necessary for self-actualisation; where Little posits a foundation, Maslow posits the opposite: a hierarchy.

Some models exhibit *incompleteness*, such as the Croskerry's universal model of clinical reasoning, which combines a cognitivist-only construal of decision-making with a welfare-only ethical justification. Incompleteness is also exhibited in Little's VBM, which provides some theoretical warrant for three foundational values without adequate empirical justification.

Some models exhibit *ambiguity*, such as the ambiguity of the value 'patient-centredness', which could be interpreted in terms of welfare or choice. Likewise, it is profoundly unclear what 'respect for persons' means and how (good) balancing is done in Fulford's VBP. It is also ambiguous what the meaning is, or could possibly be, of the decontextualized, asocial F-values of Little's VBM.

In summary, all of the models that I have explored fall short of providing an adequate characterisation of the role of values in decision-making in healthcare. In chapter 4, I contextualise this knowledge gap within an Acute Medicine Service in particular.

Chapter 4. An Acute Medicine Service

This chapter provides context for the issues identified in the previous two chapters in three steps. Firstly, I summarise the short history of an Acute Medicine Service (AMS) in order to highlight its multifaceted nature. Secondly, I identify the priorities of the work of an AMS that are evident in current literature. Thirdly, I connect these insights to the knowledge gap identified in Chapters 2 and 3; namely, an AMS is a context in which the inadequate understanding of the role of values in decision-making is particularly problematic.

4.1 A brief history of the AMS

An AMS³² has only been a feature of UK healthcare since the turn of the 21st century. It has evolved through the changing environment of the National Health Service (NHS). This environment features survival pressures not just for patients but also for general hospitals, which are required to manage increased workload with limited resources.

4.1.1 An AMS is a medical specialty and an organisational unit

In the words of the Secretary of the Society for Acute Medicine, 'there was a time when all physicians were expected to be competent in both the immediate and subsequent management of all common medical disorders, and thus were general physicians' (Dowdle, 2004: 652). In such times, the term 'Acute Medicine Service' was not used to refer to any distinct feature of, or physical location within, hospital medicine. However, doctors increasingly committed themselves to focus attention on particular organ systems. This process of specialisation accelerated during the 1970s, with the consequence that 'many physicians became more committed to their specialties than to the generalities of the acute intake' (Dowdle, 2004: 652).

Previously, a medically unwell patient who required hospital stay would be admitted to hospital via their General Practitioner (GP) or the Accident and Emergency department (A&E) onto the ward of the 'physician on call'. However, 'with the inexorable rise in the numbers of emergency admissions, ward-based admissions were lost, with patients being admitted initially to any available medical bed, and later to virtually any bed in the hospital', leaving the admitting team to spend as much time travelling to their patients as attending them (Dowdle, 2004: 652). This tortuous and time-consuming routine was colloquially termed a "safari ward round". Such a scattering of newly admitted patients throughout the hospital was deemed ineffective and untenable by a report in 1998 from the Scottish Royal Colleges of Physicians, who instead endorsed a single geographical area for the assessment of acutely unwell medical patients (Scottish Intercollegiate Working Party, 1998). This geographical area came to be known as the Acute Medicine Unit (AMU).

³² 'AMS' is not itself a commonly used term. An AMS is more frequently referred to in terms of its medical specialty, Acute Internal Medicine (AIM), or in terms of its organisational department, the Acute Medical Unit (AMU).

This concern of the Scottish Royal Colleges of Physicians was qualified and established by a report in 2000 by the Federation of Medical Royal Colleges (Federation of Royal College of Physicians of the United Kingdom, 2000), which endorsed the introduction of AMUs as an organisational unit but not yet Acute Internal Medicine (AIM) as a distinct medical specialty. On the heels of this, the Royal College of Physicians of London (RCP) formed an Acute Medicine Group which soon established the Society for Acute Medicine (SAM) (Dowdle, 2004). Facilitated by SAM and the RCP's recommendations and negotiations, AIM was recognised as a medical sub-specialty in 2003, and a specialty of its own in 2009 (Dowdle, 2004). It was claimed that the new specialty of AIM was needed in addition to the establishment of AMUs for four reasons, the first of which was 'the increasing demand for emergency care, much of which falls within the medical specialties' (Royal College of Physicians of London, 2004: 1).

The president of the RCP summarised the need for change in her own words:

'the unpredictability and intensity of caring for the acutely ill calls for the undivided attention of the teams dealing with them... Junior doctors faced with acute problems must be confident that they can call on a senior colleague who is skilled in acute medicine and receive unreserved support' (Royal College of Physicians of London, 2004: vii).

The proposal of the new specialty of AIM together with the new department of an AMU rapidly gained traction. As a result, there came a pressing need to clarify what these entities actually are. A report of a working party from the RCP was released for this purpose, entitled *Acute Medicine: Organisation and Training for the Next Decade* (2004). It defines the specialty of AIM as 'that part of general (internal) medicine concerned with the immediate and early specialist management of adult patients with a wide range of medical conditions who present in hospital as emergencies' (2004: ix). This definition was revised in 2007 to clarify that patients may present 'to, or from within, hospitals' and that their care needs may be either 'urgent or emergency' (RCP Acute Medicine Task Force, 2007: xxi). The urgency of care needs has elsewhere been enumerated to suggest that the specialty of AIM is primarily concerned with the first 72 hours of clinical management (Joint Royal Colleges of Physicians Training Board, no date; takeAIM Campaign, no date).

Alongside the birth of the specialty, the RCP endorsed the arrival of its accompanying organisational unit, the AMU, which they define as 'a specialised area of an acute hospital where patients suffering from acute medical illness can be assessed and initially admitted' (RCP Acute Medicine Task Force, 2007). The success of one depends on the success of the other.

The impact of the RCP's suggestions is evident from the subsequent rapid implementation of AMUs throughout the UK. By 2009, it was estimated that 75% of hospital patients were being admitted to AMUs (McNeill *et al.*, 2009). AMUs are now 'uniformly present in acute hospitals in the UK and... increasingly

relevant internationally' (Reid et al. 2018: 522). The AMU model has begun to be installed in Ireland, New Zealand, Australia, Italy, the Netherlands and Scandinavia (McNeill *et al.*, 2011; Realdi *et al.*, 2011; Vork *et al.*, 2011; Watts *et al.*, 2011; Providence, Gommans and Burns, 2012). Whilst professional bodies have been quick to express expert opinion in support of this new model of acute medical care, it must be conceded that the AMS model has largely emerged 'as a result of local service innovations and there is limited evidence in relation to the effectiveness of this model of care' (Reid et al. 2016: 434).

The specialty of AIM and the department of AMU, then, are twins which grew up together. Their adoption has been justified in view of two needs: the need of *patients* to receive expert acute care and the need of *hospitals* to deliver a service on limited resources with greater efficiency and co-ordination (Health Careers, no date). AIM and an AMU can be considered two closely related aspects of an AMS; an AMU refers to the *department* within a hospital and AIM refers to the *specialty* within medicine that primarily operates there.

So far, I have presented a portrait of an AMS that emerges from a particular kind of literature: reports, guidance and evidence from within the medical tradition. I now turn to alternative portrayals of an AMS that arise from other literature sources.

4.1.2 An AMS is a place for healing

Jocelyn Cornwell trained as a medical sociologist and ethnographer prior to working in NHS management and becoming chief executive of The Point of Care Foundation (Kings Fund, 2017). She rejects the characterisation of an AMS purely in medical and organisational terms. Instead, Cornwell proposes that an AMS 'would be better defined as a *place for healing*, where pain and distress can be eased by caring professionals' (Kings Fund, 2017: 73, emphasis added). The goal and value of an AMS is something that needs to be balanced by other viewpoints. As she puts it, 'when value is defined from the supply side alone, it tends to ignore the relational and non-clinical aspects of care that are critical to patients' mental and emotional wellbeing and recovery' (Kings Fund, 2017: 73).

Cornwell is concerned that if an AMS is construed only as a medical specialty and organisational unit, then the psychosocial elements of acute illness may be overlooked. Such elements include illness' impact on embodied relationality:

'Illness changes everything. It changes not only my internal organs, but my relationship to my body, my relationship to others, their relation to me and to my body... In short, illness changes how one is in the world' (Carel, 2007).

Moreover, the psychosocial impact of acute illness is not limited to a minority of cases. As Sweeney *et al* put it:

'Every patient that comes through a hospital is apprehensive. It's a strange place, you have strange sheets, you have odd tea in a plastic cup. The whole thing is vibrantly different' (2009).

The aspect of illness that Cornwell, Carel and Sweeney are emphasising has a lot in common with the biographical disruption model of sickness (see: Chapter 2 *Biographical disruption*). In view of this, to fail to acknowledge the psychological and relational dimensions of an AMS is to fail to treat all the kinds of suffering that are present. As Cornwell concludes:

'If wards were re-defined as places for healing, recovery and care, staff would aim to reduce and eliminate all avoidable suffering. The quality of relational care would have equal priority to clinical quality and patient safety, and changes in the physical environment, the conduct of staff and the organisation of care would follow' (Kings Fund, 2017: 75).

Thus, Cornwell identifies a third aspect of an AMS, which is largely overlooked in medical and organisational literature. As well as being a medical specialty and an organisational unit, an AMS is a place of healing. As well as being a place where sickness is met with treatment and triage, an AMS is a place where sickness is met with relational care.

Cornwell's account is supported by clinical researcher Sam Pannick, who notes that, like all medical wards, an AMS is not just a place of treatment but 'a temporary home... a resting place' (Kings Fund, 2017: 68). It cannot be reduced to its location on the map of medical specialties or hospital departments. Pannick *et al* note that there is a lack of clarity regarding the goals of medical ward care that shape the ward's structures, processes and outcomes (2015). This is problematic because 'without this clarity, we're putting the cart before the horse, introducing changes without really knowing what we're hoping to improve' (2015: 69). He notes that 'there isn't a consensus about the measurements that reflect *good* ward care in the United Kingdom' (2015: 68, emphasis added).

The introduction of an AMS is a change which is aimed at improvement. Like Pannick *et al*'s verdict on medical wards in general, is it a case of putting the cart before the horse? In what ways does an AMS do *good*? To shed light on this question, I turn to describe the priorities of an AMS.

4.2 Priorities of an AMS

4.2.1 Urgency

The priority of acting urgently is implicit in the definitions, empirical justification and guidance documents that relate to the work of an AMS.

4.2.1.1 Definitions

The priority of acting with urgency is entailed in the very title of an AMS as an *Acute* Medical Service. I now survey the definitions of an AMU and AIM, highlighting in italics allusions to the priority of urgency.

AMU:

- ‘Acute medical unit: a specialised area of an acute hospital where patients suffering from *acute* medical illness can be assessed and *initially* admitted’ (RCP Acute Medicine Task Force, 2007)
- ‘An acute medical unit... is an area of an acute hospital where people with undifferentiated medical emergencies who need hospital admission receive *rapid* assessment, investigation, *initial* treatment and definitive management’ (NICE 2018: 10)

AIM:

- ‘Acute medicine is that part of general (internal) medicine concerned with the *immediate and early* specialist management of adult patients suffering from a wide range of medical conditions who present to, or from within, hospitals requiring *urgent or emergency* care’ (RCP Acute Medicine Task Force 2007: xxi)
- ‘Acute Internal Medicine provides the initial assessment, investigation, diagnosis and management of patients who have an *acute* medical illness within the *first 72 hours* of their hospital stay’ (takeAIM Campaign, no date)

The healthcare that an AMS offers an individual patient is to be enacted early, quickly and not for long. This is perhaps because an AMS is not simply dealing with individual patients; rather, there is a continuous, variable and unpredictable cohort of patients being admitted to hospital as medical emergencies, with which the work of an AMS must rapidly keep pace.

Besides mere definitions, is the priority of urgency reflected in other literature about an AMS?

4.2.1.2 Empirical justification

The evidence used to justify and promote the implementation of an AMU may reveal the priorities of those who wish to implement it. According to the limited evidence base, the primary benefit of an AMU is that it ‘is associated with reduced hospital LOS [length of stay] compared to alternative models of care. The evidence that AMUs are associated with a decrease in mortality is weaker’ (Reid *et al.*, 2016: 444). ‘Length of stay’ is a marker of how quickly patients are assessed, treated and discharged from hospital. One study reports a ‘mean 1.34-day reduction (95% CI 0.01–2.67)’ (McNeill *et al.*, 2009, in: Reid *et al.*, 2016: 444).

Whilst this finding is not consistently confirmed in other studies (Bell *et al.*, 2013), the reduction in length of stay is nevertheless used to justify the need for urgent review by senior decision-maker, daily review by

consultant physician and the establishment of AMUs generally (NHS England, 2015: 10). Implicit in this empirical justification is the priority of urgency; getting patients assessed, treated and discharged quickly is seen as *good*.

4.2.1.3 Guidance

In 2018, the National Institute for Health and Care Excellence (NICE) published 4 quality standards relating to areas of the work of an AMS, with suggested outcomes to measure (2018a). One such outcome to measure is the 'length of hospital stay for adults admitted with undifferentiated medical emergencies', in order to show that the AMS is meeting its requirement of providing '*rapid* assessment, investigation and treatment for medical emergencies' (2018a: 8-9).

SAM has also released 'clinical quality indicators' for an AMS to aim for, in order to improve the standard of care. SAM suggests 3 targets, in addition to the NICE recommendations. Upon arrival, the patient is to have bedside measurements (called an Early Warning Score) recorded; within 4 hours, 'all patients should be seen by a competent clinical decision maker'; within 8 hours, all patients admitted during the daytime should be reviewed by a consultant physician; within 14 hours, all patients admitted during the night should be reviewed by a consultant physician (2014). The time-bound nature of each target reinforces the urgency with which each task is to be carried out.

The priority of urgency is also captured in broader guidance documents. For example, the title of the Report of the Acute Medicine Task Force accentuates the need to get things right quickly: *Acute Medical Care: the right person, in the right setting – first time* (2007). Similarly, the NHS England publication *Transforming Urgent and Emergency Care Services in England* reflects this emphasis on urgency in its subtitle: '*safer, faster, better*' (NHS England 2015b, emphasis added).

Some guidance is directed at patients, which also highlights the priority of urgency. Recognising that the bustling environment of an AMS may be one to which members of the public are not accustomed, one AMS released a leaflet describing the department as follows: 'AMU is a *busy* environment and we receive roughly 30 to 50 admissions every day. It is not normally a long-term stay area for patients and we expect to send you home or move you to a speciality ward *within 24 to 48 hours*' hours' (University Hospital Southampton NHS Foundation Trust, 2013, emphasis added).

As I have shown, the priority of urgency is reflected in the definitions of an AMS, in evidence justifying the establishment of an AMS, and in guidance documents about the work of an AMS.

4.2.2 Other priorities of an AMS

4.2.2.1 Medical perspective

Whilst the urgency of care delivery may be described as the *raison d'être* of an AMS according to definitions, evidence and professional guidance, there are indications that the work of an AMS is also shaped by additional priorities. For example, for all of its emphasis on urgency and the need to maintain good patient flow through hospital, NHS England's guidance to urgent and emergency care services also values cost-effectiveness, patient outcomes and patient safety (2015: 10). It is not mere urgency that is prioritised, but care which is simultaneously '*safer, faster, better*' (2015: 1, emphasis added).

With regard to the medical specialty of AIM, 'prompt practical management' is considered a key competency of a specialising physician (Joint Royal Colleges of Physicians Training Board, no date). However, in addition, the clinical decision-maker is required to develop a '*rational differential diagnosis*' to ensure '*safe and effective treatment of the patient*' : '*getting it right, first time*' (RCP Acute Medicine Task Force, 2007: 7, emphasis added). There are clear indications here that speed is not the only measure of good acute care. Other priorities of the work of an AMS seem to include accuracy, safety, effectiveness, and cost-effectiveness.

4.2.2.2 Other perspectives

The role of an AIM physician includes 'the development of multi-professional systems to promote optimal patient care' (Joint Royal Colleges of Physicians Training Board, no date). Accordingly, an AMU typically involves 'a number of professional teams... including the medical, nursing, therapies, pharmacy and administrative teams' (University Hospital Southampton NHS Foundation Trust, 2013). It is striking, therefore, to note that the rise of AMS has been supported by expert opinion from the medical profession, such as the medical royal colleges and SAM, with relatively little contribution from other healthcare professions. As such, the priorities of an AMS as stated in literature may successfully reflect the emphases of the medical profession within the NHS but leave the priorities of other healthcare professions – or patients - relatively unattended.

Michael Wise was formerly a specialist in oral surgery and restorative dentistry before being admitted to an AMS acutely unwell with near-fatal sepsis. His reflections and experience reached publication in his book *On the Toss of a Coin* (2017). Wise's clinically-informed analysis offers a caution over the unrestrained priority of urgency: 'further "efficiencies" are likely to result in degradation of acute services, not improvement' (Kings Fund, 2017: 35).

Wise notes the importance of developing trust in the clinical team. The fact that 'it can take time for trust to be established, but it can be very easily and rapidly lost' (Kings Fund, 2017: 32-33) presents a particular

challenge for the time-pressured environment of an AMS. During his admission, he noticed that the priority of urgency and pursuit of efficiency resulted in a compromise in communication. To make matters worse, 'being busy can be used as an excuse for not being human, and there is a danger of this occurring among all frontline staff due to pressures' (Kings Fund, 2017: 34). Wise expresses fear that the priority of urgency in an environment where staff are constantly pressurised can result in desensitisation to the perspective of patients, resulting in harm to patients' psychological well-being and a compromise in the quality of care. Rather than pushing staff to go faster and faster, Wise calls for the priority of urgency to be counterbalanced by concern for the smaller gestures of healthcare, which alleviate the distress and anxiety that accompany acute illness (Kings Fund, 2017).

The wisdom of these words is echoed by Cornwell, who notes that an AMS can actually aggravate psychological suffering during episodes of acute illness:

'patients are inadvertently exposed to shame and humiliation; to distress, when their requests are ignored or overridden; to anxiety, about being kept in the dark, and about discontinuities and contradictory information; and to fear, when they are unable to trust caregivers' (Kings Fund, 2017: 75).

According to Wise and Cornwell, then, one priority of the work of an AMS should also be to alleviate the psychological struggles of acutely ill patients.

In summary, as well as delivering care urgently, some literature suggests that the work of an AMS should also meet other requirements, such as being safe, accurate, effective, cost-effective and caring.

4.3 Conclusion

In Chapter 2, I identified a lack of clarity with regard to *what* values are involved in healthcare decision-making.

A review of literature relating to the concept of sickness identified *welfare* and *choice* as two values to which objectivist and subjectivist epistemologies tend to appeal, respectively. However, the situation is complicated. For example, it is not self-evident that welfare-based and choice-based conceptualisations of sickness are mutually exclusive. Furthermore, welfare and choice do not exhaust the range of possible evaluative standards; for instance, it remains unclear what fundamental value a genealogical conception of sickness might appeal to. This ambiguity in values was shown to be problematic through a review of literature relating to the concept of futility. Value-monist and value-pluralist theoretical frameworks both failed to provide clarity as to what values are involved in decisions in clinical practice.

In Chapter 3, I identified a lack of clarity with regard to *how* values are involved in healthcare decision-making. I reviewed well-established decision-making models in contemporary healthcare literature and explored their evaluative content. Each model of decision-making displays an inadequate account of the role of values on the grounds of arbitrariness, incompleteness or ambiguity.

In this chapter, the lack of clarity regarding the *what* and *how* of values in healthcare decision-making was contextualised within an AMS and found to be particularly problematic for two reasons.

Firstly, an AMS is *pressured*. Healthcare delivery, including decision-making, must be done quickly within an AMS. Patients are rapidly deteriorating and rapidly admitted, and thus must be rapidly treated and rapidly discharged or transferred. Putting it bluntly, an AMS is pressured to get patients *out*. A lack of clarity regarding what *good* decision-making is potentially impedes the efficiency of making decisions, worsening the pressure.

Secondly, an AMS is *stretched*. The priorities of the work within an AMS are multiple, reflecting its multifaceted nature. As a result, the work of an AMS is pulled in multiple directions: it must be fast, safe, accurate, effective, cost-effective and caring, for example. An AMS is thus stretched to meet various demands. A lack of clarity regarding what *good* decision-making is potentially impedes the balance of decision-making. For example, it potentially leaves an AMS vulnerable to the unbridled pursuit of efficiency, which could bring about the inhumane degradation that Cornwell and Wise caution against.

In conclusion, an AMS is a context in which the current lack of clarity regarding the role of values in healthcare decision-making is particularly problematic.

Chapter 5. Methodology

In the preceding literature review chapters (2–4), I described the theoretical landscape within which this thesis is situated. This landscape features three terrains: the philosophy of medicine, clinical decision-making and an Acute Medicine Service (AMS). I identified a knowledge gap at the interface between these three areas: the role of values in decision-making within an AMS. In chapters 6-8, I will present empirical data which address this knowledge gap.

In this chapter I respond to the following methodological questions:

1. Does this study, in theory, address the knowledge gap?
2. Is the way this study was implemented, in practice, consistent with its theoretical aim?

I address these questions in four steps. Firstly, I articulate the research question and subordinate questions with which this thesis is concerned.

Secondly, I describe this study's empirical methodology. I have carried out a ward ethnography as a participant observer, supplemented with semi-structured interviews. I focus on key features of this approach, including its theoretical, practical and experiential aspects.

Thirdly, I describe this study's analytic methodology³³. I did a thematic analysis, borrowing from the tradition of philosophical hermeneutics. As with the empirical methodology, I present theoretical, practical and experiential aspects of this analytic approach.

Fourthly, I argue that what follows in subsequent chapters is a *trustworthy* interpretive account of the role of values in decision-making within an AMS. After sketching the notion of validity in social science, I show its implications and underpinnings to be in keeping with the empirical and analytic methodology of this research study.

5.1 Aim and objectives

The question I intend to address in this thesis is as follows:

What is the role of values in decision-making within an Acute Medicine Service (AMS)?

This question entails three major topics: *values*, *decision-making* and *an AMS*. The content, context and significance of these topics was explored in literature review chapters 2, 3 and 4. This research question is

³³ I recognise that the categories of 'empirical' and 'analytic' are not neatly divisible. As with the Cartesian subject-object dualism, the empirical-analytic dualism is a dialectic relation. Observation and interviewing shape analysis, and analysis shapes observation and interviewing. Data gathering and data interpreting are epistemologically collaborative and co-dependent activities in this iterative process.

the broad aim of this thesis, which can be broken down into more specific knowledge objectives, which I articulate here as subordinate questions:

- 1 What is the *purpose* of decision-making within an AMS?
- 2 How do people *experience* decision-making within an AMS?
- 3 What *values* are involved in decision-making within an AMS?
- 4 What *role* do these values play in decision-making within an AMS?
- 5 What are the *implications* of these findings for the philosophy of medicine?
- 6 What are the *implications* of these findings for clinical decision-making?

Objective 1 relates to the *telos* of the work of an AMS and decision-making in particular. This will be primarily addressed in chapter 6, *Restoring order*. Objective 2 relates to the phenomenology of decision-making within an AMS. This will be primarily addressed in chapter 7, *Working together*. Objectives 3 and 4 focus on the norms that are evident in decision-making within an AMS. This will be primarily addressed in chapter 8, *What's best*. Objectives 5 and 6 connect empirical findings with theoretical issues raised in literature review and will be primarily addressed in chapters 9-10, *Discussion* and *Conclusions*.

5.2 Empirical methodology

My empirical methodology consists of a ward-based ethnography as participant observer, supplemented by semi-structured interviews.

5.2.1 Ward ethnography

5.2.1.1 Theory

Ethnography can be characterised as a 'qualitative design in which the researcher describes and interprets the shared and learned patterns of values, behaviours, beliefs, and language of a culture-sharing group' (Harris in Cresswell & Poth, 2018: 90). In this instance, the selected culture-sharing group is an AMS. This approximates to a hospital ward: the Acute Medical Unit (AMU). However, even a *ward* ethnography cannot be precisely confined to a 'ward' in a spatial sense; this is because the values, behaviours, beliefs and language of people within an AMS may well be shaped by actions and interactions beyond the walls of the hospital ward. As such, the AMU represents the *centre* of this study's social field but not its *boundary*.

The aim of an ethnography is to present an 'overall picture of how a system works' (Fetterman, 2010, in: Cresswell & Poth 2018: 94) by gaining an 'empathic understanding of a social scene' (May 2001: 150). The understanding of a social scene can be described as *empathic* because ethnographers typically endeavour to unveil a view of cultural life 'from within' (Gobo 2011: 18).

This pursuit of an insider-perspective of social life is reflective of the heritage of ethnographic theorists, from the early English anthropologists (such as Bronislaw Malinowski and Alfred Radcliffe-Brown) to the influential sociology department of the University of Chicago. A director of the latter was Robert Park, who shared the English anthropologists' distaste for 'desk anthropology' (Radcliffe-Brown, 1948), which relied on secondary sources to understand a society from a distance; instead he famously told his students to 'go get the seat of your pants dirty in real research' (personal note by student reported in Bulmer 1984: 97). A real sociological researcher, according to Park, sought not merely to sit at a desk but 'to stroll in order to understand the flux of social life in which the individual self is also subject to change' (May 2001: 149). The data chapters that follow, then, seek to present an empathic understanding of decision-making by presenting some of the insights of my *strolling*³⁴ within an AMS.

In order to gain an empathic understanding, an ethnographer is typically immersed within a social group for a prolonged period of time. For example, Malinowski lived for two years amongst the Kula people of the Trobriand Islands (Gobo, 2011: 18). This extended immersion enables the researcher to get to know the group as well as the group to get to know the researcher. In this way, the ethnographer is 'to some degree connected to, or part of, the object of their research' (Aull Davies 2008: 3). Subject and object cannot be easily distilled from one another because ethnographic fieldwork is inherently 'personal, emotional and identity work' (Coffey 1999: 1).

The 'overall picture' (Fetterman, 2010, in: Cresswell & Poth 2018: 94) that an ethnographer presents, then, is unavoidably personal and interpretive. To extend the metaphor, the picture is not so much a mirror or a photograph; rather, it is an impression or 'portrait' (Cresswell & Poth 2018: 94). An ethnographic account is concerned less with *measurement* than with *meaning*; less with *objectivity* than with *trustworthiness* (see: *Trustworthiness*).

It is difficult to characterise ethnographic theory beyond these broad brush strokes, as there remain a variety of different emphases within ethnographic methodologies. For instance, Herbert Blumer emphasised the need to appreciate symbolism within human interaction, in order to 'see reality from [participants'] point of view' (2011: 20-21). Anselm Strauss and Barney Glaser emphasised the need to exclude researcher preconceptions in theory construction (1967). Erving Goffman's structural analysis emphasised the influence of social context on behaviour: 'Not, then, men and their moments. Rather moments and their men' (1967: 3, in: Gobo 2011: 21). Additionally, some authors locate ethnographies along a spectrum from *realist* to *critical* ethnographies. The former emphasise the need for an account to be 'uncontaminated by personal

³⁴ Characterising social research with 'strolling' is not unique to Robert Park. For example, a fellow sociologist writes that 'it becomes a philosopher and an analyst of his time to use his feet now and again. Strolling still has its uses' (Bauman, 1992: 155).

bias, political goals, and judgment' (Cresswell & Poth 2018: 92); the latter 'advocate for the emancipation of groups marginalized in society' (Thomas, 1993, in: Cresswell & Poth 2018: 92). It is beyond the scope of this thesis to explore each of these theoretical commitments in detail. Suffice it to say that, being differences of *emphasis*, these theoretical variations need not be mutually exclusive. In this thesis I incorporate insights of each³⁵.

Before turning to the implementation of this ethnography on a hospital ward, I summarise the background to *ward* ethnography in current literature.

The literature on ward ethnographies dates back to the 1960s, which featured a flurry of interest in the hospital as a relatively unexplored social field (Cosser 1962; Glaser & Strauss 1965; Sudnow 1967; Glaser & Strauss 1968) and was followed by the first medical anthropology textbook to dedicate a full chapter to hospital-based ethnography (Foster & Anderson 1978: 163-174). Nevertheless, van der Geest *et al* note a relative paucity of hospital-based studies in anthropological collections (2004: 1995). They attribute this, firstly, to a perceived familiarity with the hospital environment, whose deceptive cross-cultural uniformity seemingly adds little *couleure locale*, a point affirmed by Long *et al*: 'It was not until postcolonialism moved the anthropological focus from the exotic of the Other to shine a light on the exotic of the Self that hospitals became of interest to anthropologists' (2008: 71). Secondly, the exclusionary nature of the hospital as institution (Foucault, 1975) has purportedly correlated with a lack of ethnographic research access due to defensiveness of hospital authorities (Van Der Geest & Finkler 2004; Long et al. 2008).

Van der Geest *et al* describe a challenge that faces the ethnographer on a hospital ward: fieldworkers who wish to appear 'natural' on a hospital ward must choose to adopt one of three basic roles: staff, patients or visitors, and they tend to select the former (2004). There are some notable exceptions, however. For example, Caudhill *et al* (1952) and Rosenhan (1973) represent two instances when researchers pretended to be mentally ill in order to describe a so-called patient perspective in a psychiatric hospital. Similarly, an experiment by van der Geest and Sarkodie (1998) featured the latter posing as a 'fake patient' on a medical ward in a Ghanaian hospital. Unsurprisingly, it 'stands virtually alone using this research technique' (Van Der Geest & Finkler 2004: 1999). This highlights one of the first challenges I faced in this study when putting ethnographic theory into practice: when I set foot within an AMS and am surrounded by staff, patients and visitors, what is *my* role within this social group?

³⁵ An exception to this is Barney Glaser's version of grounded theory, which proposes a systematic construction of theory from the 'ground' of mere empirical data, without prior commitment to theory or engagement with literature (Charmaz, 2006: 4-9; Charmaz and Bryant, 2011: 295). I find this impossible to do with integrity because empirical data is already theory-laden. Edmund Husserl's concept of *epoché* is arguably a more workable alternative, which does not require the *neutralisation* of judgment but rather the '*suspension* of judgment regarding the true nature of reality beyond perception' (Rehmann-Sutter *et al*, 2012: 442).

The role which approximates to what I am used to is the role of staff member. I am a qualified doctor and hospital physician, and have previously worked on AMUs in this region and others (although not in Middleton Hospital, the site of this ethnography.) From this starting point, I had to consider my fieldwork role in the context of an AMS.

Gold (1969) identifies a spectrum of four main fieldwork roles that are available for a researcher to adopt:

- 1 Complete participant
- 2 Participant as observer
- 3 Observer as participant
- 4 Complete observer

An advantage of the complete participant end of the spectrum is that it is easier to gain trust of social actors and to relate to their experience. An advantage of the complete observer end of the spectrum is that it maintains a critical outlook, which can be lost if an ethnographer were to 'go native' (Wind, 2008: 80).

5.2.1.2 Practice

In this study, I adopted the role of participant as observer, which is also referred to as *participant observation*. I carried out ethnographic fieldwork over a period of 16 months, commencing in June 2017. This involved 36 fieldwork shifts, where a shift's duration varied from 2 hours to 12 hours. This period of participant observation was spread across 3 phases: an *initial* phase, a *developmental* phase and a *consolidation* phase, which I will describe later in this chapter (see: *Semi-structured interviews*). First, I characterise what participant observation involves within an AMS.

Gobo (2011: 17) summarises the key characteristics of participant observation as follows:

- 'The researcher establishes a direct relationship with the social actors
- Staying in their natural environment
- With the purpose of observing and describing their social actions
- By interacting with them and participating in their everyday ceremonies and rituals
- Learning their code (or at least parts of it) in order to understand the meaning of their actions.'

What the role of participant observer actually involves depends on the social field which is being studied. I now describe three features of my role as participant observer that are specifically shaped by the environment of an AMS.

5.2.1.2.1 Self-introduction and access

To participate in the social field of an AMS requires authorisation. Nobody simply *happens* to be there. Entry to the ward is controlled by a card reader and monitored by CCTV. There are two windows of time in which

friends and family are authorised to visit patients: 2:30pm to 4pm and 6:30pm to 7:30pm. Patients are referred to the AMS by the Emergency Department. In short, patients and visitors are authorised by staff and staff are authorised by the organisation.

Aware of the need for authorisation to participate within an AMS, my first contact with participants was to gain permission from gatekeepers: the senior nurse (“ward manager”) and the senior doctor (“clinical lead”).

The ward manager is responsible for the everyday running of the ward. In my experience, ward managers often represent the ward in interactions with senior hospital management and have a significant influence on the culture of a ward. An initial email was followed by a one-to-one meeting, in which I introduced myself, summarising my clinical and research background. I gave an outline of the study and what, in practice, it might involve. I showed her some of the materials that I had prepared in order to gain ethics approval. This included an information sheet and poster. To my relief, she agreed to post these in a clearly visible space on the ward. In addition, she agreed to forward information by email to all of the ward staff (see: *Appendix A* and *Appendix B*).

The clinical lead is a consultant who is responsible for the clinical decisions made within the AMS. I had briefly worked with him in 2015 in another healthcare setting within this trust and we got on well. Following email contact and a one-to-one meeting, he endorsed this research study and agreed to forward information by email to all current medical staff within the AMS (see: *Appendix A* and *Appendix B*). I was thankful for this, aware that some trainee doctors rotate across sites every 3-6 months and may be missed off the senior nurse’s mailing list.

Once the empirical phase of this ethnographic study was underway, it was extremely useful to have established rapport with, and gained permission from, these gatekeepers. Sometimes ward staff seemed nervous to be talking with me and, in particular, they were unsure if they were authorised to leave their usual site of work on the ward to speak with me privately. It seemed a comfort and reassurance to them when I would indicate that my research has been endorsed by the authority figures about whose opinion they were concerned.

On this ward, all members of staff have an 8 o’clock meeting called a “morning huddle”. After some notices from the senior nurse, each staff member in turn gives a short self-introduction. This consists of saying their name, role and finish time. In order to be a participant among staff, I frequently joined in with this huddle and complied with the style of communicating. In order to not be a complete participant, I would take pains to emphasise that “I’m not here in a clinical capacity; here as a researcher”.

As well as accompanying staff, I was also a participant observer among patients and visitors. Patients in a multi-bedded bay would often talk to one another. Patients who were alone in a cubicle would often be speaking on a mobile phone or be keen to chat when I entered their cubicle. When visitors arrived, social activity became all the more prominent. One way I was able to participate with patients and visitors was by spending time chatting at the bedside.

5.2.1.2.2 Dress and appearance

Most people within an AMS are dressed in uniform. However, the uniform is specific to the person's role within an AMS. For example, the uniforms of senior nurses, staff nurses, healthcare assistants, pharmacy technicians and physiotherapists are each of a different colour. Patients are given a uniform gown of white and green. Some people do not wear uniform, however. These people are visitors, trainee doctors, some consultants, the psychiatry liaison team and the hospital-to-home assisted discharge team.

How I dressed would thus influence my social identity. Wearing my own clothes is not a socially neutral act but rather one which would most likely associate me with doctors. Some of my personal attributes may also give the impression of me being a doctor. These include being male, not speaking with an accent of the local region and some unconscious features of my demeanour. In addition, a small number of nurses and doctors recalled working with me in previous healthcare settings within this NHS trust. Thus, it seemed to me that this is likely to be how I am perceived unless I make conscious effort to appear otherwise.

After reflection, it seemed to me that the benefits of distancing myself from doctors in appearance were outweighed by the cost of inauthenticity. To many, especially those who know that I am medically trained, dressing in any other way might seem like I was pretending. I suspected that a perceived lack of sincerity is more detrimental to the study than a perceived medical air about me.

I chose to dress in a collared shirt with smart trousers and work shoes. Whilst this is not a neutral impression to make, at least it is predictable. The advantage of this predictability was that I could then try to counter this affiliation by other means.

5.2.1.2.3 Timing and posture

For most staff within this AMS, a shift begins with a handover. For example, the night nurse hands over to the day nurse at 7:30am; the night doctor hands over to the day doctors at 8:10am. To enter the ward in time for the nurses' 7:30am handover showed dedication to accompany them in their work, rather than simply joining them as second choice to the doctors. In this way, the timing of my shifts itself was of relational importance; it influenced the kinds of participation that were available to me.

On fieldwork shift 17, I stayed into the night shift. I primarily did this because I wondered whether decisions about different issues were made at night. I also wondered whether decision-making was done in a different way by the different staff in the different circumstances of night shift. What surprised me, however, was not what I *saw* but how I was *seen*. I noticed that staff were particularly welcoming towards me during this shift, and these staff members continued to be warm towards me subsequently. After some initial joking about whether or not I had “better things to do than be here on a night”, I found it much easier to develop rapport with members of staff on this night shift.

On reflection, I think there are two reasons why it was easier to establish rapport with staff at night. Firstly, my being there at night-time showed my dedication to this project. Secondly, there are relatively few senior nursing and senior management staff around during a night shift. As a result, ward staff are less monitored and may feel freer to interact with me and speak their mind.

I varied the timing of my shifts. Encompassing early morning or late at night helped connect with nursing staff; encompassing visiting time helped me to connect with patients and visitors. This is not to imply that the timings of my shifts were rigorously calculated; I was not merely pursuing diversity for diversity’s sake; nor was I simply avoiding doctors. Rather, I was being mindful of the relational dynamics that are inevitably involved in ethnographic research and the contributory factors over which I exercise a degree of control.

Beyond timings, I became acutely aware that my identity in this social field was also shaped by subtle features like my posture. Doctors tend to assess a patient from the patient’s right hand side with an analytic facial expression; junior doctors on a ward round typically stand back on the far side of the bed, keeping quiet, writing notes. Nurses tend to move quickly, wearing trainers, and do their writing at a notes trolley, not in front of patients. Patient visitors tend to sit down, speak quietly, and not write at all.

Initially, my posture resembled the doctors, out of habit. However, as time went on, I learnt to adjust my manner to look less analytical, and to reduce the time spent writing in field notes during a ward round. During ward rounds, I would endeavour to stand separate to the team of doctors and not to mirror their posturing, which required conscious effort at times.

As van der Geest *et al* suggested, a ward ethnographer usually has to adopt the role of staff, patient or visitor (2004). In this study, I endeavoured to be participant observer across these three roles. Rather than trying to be all at once, which seems to me to be a psychological impossibility, I varied the nature of my ethnographic participant observation. This was made possible by paying attention by such features as I have described above: self-introduction, access, dress, appearance, timing and posture. I sought to emphasise my *participant* status more towards those sub-groups with which I did not naturally belong (non-doctors) and I sought to emphasise my *observer* status more toward the sub-group with which I did naturally belong

(doctors). In summary, my role as participant observer was continuously negotiated in response to circumstantial and relational factors.

5.2.1.3 Experience

Prior to stepping foot on this Acute Medical Unit (AMU), I expected some resistance from staff and patients. I expected to have to be very thick-skinned, pressing ahead with the project despite being excluded from involvement at various moments along the way. To my surprise, I experienced extremely little resistance to my research. The vast majority of patients and staff were interested and welcoming. Ironically, it was the researcher himself who presented the most resistance to his own research! This was perhaps related to three desires.

5.2.1.3.1 Desire to help

I informed participants that I did not intend to take part in the clinical work of this AMS. This was stated and illustrated for research ethics approval (see: *Appendix A* and *Appendix C*), described in a ward poster (see: *Appendix B*), described in participant information sheets (see: *Appendix A*), declared during staff huddles, and reinforced during informal interaction with staff and patients.

There was a part of me, however, that *did* wish to take part in clinical work. I missed being useful in a clinical sense, especially when there was evident need expressed by patients or staff. For example, a nurse needed a doctor to “look at this ECG [electro-cardiogram] for me”; a consultant asked me for “any ideas?” when the team were struggling to diagnose the cause of persistent coma; a patient asked me “so what will they do, then, if they find a mass on the scan?” As per my research ethics approved plan, I would decline to offer clinical contributions. I did, however, find this difficult. In particular, I felt like I had let the person down when they responded to me with apparent disappointment. This discomfort was worsened at times when staff were overburdened with the clinical workload; loitering seemed out of place.

Over time this anxiety settled as I gained more acceptance among the group within this AMS. I found ways of looking less conspicuous whilst loitering: I would take my pen out, I would write more in my notepad (even simply writing more slowly), I would echo the postures of those around me as I stood near a work station. In addition, I would take short breaks to provide enough discontinuity to alleviate my anxiety about being conspicuously useless, whilst providing enough continuity to return and carry on.

5.2.1.3.2 Desire not to get in the way

From previous experience in clinical work, I was aware of the pressure to get through work quickly within an AMS. I imagined that this pressure is likely to be intensified in the context of a hospital specialising in emergency care. If I were the doctor, I surmised that my response to having a researcher join me would

initially be one of concern: “will they slow me down?” Besides doctors, other staff members are also under pressure to work efficiently.

For example, a staff nurse was rushing around to find treatment for a patient of hers with a worryingly low glucose. I did not want to interrupt her with questions, when she was clearly needing to focus. Additionally, I did not want her to feel the burden of giving me commentary, a burden which was brought about simply by me being present. However, if I were to go away to let her ‘get on with it’, this would impede my data collection; I might fail to gain deep understanding of decision-making in emphatically time-pressured circumstances.

Clarificatory, concrete questions seemed to be easier and more quickly answered by participants than questions which were exploratory and abstract. For example, to a consultant who had just discussed resuscitation with a patient during a ward round: “what makes you lean toward a DNAR [Do-not-attempt-resuscitation order] with him?” is an easier question to answer than “what is it, in general, that makes CPR [cardio-pulmonary resuscitation] not worth doing?” The latter may seem like a change in mode of thinking that takes more effort and time. As a result, when I was aware of the perceived pressure and I was particularly keen not to get in the way, I would tend to pose clarificatory, concrete questions and leave more exploratory, abstract ones for a subsequent interview.

During busy ward rounds, I found myself almost apologising for my existence: “I don’t want to slow you down at all; happy to be ignored!” I found this light-hearted comment would often help to gain the trust of a busy clinician by demonstrating an appreciation for the priority of efficiency and the primacy of the delivery of clinical care. Ironically, perhaps this gained trust so as to increase the amount of interaction with me; requesting to be ignored may have reduced any desire to ignore me.

5.2.1.3.3 Desire not to seem a fool

In the past, I have worked with some of the staff in this AMS. In the future, I am likely to work with many of these staff in this AMS in a clinical capacity. If so, I am likely to work as a registrar (a grade of trainee doctor) under the authority of the consultants, who would have a part to play in my career progression. As such, it may come at personal cost if my role as participant observer in this study erodes my reputation as a competent clinician.

On a psychological level, I felt very unsettled being back on a hospital ward with relatively little sense of belonging. I was accustomed to being embedded in a clinical team and had not felt out-of-place since being a medical student on placement. I therefore found this research role uncomfortable to embrace, a sentiment which was exacerbated when I was once asked “so you’re... medical student?”

To understand decision-making, to see decision-making through new eyes, and to bring the role of values to the fore, involved asking questions. Many times, these questions would be seen as obvious: questions to which any sensible doctor would know the answer. These were the questions which could most undermine my image as a reliable medical colleague. As such, 'easy' questions were the hardest to ask! However, this discomfort eased over time as participants became more familiar with my role, and as I became more fluent in signposting that have to ask some "daft questions".

5.2.2 Semi-structured interviews

5.2.2.1 Theory

Observation, especially participant observation, is regarded as the primary data collection technique for an ethnographer (Toren, 1996). Within qualitative research more broadly, interviews are the most common method of data collection, often categorized along a spectrum from structured to unstructured: *structured*, *semi-structured*, *in-depth*, *unstructured* (Taylor, 2005).

The two extremes are contentious. A typical example of structured interviewing is the completion of a multiple-choice survey. Arguably, the well-circumscribed nature of this data renders it a form of quantitative research (Taylor, 2005: 39). A typical example of unstructured interviewing is casual conversation. However, this is arguably not truly unstructured, as even the most informal interaction is shaped by habits, traditions and culturally conditioned expectations. Thus, from an ethnographer's perspective, structured interviewing is possible but not qualitative, and unstructured interviewing is qualitative but not possible.

Interviewing entails a mixture of multiple agendas: the interviewer and the interviewee³⁶. Semi-structured interviewing enables sufficient structure for the interviewer to set some direction, in keeping with the research agenda. However, it also enables sufficient flexibility for the interviewee to take conversation in another direction, in keeping with the participant's agenda. This balance enables interview data to be both relevant and exploratory.

In-depth interviewing focusses on a particular issue within a participant's account and provides a rich characterisation of it (Taylor and Bogdan, 1984). Rather than mapping out the broader relations of such an issue in *general* terms, in-depth interviewing tries to articulate a thick, contextualised description of the issue in *particular* terms. This emphasis on the contextualised particular over the abstracted universal is an essential feature of ethnography. Where a positivist pursues the naked truth, laid bare in perfect abstraction, the ethnographer respects the contextually-clad nature of social reality; the ethnographer seeks truth with its clothes on.

³⁶ In less formal interactions it may be unclear who is playing which role.

Both semi-structured interviewing and in-depth interviewing, then, are well-suited to an ethnographic enterprise. In this ethnography, my interviewing was primarily semi-structured. This enabled sufficient structure to address the research question of values in decision-making within an AMS, whilst also providing sufficient flexibility to explore participants' accounts in their own words.

However, semi-structured interviewing need not be exclusive of depth. When a particular event or topic was of particular interest and particular relevance to the research question, interviews would momentarily become in-depth interviews in order to explore this area in more detail. For example, my interview with Kylie, a palliative care nurse, was semi-structured. I had some pre-formed topics and broad questions to ask, which she took in new directions; our interview became in-depth when she described her discussion with Mr Whitehead about his discharge home to die, which became a focal point to explore in detail.

5.2.2.2 Practice

5.2.2.2.1 Overview

In total, I carried out 27 interviews across the 16 months of fieldwork. As I mentioned above, this fieldwork was divided chronologically into 3 phases: an *initial* phase, a *developmental* phase and a *consolidatory* phase. The initial phase consisted of the first 3 months within this AMS. The priorities of this phase were to gain the trust of participants in this field, to negotiate the most effective ways of gaining appropriate data, and to learn to see the AMS through new eyes (as ethnographer). This phase was as much about de-constructing my preconceptions as constructing new conceptions. Field notes, memos and reflections were shared and discussed with my supervisory team.

The developmental phase consisted of the following 9 months. The priorities of this phase were to improve the quality of data gathered and identify key themes in empirical data which may serve as a basis for an explanatory narrative. The quality of the data gathered was improved with input from my supervisory team, who read all transcripts of field notes and interviews. Two ways in which data-gathering was improved during this phase are:

- Increased richness of description
- Increased triangulation by multi-perspectival accounts

These improvement measures required me to pay more attention to contextual, non-verbal factors of social interaction, and to seek opportunities for multiple accounts of the same encounter – which I refer to as an 'experiential cluster'.

During this time, I began to carry out interviews alongside participant observation. 24 interviews were carried out during this developmental phase. Initial availability sampling progressed to representative

sampling and then to theoretical sampling. Interviews were carried out with patients, relatives and different staff members, as summarised in table 5.1. The development phase also involved contemporaneous transcription of field notes and interviews, with early thematic analysis.

Participant role within AMS	Number of interviews
Patient	11
Relative	2
Consultant doctor	4
Trainee doctor	3
Nurse	5
Healthcare assistant	1
Pharmacist	1
Physiotherapist	1
Psychiatry liaison	2
Palliative care liaison	1
Total ³⁷	28

Table 5.4: Research participants by role within AMS

There was a deliberate interval of 2 months between development phase and the consolidatory phase. During this time, I did extensive transcription and thematic analysis in order that a provisional explanatory narrative might develop from my interpretation of data. A final consolidatory phase was required in order to challenge and check areas of this provisional narrative, with particular attention to exceptions and anomalies. 3 interviews were carried out during the 2 months of consolidation, arranged on the basis of theoretical sampling.

5.2.2.2.2 Specific considerations

5.2.2.2.2.1 Timing

The workload within an AMS is unpredictable. I suspected this prior to my arrival, informed by clinical experience, and it was confirmed in my time as ethnographer. How many patients are admitted into the department, how sick they are, what tasks are required, which staff are responsible for these tasks, how patients progress: all of these aspects of the workload are difficult to anticipate in a given shift. Similarly, patients also experience a degree of unpredictability: how they are responding to treatment, how things are

³⁷ The 27 interviews feature 28 participants because one interview was carried out with 2 participants (Sheila and her mother).

going to happen next, what time discharge or transfer is going to be. Patients often find themselves waiting with uncertainty. This makes it difficult for interviews to be scheduled or for them to be long.

In order to accommodate the unpredictability and busyness of the workload within an AMS, I adapted the timings of interviews. Instead of trying to book a participant for a certain time in the future, interviews were usually spontaneous. Instead of lengthy exchanges, they were as short as possible and interruptible at any point. The assurance that interviews could be interrupted and stopped at any point enabled participants to commit more easily.

5.2.2.2.2 Location

Many staff are closely monitored within an AMS. For example, some nursing staff expressed concerns that if they were speaking with me on the ward, their senior would reprimand them for not working. In addition, they were not free to leave the ward without permission from their senior.

In order to be able to interview nursing staff, I took four steps to help this situation. Firstly, I provided assurance that the most senior ward nurse had given approval to this research project. Secondly, I would sometimes interview nursing staff in the evening or night-time, when they felt less policed by their senior. Thirdly, interviews could be done in short episodes of a few minutes at a time, enabling the nurse to tend to clinical duties as they arise. Fourthly, I identified some non-clinical spaces which were nevertheless still on the ward. By interviewing in these spaces, the nurse was still reachable by other staff but also gained the privacy to speak freely. Examples of these spaces are the quiet room and the ward kitchen.

The location of an interview has an impact on the content of the interview. For example, the quiet room is more than a room which is quiet. As I reflected in field notes, the quiet room is a room where people go to speak about death. Likewise, the ward kitchen is more than a kitchen. It is a room which is out of sight of colleagues, where staff might go to make a cup of tea or to have a light-hearted conversation. Interviewing in the quiet room feels different to interviewing in the ward kitchen, and I needed to be mindful of this when interpreting interview data.

Some patients are in their own cubicle. Other patients have a bed in a shared bay, individualised by curtain rails. Whether or not the curtain is drawn round, an interview can be easily overheard by other patients in a bay as well as staff walking in and out. Patients in their own cubicle were thus able to speak more freely, without worrying about who is overhearing the conversation. A difficulty would arise when I wished to interview a patient in a shared bay. To speak at the bedside may be limited by confidentiality rules and social inhibition. To remove the patient from their bedside into the quiet room, for example, may be limited by the patient no longer feeling relaxed in a familiar environment. In such situations, I would weigh up the benefits

of different interview locations according to the patient's preferences, the specific circumstances and the anticipated interview content.

5.2.2.3 Experience

5.2.2.3.1 Evolution of interviewing style

The manner in which I conducted interviews was constantly negotiated over the course of this ethnographic study. To begin with, I had little rapport with ward participants, little understanding of what topics and areas are likely to be theoretically fruitful, and little experience of what doing semi-structured research interviews is like.

As a result of my limited interview experience, I tended to default to the interviewing style to which I am accustomed: the clinical consultation. Having worked as a doctor, I am used to interviewing patients according to an approach known as the Calgary-Cambridge framework. In this approach, interviews start with open questions and progress to more closed questions in order to focus on key details (Silverman *et al*, 1996).

One advantage of this approach is that it permits a degree of both structure and flexibility, which is essential for semi-structured interviewing. One disadvantage of this default approach is that it assumes that one conversation partner (the doctor) has the authority to shape the open-to-closed consultation and decide which areas are worth focussing on. The implicit authority asymmetry in this approach felt particularly problematic when, adopting a doctor role, I interviewed participants who are doctors.

With greater rapport with participants, I was more able to pose more challenging questions and comments, to enable greater critical exploration of an account. At times this would be by way of clarifying what participants mean by certain phrases used. For example, I challenged consultant Tony to clarify what he meant by "quality of life" and "futility", in a manner that was supported by our well-developed rapport over the course of ethnographic observation. At times I would challenge participants not by asking a question so much as by imagining the described scenario was different in a significant way. I did this with a patient called Heidi, for example. This had the effect of challenging Heidi to articulate her feelings on the matter in more detail and with renewed vitality.

As I gained more experience of what doing semi-structured research interviewing is like, I became accustomed to the emotional aspect of interviewing. In many ways, conducting semi-structured interviews involved the same relational dynamics that I noted when conducting ward ethnography, which reflected my own desires: a desire to help, a desire to not get in the way, a desire to not seem overly critical, and a desire to not seem a fool. The anxiety that I experienced as a result of these desires was eased to some extent by providing an introduction prior to the interview. In this introduction, I would describe to participants that "I

have to ask some daft questions” and that I’m speaking “as Luke the researcher, not as a doctor, so some of the questions I ask might be a bit odd or surprising”.

5.2.2.3.2 *Tensions*

Despite my best efforts at a clarificatory and preparatory introduction, there were nevertheless some tensions I experienced whilst conducting semi-structured interviews that could not easily be ironed out.

5.2.2.3.2.1 *Eliciting and challenging*

Interviewing was intended to supplement ethnographic observation by way of triangulation (Taylor, 2005: 42). Spoken accounts during formal interviews could provide a detailed impression of the participant’s perspective. Essential to this process is description: hearing the participant’s account of what happens within an AMS from their perspective. Thus one priority of my interviewing is *eliciting* and, specifically, eliciting the participant’s point of view.

However, another element in interviewing participants was *challenging*. At times, challenging was a useful way to prompt participants to sharpen their description in some way, such as by adding a clarification, justification or example.

This was a difficult balance to strike. To challenge the participant too early or too sharply might hinder the trusting relationship between us and thereby inhibit the participant from opening up for the rest of the interview. To challenge the participant too little or too late might reduce the clarity, richness or usefulness of the interview data they are providing.

5.2.2.3.2.2 *Directing and exploring*

A tension I experienced which is perhaps ubiquitous in semi-structured interviewing is the tension between *directing* and *exploring*. Given the rushed environment within an AMS and the possibility of being cut short at any moment, it was important that interviews had some structure and did not require excessive amounts of time. I needed to direct the participant to some extent: *semi-structured* interviewing.

At the same time, however, this is qualitative interviewing which seeks to not simply check or enumerate but to *explore* a complex phenomenon. This requires giving the participant enough freedom to narrate their impressions and experiences in their own words, using their own categories and frames of reference. In this way, it was important that such exploration was not impeded by excessive direction on my part: *semi-structured* interviewing.

The balance between directing and exploring, I found, depended on the circumstances of each interview. An interview with consultant Tony, for example, was scheduled for a day when Tony was off the ward and not so time-pressured. He listened carefully to each question I posed and tended to answer precisely and

concisely. During this interview, then, the priority of *exploring* pressed on me more prominently than the priority of directing.

In contrast, during my interview with a patient's husband, Chris, I was more aware of the priority of *directing*. As a former college lecturer with an interest in NHS reform, he was ready to share his views on NHS structure and how to fix an array of problems. As a result, a merely exploratory interview style may have been very interesting but the data might rapidly depart from the particular observed interaction which prompted this interview. In order to serve its triangulatory purpose, this interview required me to enact a more directive interviewing style than I had implemented with Tony.

So far in this chapter, I have described the two main aspects of this study's empirical methodology: ward ethnography and semi-structured interviewing. I have presented each aspect of data-*gathering* in terms of theory, practice and experience. Next, I describe the process of *analysing* data³⁸.

5.3 Analytic methodology

5.3.1 Philosophical hermeneutics

5.3.1.1 Theory

Hermeneutics is the science or art of interpretation (Grondin, 1994: 1). The term originates from the ancient Greek word *hermeneuein*, which meant to explain or translate (Zimmerman, 2015: 3). Hermeneutics, as a field of study, developed in the disciplines of jurisprudence and theology, where it related to the application of legal guidance and scriptural exegesis respectively (Zimmerman, 2015).

The advent of *philosophical* hermeneutics, however, marks a shift in emphasis. No longer is hermeneutics merely the property of theologians and lawyers and no longer is it restricted to the study of authoritative texts. Philosophical hermeneutics is a tradition which portrays interpreting as a way of life; humans are interpreting animals (Heidegger, 1999; Zimmerman, 2015: 9). Beyond legal and scriptural text, interpretation is involved in all human interaction, including understanding actions, gestures, speech and writing; for this reason hermeneutics is described as universal (Grondin, 1994: 3).

In what follows, I assume a degree of familiarity with the history of philosophical hermeneutics (see: *Appendix E*). For the purposes of this thesis, the pertinent insights of its history are two-fold. Firstly, *interpreting* is an essential feature of all human being-in-the-world; hermeneutics is universal. Secondly, there is a recursive connection between subject and object, whole and parts; this phenomenon is

³⁸ The relationship between data-gathering and data-analysis is dialectical; the one influences the other and the other influences the one. As such, these broad categories are not intended to describe a two-stage, linear process but rather a circular, iterative one.

conceptualised as the *hermeneutic circle*. Next, I apply these theoretical insights to the practicalities of data analysis in this study of decision-making within an AMS.

5.3.1.2 Practice

5.3.1.2.1 Universal hermeneutic

According to the tradition of philosophical hermeneutics, all forms of human interaction involve interpretation. Whether ward ethnography or semi-structured interviewing, such forms of human interaction are in a sense textual, since they are a hermeneutic enterprise. Ethnographic observation was recorded as text in field notes. Semi-structured interviews were recorded as text in transcriptions. Such texts require interpretation. My task is to interpret text in two layers: I am to interpret the text of field notes and transcriptions as well as to interpret the 'text' of human interaction within an AMS.

In a sense, all of my experiences and interactions within this AMS over the 16 months are data. As Barney Glaser put it, 'all is data' (in Charmaz, 2006: 16). Even interaction which I did not record in field notes or interview transcripts is nevertheless context which frames and shapes the interpretation of interaction on which I have focussed. It is therefore important to pay attention to this unrecorded data. I was assisted to be conscious of unrecorded data by discussion with my supervisory team, one of whom also attends this AMS regularly in a clinical capacity, is familiar with the environment and would frequently ask me "what is missing in your notes?"

Seeing as all my experience and interaction within this AMS is data, it is impossible that an analysis of empirical data would ever be exhaustive. In this way, an approach that borrows from philosophical hermeneutics sits comfortably with the intention of a ward ethnography which is self-consciously situated and perspectival. I do not seek to provide a complete map of the role of values in decision-making within an AMS, covering every area from every angle. Instead, I seek to provide a plausible 'portrait' (Cresswell & Poth 2018: 94) of the role of values in decision-making within an AMS: limited by circumstances and my pre-understandings, yet acknowledging that such limitations make understanding possible.

5.3.1.2.2 Hermeneutic circle

5.3.1.2.2.1 Whole and parts

A sentence of my field notes is part of a whole paragraph. A paragraph is a part of the notes of a whole shift. The notes of a whole shift are a part of a whole collection of field notes. The collection of field notes is a part of a whole series of personal interaction which I experienced within an AMS. Personal interaction that I experienced within an AMS is a part of a whole network of interactions of the hospital or a community. According to the tradition of philosophical hermeneutics, such parts can only be understood in relation to their wholes (and vice versa). In view of this, the interpretation of recorded data of field notes requires

contextualisation within the broader whole within which they are located. Understanding field notes, then, requires supplementation with 'head notes' (Okely, 2008): a recollection of how this event happened. I identify two specific implications of this.

Firstly, it is imperative that I, as ethnographer, carry out the analysis of recorded data. This is not to say that others cannot usefully contribute to such analysis. It is to highlight that the analysis of recorded data without appreciation for the historical context of which it is a part is to divorce the part from its whole and compromise the validity of any subsequent interpretation. Experience and interpretation should not be subjected to a division of labour.

Not only did I carry out the primary analysis of all recorded data, I also carried out all transcription of interviews. Whilst this 'data-logging' (Lofland and Lofland, 1995) was a time-consuming activity, it is also an interpretive one. How to transcribe the language and sounds made during interview involves addressing such questions as: shall I articulate that phrase in order to reflect this participant's dialect and accent, or in order to reflect standard spelling and grammar (authenticity versus clarity)? What is the significance of non-verbal expressions such as sounds and silences, and how should these be graphically represented? Interview transcripts include 'coughs, pauses, laughs and so on... all of these have meanings and may influence interpretation of data' (Bluff, 2005: 153). Despite its demand for time and resources, the process of transcribing I found to be a fruitful time, during which I might notice new details which I had not noticed during the interview itself.

Secondly, the interdependence of part and whole implies that thick description in field notes is hermeneutically more useful than a thin description. A thick description is one which features a wealth of contextual information (Holloway, 2005: 296). This enables the reader to appreciate the whole of which this interaction was a part. It took time for me to recognise the importance of this. In the first three days of ethnographic observation, my field notes mostly consisted of bullet points containing quotes and short reflections. It was not that I did not experience contextual features but that I did not 'see' them. After critical input from my supervisory team, who read each day of field notes, I rapidly learned the importance of describing the social, emotional, clinical and temporal context of a recorded encounter: What time was it? What was the room like? What was their emotional state? What were they wearing? What was going on in the background? What struck me about this? This helped to expand and support the interpretive analysis of such data.

5.3.1.2.2.2 Subject and object

According to the tradition of philosophical hermeneutics, the subject is not separable from the object; the two are mixed. I am a part of the AMS that I studied. Indeed, it was not so much that I, as researcher, studied

it, the researched; rather, I *participated* in the social field of an AMS and developed understanding through this engagement. The ontology of this process cannot be neatly divided into subject and object, and the epistemology of this process cannot be reduced to rational principles (Gadamer, 2013). I identify two implications of this, which I gradually realised over the course of this study.

Firstly, field notes are not intended to be a summary of *all* events. Instead, they are to be descriptions of interactions within an AMS that seem to bear significance for the research question with which I am concerned. This involves a process of selection that is inevitably interpretive; I am to provide a rich description of moments that seem *to me* to be significant.

Secondly, field notes are not intended to be a *detached* summary of events. My early field notes featured what was said, what was done and what it looked like. However, there was relatively little description of my personal involvement: How was I positioned in this encounter? What did I expect? How did this make me feel? Over the course of this ethnographic study, my field notes expressed my own personality more openly. Given the subject is part of the object, being more present in the data ironically renders my ethnographic account simultaneously more subjective *and* more objective.

5.3.1.3 Experience

The way in which I recorded and analysed data evolved over the course of this study. Whilst I could render cognitive assent to the hermeneutic circle and the need for a dialectical relation between part and whole, and between subject and object, it took time for me to appreciate the ramifications of these dialectic relations in this research. I was helped to appreciate this by my supervisory team, further reading, and critical reflection during the initial phase of ethnography.

Whilst I am encouraged that such adjustment is an ordinary feature of the iterative process of social research, it was nevertheless an uncomfortable process to go through. With a background in hospital medicine, which intellectually leans towards positivist science (Higgs and Loftus 2008: 215), my journey towards a fully-fledged hermeneutic approach to this qualitative study was at times one of discovery, self-discovery, discomfort and self-discomfort.

This reflection is in keeping with social research fieldwork generally. Hammersley and Atkinson note that field researchers 'do not always leave the field... emotionally unscathed, and they rarely leave unaffected' (1995: 120). Lofland and Lofland (1995) go further to give a typology of different kinds of emotional stress involved in social research fieldwork. Coffey summarises these as: 'deception and fear of disclosure, loathing and the desire to withdraw, sympathy and the impulse to help, marginality and the temptation to convert' (1999: 5). I can identify with each of these stresses, and with loathing and sympathy in particular.

5.3.2 Thematic analysis

As I stated earlier in this chapter, the aim of this thesis is to address the question: *What is the role of values in decision-making within an Acute Medicine Service (AMS)?* The purpose of my engagement with an AMS is to provide an explanatory theory which responds to this question. Such an explanatory theory is not intended to take the form of generalisable formulae, as in the natural sciences. Rather, in the social sciences, an explanatory *narrative* is considered a better tool for explaining the complexity and particularity of social life.

In this section, I describe some theoretical considerations that support my thematic analysis of empirical data in order to construct an explanatory narrative. I then describe how I did this (practice) and how I found this (experience) before moving on to discuss issues relating to validity.

5.3.2.1 Theory

5.3.2.1.1 Data to narrative

The use of stories as explanatory theory in the social sciences has become increasingly evident since the 1980s (Lieblich, Tuval-Mashiach and Zilber, 1998: 1), and is reflected in social research in the healthcare setting (Horrocks *et al.*, 2003). This has been described as the ‘narrative turn’ of the social sciences, as Denzin describes:

‘The narrative turn in the social sciences has been taken... Everything we study is contained within a storied, or narrative representation. Indeed, as scholars we are storytellers, telling stories about other people’s stories. We call our stories theories’ (2003: xi).

Somers (1994) considers narrative to be an ontological condition of social life, such that to fail to describe it in storied terms is to inadequately characterise social life.

Unlike the universal formulae of the natural sciences, research in the social sciences typically seeks to describe the *situated-ness* of human activity. Polkinghorne deems narrative to be well suited to this anti-abstractionist purpose, describing narrative as the ‘linguistic form uniquely suited for displaying human existence as situated action’ (1995: 5). In his eyes, this is because narrative portrays human activity as ‘purposeful action in the world’ (1995: 5). Narrative has the capacity to explore the subjectivities of both individual and group (Sparkes, 2005: 192). As Cortazzi pictures it, an explanatory narrative is a way of ‘opening a window on the mind, or... opening a window on [a group’s] culture’ (1993: 2).

Thus, in order to describe the complexity of social life within an AMS, which includes purposeful action in the world as well as individual and group subjectivities, an explanatory narrative is an effective means of doing so. However, in the words of Coffey and Atkinson, ‘there are no formulae or recipes for the “best” way

to analyse the stories we elicit and collect' (1996: 80). (I would add that stories, in an ethnography, are not only elicited and collected but also *constructed*.) In order to construct an explanatory narrative of the role of values in decision-making within an AMS, the approach I take in this thesis is a *thematic* analysis.

In a thematic analysis, themes provide the interpretive building blocks for putting an overarching narrative together. Themes must reflect the directionality of narrative; that is, they must 'structure events in such a way that they move over time in an orderly way toward a given end' (Gergen and Gergen, 1983: 257). At the same time, themes must be rooted in the data. That is to say, themes must be demonstrably derived from empirical findings. To ensure themes are connected to the interpretation of observational and interview data, I constructed themes from lower-level interpretive categories: codes.

The process of coding empirical data has been largely developed by proponents of grounded theory (Charmaz, 2006). 'Level 1 coding' (Strauss and Corbin, 1998) consists of giving a name to small sections of data (e.g. a line of text or a sentence) and sticks closely to participants' own words (Bluff, 2005: 154). Similar codes can be accommodated into a broader category. During this process, the researcher generates questions and seeks answers in the data (Bluff, 2005: 154). These questions include the overall question of 'what is actually happening in the data?' (Glaser, 1992: 51) as well as *who, what, where, how, when* and *what if* (Stern, 1980; Strauss and Corbin, 1998).

This process of interrogation is followed by 'level 2 coding'³⁹ (Hutchinson and Wilson, 2001), the purpose of which is 'to make connections between categories and sub-categories and [allow] a conceptual scheme to emerge' (Bluff, 2005: 154). Level 2 codes need not align so closely with participants' own wording; they are intended to be transformational, integrating the level 1 codes (parts) within the emerging themes (whole).

In summary, the explanatory narrative is constructed from themes, which are constructed from level 2 codes, which are constructed from level 1 codes. Such a process of construction is necessarily interpretive but not necessarily linear. I employed a non-linear interpretive approach, the *constant comparative method*, which I will describe below.

5.3.2.1.2 Data sufficiency

'Theoretical saturation' is commonly used in social research to refer to a phase of fieldwork when the researcher keeps finding the same patterns, which yield no new theoretical insights (May, 2001: 113). The term was originally used by grounded theorists Glaser and Strauss (1967). Compared to its common usage, Glaser offers a more sophisticated view of saturation:

³⁹ Level 2 codes are also called 'axial' codes (Bluff, 2005; Charmaz, 2006).

‘Saturation is not seeing the same pattern over and over again. It is the conceptualization of comparisons of these incidents which yield different *properties* of the pattern, until no new properties of the pattern emerge’ (2001: 191, emphasis added).

Whether defined in terms of patterns or properties of patterns, theoretical saturation is characterised by same-ness, by the absence of new discovery. As one contemporary author describes it, theoretical saturation is ‘the time when observations no longer serve to question or modify the theories generated from earlier observations, thus rendering the theory “saturated” with data’ (May, 2001: 160).

However, the metaphor of saturation is arguably problematic when used in this way. As Dey points out, ‘saturation’ implies that all the data have been coded, and all the codes have been theoretically exhausted; this is too bold a claim for an interpretive process that inevitably leaves some data uncoded and some codes only partially explored. Theories, themes and codes are not *saturated* by data, they are *suggested* by data and hence Dey prefers the term ‘theoretical sufficiency’ (1999: 257).

5.3.2.2 Practice

Theoretical sufficiency recognises the situatedness of any research study; the theory is sufficient *for* something, namely, its research aim. This seems to reflect more accurately the nature of this study; I do not seek to answer all questions relating to decision-making within an AMS. Rather, I seek to construct an explanatory narrative which is *sufficient* to address the specific aim of this qualitative study. This does not require an exhaustive depiction of the data but a plausible one, a ‘portrait’ (Cresswell & Poth 2018: 94). A portrait is inevitably limited and *perspectival*; it is ‘a view of something by someone from somewhere’ (Poitress, 2018) (see: *Reflexivity*). I construct a narrative which is *sufficient* to provide a plausible account of the role of values in decision-making within an AMS.

5.3.2.2.1 Codes, themes and theory

Each day of field notes and each interview transcription was coded by level 1 codes, as line-by-line coding. This would typically be done after reading through the text multiple times. In this way, coding exemplifies the dialectic relation between the whole and its parts (see: *Appendix E*).

All field notes and interview transcripts would then be coded with more interpretive level 2 codes. Where interviews related closely to a particular day of field notes, these would be coded together because the one would provide useful context for the other, which enables deeper understanding. This again is an example of the circular hermeneutic relation between part and whole (see: *Appendix E*).

In addition, I created a mind map for each interview transcript. This was a diagrammatic representation of level 2 codes, which facilitated drawing connections and contrasts between codes. This ‘dimensionalization’

(Bluff, 2005: 154) was a creative means of interrogating my interpretation of the data in such a way that would facilitate the recognition of themes.

All four supervisors read samples of the empirical data, both in the form of field notes and interview transcripts. One supervisor, who has a background in qualitative research and clinical practice, read all field notes and interview transcripts. She coded large portions of this data, reviewed all of my coding, and met with me on a monthly basis to discuss the emerging themes and theory. This served as a means of 'peer debriefing' (Noble and Smith, 2015), to scrutinise the interpretation of data and enhance trustworthiness (see: *Trustworthiness*).

The process of data-logging, transcribing, level-1 coding, level-2 coding, recognising themes and constructing theory was not a neatly linear process, however. These activities would usually be going on simultaneously during the empirical period (developmental phase, consolidatory phase) as well as during the post-empirical period, according to a constant comparative method.

5.3.2.2.2 *Constant comparative method*

The constant comparative method is defined as 'a method of analysis that generates successively more abstract concepts and theories through inductive processes' (Charmaz, 2006: 187). It is thus a method of going through data to theory. Such progress is made through interpretive comparison: the researcher compares 'data with data, data with category, category with category, and category with concept' (2006: 187). Thus, the social researcher repeatedly scrutinises any analytical steps towards the construction of theory.

These steps are not always forward. For instance, once analysis of a set of data has produced codes, themes and a portion of theory, this would then be compared with subsequent analysis of other data. Sometimes subsequent data analysis would show the provisional interpretation to be inadequate. This would prompt a return to the original dataset and a search for an interpretation which is able to integrate both contrasting datasets.

This process requires not just familiarity with the *data* of the interpreter, but the *interpreter* of the data. The reliability of my proposed explanatory theory, in the form of narrative, depends upon the validity of the interpretation I propose. Next, I present three elements that enhance the validity of the narrative I present in the data chapters: reflexivity, trustworthiness and ethical approval.

5.4 Validity

5.4.1 Reflexivity

The notion of reflexivity ‘refers to the ways in which the products of research are affected by the personnel and process of doing research’ (Aull Davies, 2008: 4). To be aware of this effect is thus a means of ‘turning back on oneself, a process of self-reference’ (Aull Davies, 2008: 4). Reflexivity entails ‘exploring the dynamics of the researcher-researched relationship and how the research is co-constituted’ (Finlay, 2002: 536).

As participant observer in this ethnography who is “here as a researcher”, I exert some influence over the behaviour of others in the field. One such influence is a possible change in participant behaviour upon recognition that they are being observed, a phenomenon known as the Hawthorne effect (Lexico, 2019). However, even covert participation and objective attempts at social research exhibit reflexivity, albeit in a less visible way (Aull Davies, 2008: 4).

For example, a doctor may adapt their style of communicating with a patient when being watched by a researcher. A healthcare assistant may be reluctant to share any opinions if they might be recorded in my field notes or by my Dictaphone in interview. The process of speaking with a patient about their experience of hospital may itself impact their experience of being in hospital. Furthermore, my preconceptions of a participant and my relationship with them influences how I perceive and understand their behaviour and communication. As these examples illustrate, I am a part of the social field which I study. Consideration of reflexivity thus entails a consideration of subjectivity and objectivity (Aull Davies, 2008: 4) and a return to the hermeneutic circle (see: *Appendix E*).

As with the hermeneutic circle, there is no means of eliminating reflexivity entirely from the social research process. What maintains the validity of an ethnographic account is not the illusory avoidance of reflexivity but rather an appreciation of its effects. This requires the ethnographic researcher to be both involved and detached, ‘stepping in and out of society’ (Powdermaker, 1966: 19). I endeavoured to achieve this in various ways, such as the following four examples.

Firstly, I deliberately took frequent short breaks during a shift of observation, when I would leave the ward for a few minutes before returning – literally ‘stepping in and out’ of the ward’s society. Secondly, I would keep a reflective log of how I have experienced being on the ward, including what I found difficult and what had surprised me. Thirdly, I wrote an extensive reflection on my first impressions of the hospital and this AMS during the first week of participant observation. This ‘arrival story’ (Aull Davies, 2008: 11) enabled identification of my initial expectations, assumptions and relationships. Fourthly, I would discuss data interpretation with my supervisors, who have varied backgrounds in general medicine, palliative medicine,

philosophy and bioethics and all have an interest in qualitative research. This peer debrief was an opportunity for my assumptions about the field and influence upon it to be scrutinised.

The recognition of my influence on the social field and the data I gathered improves the validity of my interpretive analysis. In this way, reflexivity is closely related to trustworthiness.

5.4.2 Trustworthiness

The question of how much a qualitative account such as an ethnography can be trusted remains a live issue; there is still no consensus on the criteria for good qualitative research (Sparkes, 2001; Rolfe, 2006). Yet without any such criteria, qualitative research findings could be deemed 'merely a collection of personal opinions subject to researcher bias' (Noble and Smith, 2015: 34).

Reliability, generalisability and validity are criteria frequently used in quantitative research (Long and Johnson, 2000). When applied to ethnographic research, generally such research is judged 'deficient as regards its reliability as well as the generalizability of its findings, while given high marks for validity' (Aull Davies, 2008: 95–96). However, social research theorists have argued that criteria for demonstrating rigour in the natural sciences are not appropriate for the social sciences. Such criteria need translating within the qualitative research context into alternative terminology, involving truth value, consistency and applicability⁴⁰ (Lincoln and Guba, 1985). The best-known set of criteria for establishing whether qualitative findings can be trusted is that of Lincoln and Guba (Korstjens and Moser, 2018: 121), who proposed a four-part framework consisting of *credibility*, *transferability*, *dependability* and *confirmability* (1985). I consider each criterion in turn and apply it to this study.

Credibility is the qualitative equivalent of internal validity in quantitative research (Lincoln and Guba, 1985). It relates to the degree of confidence that can be held in the researcher's interpretation of participants' original communication (Avis, 2005: 13), and can be supported by such strategies as prolonged engagement, triangulation and member check (Korstjens and Moser, 2018: 121). With regard to prolonged engagement, I was a participant observer across 16 months and included a 3-month initial phase, during which to build trust and become familiar with the research setting. With regard to triangulation, I used a diverse range of approaches to data collection. This includes *data* triangulation, by gathering data at different times of day and times of year, gathering data in different situations and gathering data with different groups of people. It includes *investigator* triangulation, by having regular input into coding and analysis from my supervisory team. It also includes *method* triangulation, by gathering data not just through participant observation but also through semi-structured interviewing. With regard to member check, this was done informally in

⁴⁰ These are intended to be qualitative equivalents to the quantitative criteria of validity, reliability and generalisability respectively (Noble and Smith, 2015).

conversation with participants who asked “how’s it all going then?”. A more formal member check was performed when I presented my provisional findings at a national conference for acute medicine staff and responded to questions⁴¹.

Transferability is the qualitative equivalent to generalisability in quantitative research (Noble and Smith, 2015: 34) and describes the extent to which research findings can be applied to other contexts. It is facilitated by providing a ‘thick description’ (Lincoln and Guba, 1985; Tracy, 2010; Korstjens and Moser, 2018). This is progressively evident in my field notes, which were thin in the opening few shifts but rapidly became rich in contextual detail, as is evident throughout the development phase and consolidatory phase. Whilst there is no calculable threshold of transferability, ‘the more illustrative, explanatory and sophisticated [a] portrayal is, the more extended or applicable the acquired knowledge becomes’ (Mantzoukas, 2004: 994).

Dependability and confirmability are the qualitative counterparts to the quantitative criterion of reliability (Noble and Smith, 2015; Korstjens and Moser, 2018). The former relates to the stability and accountability of the research process across time. The latter relates to degree to which the findings are evident in the data and not merely figments of the researcher’s imagination (Lincoln and Guba, 1985). Both dependability and confirmability are supported by procedural transparency, which I maintained in this study by keeping records of research decisions, research diary entries and supervision meetings so as to ensure an auditable trail of research decision-making alongside the data.

The purpose of this attention to reflexivity and trustworthiness is to be able to answer affirmatively to the question ‘can the findings be trusted?’ (Lincoln and Guba, 1985) and thus assure the reader that what follows in this thesis is a plausible account of the role of values in decision-making within an AMS.

5.4.3 Research ethics approval

Methodological issues in healthcare research are closely related to ethical issues (Seymour *et al.*, 2005). For this reason, my proposal for this research study required consideration from an ethical perspective. As well as gaining approval from the research and development department of the relevant NHS trust, which also acted as sponsor of the research, I required approval from the Health Research Authority (HRA). After discussing my proposal with a regional ethics committee (REC) (reference: 17/NE/0106), HRA approval was granted on 22/05/17. My application form, protocols, supporting documentation and clarifications anticipated ethical aspects of this study such as the consent of participants, the involvement of patients lacking capacity, data retention and any influence on the delivery of clinical care. Members of the REC were

⁴¹ *Values and decision-making in an Acute Medicine service*. Society for Acute Medicine conference, Bournemouth International Centre, Bournemouth 21/09/18

satisfied that the plan for this study satisfied the ethical demands of good research practice as well as the legal demands of the Mental Capacity Act 2005 (England & Wales).

5.5 Conclusion

In this chapter, I have surveyed the empirical methodology, analytic methodology and validity of this study. Theoretical considerations describe how this study is designed to address the knowledge gap that was identified in literature review, in terms of methodology. Practical and experiential considerations describe how this study was implemented in such a way that does indeed address this knowledge gap. However, it is only useful for research to address a gap in contemporary knowledge if a scientific community can have confidence in its findings. Such confidence is supported by the validity of this study, which is described in terms of reflexivity, trustworthiness and institutional ethics approval. In conclusion, then, what follows is a trustworthy account of the role of values in decision-making within an AMS.

Chapter 6. *Restoring Order*

This is the first of three chapters in which I present my interpretive analysis of ethnographic and interview data. In this chapter, I present the aim of an Acute Medicine Service (AMS): *to restore order*. Restoring order is not simple, however. It involves patients and problems. I start by characterising what patients are and what problems are within this AMS. This will lead to a consideration of what the point is of all of this work: what does restoring order require?

6.1 What is the patient?

6.1.1 *Journey*

A white canopy stretches over the paving in front of the glass door of the hospital. In its shade, members of the public are deciphering the instructions on the screen of the car park ticket machine. There are two types of car park here: 'staff', who have permits, and 'public', who buy tickets. A CCTV camera looks out across the paving. A couple of young women looking deprived of sleep are stood at the edge of the paving. One is wearing a purple dressing gown, the other a white-and-green hospital gown. They must be patients. Each is holding a smoking cigarette.

Crossing the shade of the canopy, I am offered an automated welcome by the glass doors of the main entrance, which open as I approach. There is a reception area to my right and a spacious atrium ahead of me. In the words of a patient I would later encounter, "this place looks like what you see when you finally step off the coach for your hotel break in Alicante!" Yet, further ahead, I notice rows of people seated, waiting. They must be patients. This hotel atrium is in fact the Accident and Emergency (A&E) waiting room. The whiteboard ahead displays an estimated waiting time in rushed handwriting: "2 hours". Heads turn as I enter to see if I am one of the sick that wait here or the healthy that work here. Self-conscious, I become aware of the click-clacking of my shoes. I walk across the margin of the atrium with my head down. As I do so, I notice the cartoon illustration printed on the floor. It pictures a tree and fresh air, with the caption "we are smoke free".

Upon setting foot in Middleton Hospital, then, I make two observations. Firstly, there are clear categories here: some people are staff and other people are patients. Secondly, there is something complex, even paradoxical, about the categories here: this is both a smokey and a smoke-free place. A complex relation between categories is a feature of what I would encounter downstairs in the AMS.

6.1.1.1 *From doors to doors*

The AMS is a part of the hospital whose entrance is marked by another set of automatic doors. Unlike the main entrance doors, however, these doors automatically close rather than automatically open. To enter

the AMS requires action and authorisation, and marks a milestone in my journey into the field. Having parked in the 'public' car park, I became 'staff' as I was watched walking through the atrium. Then, having taken the 'public' staircase, I employed a 'staff' privilege in order to enter the ward. As I noted at the time:

To enter the AMS I had to tap my ID badge against an electronic card reader... On entering the ward, there is a long corridor straight ahead. There was a lady in uniform... seated at a desk 15m ahead. Beyond that, I could see nurses in blue uniforms at another desk about 25m ahead, who looked towards me as the doors opened. [1a]⁴²

This time, the heads turning to watch me were those of nursing staff. The illustrations are not on the floor, which was plain, but on the walls. The collective 'we' of the "smoke-free" cartoon now features implicitly in a poster of a nurse looking caringly towards a patient: "if it matters to you, it matters to us".

The automatic double-doors are the single entrance and exit of this AMS, which are at one end of a long corridor:

The shape of the ward is of three corridors, which are connected to a central area like three spokes in a wheel. Along each corridor there is a circular bulge. Patient's cubicles and bays are around this circular bulge which sometimes I have heard referred to as a 'pod'. The entrance corridor, unlike the other two, extends beyond this pod a further 15m to the entrance of the ward. [1a]

The passage through these automatic double-doors marks the moment a patient becomes a part of the AMS. Patients who come through the doors are allocated a place in a pod of the ward, and eventually exit the ward through the same doors. The doors are therefore symbolic of the start and end of the care journey of a patient.

Tony⁴³ is a consultant in Acute Medicine who was reflecting on what the unique features are of Acute Medicine. He refers to the doors of the department symbolically in his wording:

*We're all, I think, coming with fairly wide open eyes to what might be coming through the doors.
[Tony, 61]⁴⁴*

⁴² I divided my transcripts of 36 shifts of fieldwork into 9 groups of 4. Each group shares a number, and each shift within a group is assigned a letter (a-d) at random. The reader can thus gain a sense of where a data excerpt occurs in a series of 1-9 but not with sufficient accuracy to identify the actual day an event occurred.

⁴³ Some consultants within this AMS were called by their first name, and others by their title and surname. This is reflected in the pseudonym I have assigned each consultant.

⁴⁴ Interview excerpts feature the interviewee's name, followed by its location within the interview by line numbering.

What comes through the doors, according to Tony, is a “case mix” [Tony, 47] of patients. A patient is someone who comes through the doors. More than that, a patient is someone who also has a medical condition. That is what qualifies them to enter the AMS:

Acute Medicine, to me, means whatever that undifferentiated take is, the collection of physical, physiological, and actually quite a significant amount of psychological or mental health problems that people experience. That leads them to a point where there's a tipping point of some kind and either a GP is called or 111 or 999 is called. And then they end up filtering through the system and ending up in the system as an Acute Medicine patient. [Tony, 23-27]

This AMS is a part of the hospital system. A&E is the preceding step in a patient's journey; it is the part of the system a patient ‘filters through’ in order to make it into this AMS.

Dr Williams is a consultant in this AMS who was speaking to me towards the end of his shift. He seemed exhausted and was rubbing his forehead wearily as we spoke. After recounting the challenges of the day, which included dealing with the “weird and wonderful that falls in the cracks that no one else wants” [9a], he also spoke of the process of ‘filtering’ through A&E into the AMS:

The point of triage is the junior doc in A&E. They're the one that makes the decision. [9a]

As is common practice nationwide, sick people are triaged in Middleton Hospital on the basis of medical conditions. Other medical wards correlate with a body system, such as cardiology and gastroenterology⁴⁵. An AMS, however, is not so physiologically demarcated. As a result, patients with a medical condition that “falls in the cracks” [9a] also qualify, according to the judgment of the doctor in A&E.

There is nevertheless a degree of selection as to which sick people are entitled to enter the AMS doors as a patient. Some are specifically *excluded* from this AMS:

In our service we no longer see what are clearly acute new strokes, acute new heart attacks... in general, acute new jaundice and very specifically abdominal problems, for example. [Tony, 30-33]

Likewise, some sick people are specifically *included* in this AMS:

We specifically take a cohort of patients who have overdoses or self-harm. Okay? So that poses some challenges for the nursing staff and for ourselves because of the patient cohort. Many of them who

⁴⁵ An exception to this is a ‘care of the elderly’ ward, which instead is characterised by the age-related needs of an admitted patient.

very definitely not only don't want to be in hospital, some of them don't want to be alive.

[Tony, 38-41]

Whilst the journey of a patient through the hospital system may begin in the A&E waiting room, the journey through the AMS is one that starts and ends with these automatic double-doors. So long as the sick person is sick with a medical condition that satisfies the judgment of the doctor in A&E, the sick person becomes a patient within an AMS. This 'filtering' process of triage qualifies a patient to start their AMS journey, which is a circular journey from doors to doors.

6.1.1.2 The pressure and the pace

Such itinerant circularity is common to all medical wards within Middleton Hospital, which share the same layout. What makes the AMS special is the pressure and pace of this journey.

Fergus is a senior pharmacist who has been working within this AMS for many years. I notice his cheerful demeanour on the ward as he checks ward prescriptions, clarifies community medication lists with patients and responds to queries from colleagues. As well as cheerful, his manner seems rushed; he speaks in rapid bursts, which are separated by momentary pauses, as if to let the listener catch up. Fergus describes his impression of this AMS, why he enjoys it and how it compares to other wards:

I love the insanity of [the AMS]... I'm not easily bored but I like being constantly engaged and things? And Acute Medicine, with the variety of patients, and the absolute insanity of it, feeds into that [laughs]. *[Fergus, 6-9]*

Even in interview away from the ward, Fergus maintains his quick-fire style of communicating. He expands on what he means by the "absolute insanity" that distinguishes an AMS from other wards:

It's the pace. You've seen [the AMS]. It is non-stop. The turnover is huge. *[Fergus, 6-11]*

This 'huge turnover' is characterised by its speed:

Well [within the AMS] it's slash and burn, it's in and out!... they want a quick sort, they want to sort the initial problem and get rid of them [smiles]. *[Fergus, 457-459]*

Within an AMS, according to Fergus, problems are sorted and patients are got rid of. What is a unique feature of this ward, an AMS, is not so much the shape of this journey as its "slash and burn", "in and out" pace. Fergus expands on where this pressure to maintain this pace comes from. Besides the training and experience of doctors and nurses, he identifies an additional factor:

It's bed management going "we want the bed 5 minutes ago", or the patient! Or get rid of them or get them somewhere. And that fight! Bed management or the OSMs [Operational Services Managers]

are on the ward every day going “we need beds.” And no other ward gets the same pressure.

[Fergus, 457-468]

Bed management and OSMs, agents of the hospital at large, reportedly apply particular pressure to the AMS staff to discharge patients. As hospital staff who exert pressure on AMS staff whilst not belonging to the AMS, bed management and OSMs are frequently referred to by ward staff simply as “they” [3c].

I join Sarah and Sandra on their morning coffee break in the canteen, as they start speaking of the “they”. It is the first time either of them has sat down this morning. As we pull out plastic chairs, there is a sigh of relief before conversation begins. Both Sarah and Sandra have worked here for many years and also note the fast pace of the AMS as its distinguishing feature:

Sarah: It is tough. But that’s also why we like it. We like the busy-ness. The people that we are, we like getting things done.

Sandra: Sometimes when you have a slow shift we’re all like “what’s going on, it’s boring”; we complain even then.

Sarah: We’re a bit crackers. [3c]

The pressure to sustain the pace of turnover within an AMS, whether spoken of as “absolute insanity”, “tough” or “crackers”, is also understood by Sarah and Sandra to be maintained by management. As Sandra says:

“Ah, [the pressure is] all the time. They’re always getting you to do more.” [3c]

The pressure from management to maintain the pace of turnover is recognised by consultant Dr Taylor. Dr Taylor is an energetic consultant who wears scrubs and trainers during her ward rounds. Sometimes walking swiftly, sometimes crouching at the bedside, Dr Taylor only sits still briefly to check clinical information on a computer screen before moving on. Looking back on the previous two days of busy ward rounds, Dr Taylor describes her sense of pressure within this AMS:

I think there’s a push, clearly this hospital won’t function if people don’t move through wards pretty quickly, so there’s clearly quite a big push of getting people home... when I go to see a patient the question in the forefront of my mind is “can they go home? Do they need to be here?” [Dr Taylor, 23-27]

Thus the pressure on discharge, referred to as “turnover” (Fergus), the pressure to “do more” (Sandra) and the pressure to “[get] people home” (Dr Taylor), is a widespread phenomenon reported amongst AMS staff. It involves factors which are external to the AMS such as the “they” of management; however, it is also

internalised in the mindset of staff who “like the busy-ness” (Sarah) and hold patient discharge in the “forefront of [their] mind” (Dr Taylor). What is more, this sense of urgency is not limited to staff.

Gary is not staff. He is a patient, sat upright in the armchair in the corner of his cubicle. His room, called “bed 5” by nursing staff, is unusually spacious. It is the so-called bariatric room, which is designed to be able to manage extremely heavy patients. Gary himself is slim and looks very fit. He is well-tanned and wearing a T-shirt and football shorts as he reads the newspaper beside the sunlit window [3c].

Gary is then joined by another patient in his cubicle. The hospital is short of beds and so this extra patient, Arthur, has been put in with Gary for the time being. Nurse Sarah explains to me that this decision comes from “management”. With a despondent tone, she adds that there is no point in disputing it “because if I say the patient in there isn’t suitable to share the room, they’ll just say ‘find a patient who is and swap them’” [3c].

Arthur is wheeled into room 5 by two porters as he lies on a bed. Arthur is extremely hard of hearing and shouts “I can’t hear you!” to any nurse who approaches. Arthur appears elderly, agitated, thin and frail. He breathes heavily into an oxygen mask which hisses loudly. His bed is parked opposite Gary as a healthcare assistant positions a thin fold-out screen between the two patients. The whole scene feels a little chaotic and clumsy; Arthur’s bed is blocking the toilet entrance and his oxygen supply tube stretches across the room to attach above Gary’s bed. There is no opportunity for the two patients to greet one another. The nursing staff appear embarrassed and frustrated as the porters walk away [3c].

Five minutes later, I return to speak with Gary, who smiles warmly and comments:

“I’m very impressed with the staff here. Can’t fault them. Some of them I’ve seen on their feet for 13 hours and then, once they’ve finished, they go round offering teas and coffees! Very impressive. Call you by your first name and everything. The doctors are very nice too. Like the one with the beard, he’s very good.” [3c]

Gary’s facial expression drops for a moment, after this string of compliments. He folds his newspaper and adds:

“Mind, I’ve overstayed my welcome... I’m well now. Better give the bed to somebody else. Arthur has come in; may as well have my bed!” [3c]

Gary goes on to give a light-hearted illustration of how fast things are done on this ward:

“I tell you what is impressive: In the morning I have a shower. Problem is, the whole bathroom gets very wet. Within 5 minutes, the lady comes in and mops it up! I didn’t even know they were watching us! I don’t know even how they knew.” [3c]

Gary chuckles with amusement at how rapidly his shower room is tended to. Yet, despite this impressive service, he wishes to leave. Despite the welcoming main entrance, complete with a decorative canopy, automatic glass doors, atrium and reception desk, Gary recognises that this is *not* a hotel. Witnessing the hard-working staff, the sickness of his room-mate and the shortage of space, Gary feels an obligation to vacate his bed. It is not because staff have indicated he ought to leave now but because of his sense of the urgency with which this place operates. Sensing the pressure and pace of the ward, Gary feels he has “overstayed [his] welcome” [3c].

The circular journey of patients from doors to doors is thus not a gentle meandering; it is an active, consistent process of ‘turnover’. To work in AMS is to work under pressure; there is a ‘push’. This is a push with direction: a push to get patients home, working to a pace described as “absolute insanity” (Fergus). Within the world of an AMS, to be a patient is to be on a journey: a journey from doors to doors as fast as possible.

6.1.2 Whiteboard

The patients who are currently journeying through the AMS are recorded and tracked on a whiteboard. The ward whiteboard stands prominently beside the central work station. Before a patient arrives in the AMS from A&E, their name is written on the whiteboard; the patient’s reputation precedes them. This reputation consists of a summary of the patient given by a phone call to a nurse within the AMS, which enables the nurse to know which bed the patient is due to occupy on the ward. After this phone-call is received, the patient’s name is written on a row of the whiteboard next to the central work station, with a box drawn next to it to indicate the patient needs to be seen by a doctor. Each row of the whiteboard relates to each bed of the ward, to which names are then added as patients come and go.

The columns feature the patient name, and then information which is mostly written in abbreviations relating to tasks of clinical relevance (e.g. “Flexi-sig”) or logistical (e.g. “W15, SSH” [going to ward 15 at South Side Hospital]). [1a]

This whiteboard is a pivotal point, which staff of all kinds stop to interact with at some point during their shift. For instance, staff survey the whiteboard to gain an impression of how busy the ward is as a whole:

I arrived on the ward at 18:45 and approached nurse Ryan, who was standing back and looking over the whiteboard beside the central work station. He had a serious look on his face, had his hands on

his hips and was looking up and down the board, as if he were more concerned by the overview of the whiteboard rather than any particular patient's row. [4b]

Ryan's eyes would skirt vertically, pause, and then glide horizontally to see what tasks remained outstanding for that particular patient. I ask him how today is going. Ryan glances back over the whiteboard as he replies: "busy!" [4b].

During my time on the ward, management attempted to have the whiteboard removed and replaced with an electronic alternative. This prompted a response from staff, who made their cherishing of the whiteboard more explicit.

Laura is a trainee doctor who is seated at the central work station with her back to the newly-mounted electronic screen. She is rapidly typing and clicking at a computer, gathering the relevant information about a patient before the consultant Dr Morrison asks her. I notice she glances intermittently at the ward whiteboard but does not turn to look at the new electronic screen behind her [3a]. I ask Laura about this as she gets up:

"[The electronic screen] is nice for just having a quick look. But looking at it, it doesn't say to me how many patients I've got to see and the little jobs that need doing. The whiteboard is really good for that... it's better for a quick overview." [3a]

Laura's preference for the whiteboard is shared by Dr Morrison, who specifies that "it's all about flow" [4b]. 'Flow' is a term used to describe the movement of patients through the hospital, as they are transferred and discharged.

She continued to describe to me how there is pressure to "do everything on [electronic software for tracking clinical tasks]" but that the electronic handsets and electronic board are not as good at giving a feel for the overall state of the ward; in particular, what tasks are outstanding before transfer or discharge. [4b]

The whiteboard is a visual representation of how the work of the ward is divided into beds, and beds are in turn divided into tasks. Surveying the whiteboard thus gives a 'feel' for the ward. Not all tasks make it onto the whiteboard; only those which are required in order for the patient to be discharged and for the bed to become available again. "It's all about flow" (Dr Morrison).

The following month, I notice that the ward whiteboard has disappeared. The electronic screen seems to have won the conflict. Harriet is the consultant on duty today, who smiles with amusement as I inquire about this:

She has a very friendly demeanour and tells me about the “dramas” concerning the ward whiteboard. Having previously been positioned beside the central work station, it has disappeared: “taken down by management. I don’t have a problem with them taking the whiteboard, but not until we’ve had our questions answered.” Harriet continues to describe to me how useful the whiteboard is for how the ward runs, and especially for getting the big picture overview of who’s going where, and who needs what done.

With a relieved expression, she says that she has got permission to put it back up. As I walk across the ward, I notice that the whiteboard is still on the ward, without its legs, tucked in a corner of the procedure room. [4a]

Harriet speaks with fondness about the ward whiteboard, and this is reflected in the relief she expresses at the victorious efforts to have it restored.

Within the AMS, a patient is someone whose name makes it onto the whiteboard. A patient’s name makes it onto the whiteboard when it is assigned a bed and whilst there are outstanding tasks before discharge. In order to become a patient on the whiteboard, a sick person undergoes four translations. Firstly, they are translated to individuals; family members do not accompany them onto the whiteboard row. Secondly, they are translated to a first name and surname; titles and descriptors are not required. Thirdly, they are translated to tasks; the 30 rows of the whiteboard represent 30 journeys towards discharge. The columns of tasks are the logistical steps in this journey. Fourthly, they are translated to parts of a new whole. Outside of the whiteboard, the patient may be understood as a member of a family or community. Inside the whiteboard, however, they become a member of a new 30-bedded society, defined by a logistical map which provides the “big picture overview” (Harriet) .

As well as being a sick person in a bed on a journey from doors to doors, a patient is a name in a row on a journey from left to right. As well as being a sick person who is some distance away from going home, a patient is someone who makes it onto the ward whiteboard, who is some tasks away from discharge.

6.1.3 Anatomy

In the world of the ward, what people do can be seen from what people wear. Patients come in white and green: a unisex gown which they put on until the day of discharge. Nurses come in blue: light blue for junior nurses, dark blue for senior nurses. Healthcare assistants come in brown, discharge co-ordinators in grey, and so on. There is a poster on the ward which is a diagram, identifying the role to which each coloured uniform relates. Those who enter the ward in their own clothes are visitors, doctors, psychiatry liaison, and the ‘hospital to home’ team (who facilitate complex discharges into the community).

This dividing up of the workforce simultaneously indicates a colour-coded dividing up of each patient. That is to say, each role is concerned for a particular part of the patient's journey from *through the doors* to *out the doors*. Each part of the professional workforce concentrates on a part of the patient. In a sense, the division of labour is the division of the patient.

For example, Rahul is a physiotherapist who has just been assessing Mrs Beatrice Jones for discharge. Wearing blue and white, he had come to see her, in her white and green gown. Mr Chris Jones, in his own clothes, was seated on a plastic chair in the corner. Beatrice is recovering from an asthma attack. She pushes her oxygen mask to the side to speak with Rahul, as they discuss the layout of her home and how she feels about walking on her own. Following this, Rahul and Beatrice leave Chris behind as they go in search of a nearby staircase to test her ability to go up and down stairs.

Immediately afterwards, Rahul summarises his general approach to assessing patients:

From a physio point of view, like what mobility aid they need. If they need further community physio, or if they need out-patient physio. Just sometimes you give basic, generic exercises, depending on the patient, just help improve them like a little bit more. More from physiotherapy point of view, it's more looking at the functionality so, getting in and out of bed, get up out the chair. [Rahul, 23-27]

Rahul clarifies how he assesses 'functionality':

If it's quite a competent patient we would do it on and off the toilet, because toilets here are normally the average height, for toilet normally. Doing the stairs if they've got stairs. If they have a bungalow, if they've got steps outside, so then we'll take them to stairs and do a couple of steps. If they have no grab rail, we'll do them without any handrails. Or if they have a handrail, obviously one handrail... [Rahul, 27-32]

Beatrice was off her oxygen whilst Rahul tested her mobility on the staircase. She needed to pause and catch her breath, complaining that her chest feels tight. Rahul describes how he felt at this moment:

In the middle of the stairs you start panicking. That could have led to her falling, essentially. [Rahul, 187-188]

After walking Beatrice gently back to her bed to be reunited with Chris, Rahul immediately went to inform a doctor of her ongoing difficulty breathing.

The main concern for her quality of life to be improved, from my point of view, is making sure that the doctors had everything in place for her chest. [Rahul, 190-192]

Whilst Beatrice's breathing was a concern from his point of view, Rahul recognised it was the responsibility of the doctors to deal with this. As a ward physiotherapist, he is more interested in the mobility side of things than the respiratory side of things.

Beatrice herself adopted a similar division to Rahul. As she sees it, there is a medical side of her, which concerns her breathing, and a physical side of her, which concerns her mobility:

I'm still wheezy, and it's scary when you can't breathe. It's terrifying actually. So from my point of view, not so much the physical side as the medical side. I have to know what I do to help me, because I certainly don't want to come back into hospital. [Beatrice, 22-25]

Whilst the "medical side" of her is worrying, Beatrice contrasts this with the "physical side", which she sees as reassuring:

I have my husband. I can go up and down. We have three bathrooms in the house, we have a downstairs toilet. I have a walk-in shower. And these facilities work well. And once I'm upstairs I'm upstairs, once I'm downstairs and I do have toilet facilities and bathing facilities. I have my husband, which is good because not everybody has that. [Beatrice, 22-34]

The categories of 'mobility' and 'chest', or 'physical' and 'medical' represent different aspects of Beatrice's healthcare needs along her journey through the AMS. Different categories may be used for different patient journeys.

Another way a patient journey may be categorised is drawn by Brian. He spoke to me from the armchair in cubicle 5, the so-called bariatric bed. Brian was an obese man, wearing the white and green hospital gown. As he put away his mobile phone, I noticed extensive bruising along his arms. He summarised the situation to me:

Without hesitation, he started telling me "the staff here have been great. The nurses: nothing's a bother. Especially as, with me, the things they've got to do are not exactly pleasant, ya na? I had pretty bad diarrhoea when I come [sic] in." He continued to describe his injured spleen which resulted in a large bleed into his abdomen and "downstairs". The doctors, he continued, are having to make a difficult decision because he's in a "difficult balance: having to get the blood clotted, but also having to get me on tinzaparin [an injected medication which thins the blood to prevent stable clot formation]." [8b]

We spoke a little more about this "difficult balance", and he mentioned that the doctors are helping him through this:

“They know what they’re doing. I know my body, but they know the medications ‘n that, ya na?”

[8b]

He expanded a little on the distinction between the doctors’ knowledge and his own:

If it’s a medical thing you wanna trust the doctors. Because they know the facts ‘n figures. They’ve got all the data, all the experience. If it’s a medical issue, it’s acceptable. If it’s a lifestyle issue, then it’s about choices... Medical things they’ll tell us to take certain medicine, so you behave in a certain way. And a lifestyle thing is the choice that I make to do it. If I choose not to do it, after being given sound medical advice, well then, ya na, it’s me fault isn’t it? That’s the way I look at it. [Brian, 74-81]

Going home on regular tinzaparin injections crosses both the “medical” and “lifestyle” categories, in Brian’s opinion:

It’s a temporary measure, it’s a bit of both, yes. ‘Cause medically it has to be done, lifestyle it has to be done as well, ya na? [Brian, 84-85]

Where Beatrice had a medical side and a physical side, Brian has a medical side and a lifestyle side. Even though these categories can become mixed, they show that an individual patient is not necessarily an *indivisible* patient. Patients and their journeys can be divided into different components.

Another way of dividing a patient is alluded to during consultant Harriet’s interaction with a patient called Alan. Alan is in his fifties and has been admitted to the AMS after taking an overdose with the intention of ending his life. I pull round the curtain as Harriet greets him cheerfully:

Alan was wearing a football shirt and was seated looking straight ahead. The consultant Harriet sat to his right, on his bed, at eye level. He made occasional eye contact with her but mostly looked ahead and showed minimal emotional change. His answers were mostly “right. Right”. [3d]

Harriet’s voice softens and quietens as she realises that Alan is not in the mood for talking. He mostly avoids her gaze and looks fed up of being here. When Harriet asks “how are you feeling?”, Alan replies straight away: “No feelings. I want to go home” [3d]. At this, Harriet stands up and says:

“Well I’m the doctor who looks after the physical side of things. You’re on this antidote to protect your liver, and you’ll need to be in until it finishes. We’re looking at a little while, most likely tomorrow from the looks of things.” [3d]

Harriet points to the ‘time remaining’ digital display on Alan’s infusion pump, as he nods and then looks away. Harriet’s focus on the “physical side of things” suggests there is another side of things which she is

less concerned to address. Perhaps it is the mental side of things? Consideration of two similar interactions may shed light on this.

Trainee doctor Laura is speaking with a patient called Charlotte, supervised by consultant Charles, during the morning ward round:

As Charlotte relayed the timing of events and the details of the overdose she had taken, Laura crouched down at the bedside on one knee, leaning forward with a caring and concerned posture. I noticed that the conversation related to what had been taken, any bodily impact of this, and then a plan for her going home. Charlotte and Laura had not talked about the psychological reasons for choosing to take an overdose. [8b]

As Laura emerged from the cubicle, followed by Charles, I ask her “how much detail do you tend to go into in terms of the intention behind taking an overdose, or relational issues?”

Laura looked at me, wide-eyed, as if I’ve put her on the spot by asking her in front of the consultant. “Well, it depends. I don’t really know how it works here because I’m new. I’m assuming that everyone gets seen by psych [psychiatry liaison team], or were seen in A&E”. She glanced towards Charles, who nodded and added “I don’t at all. I have to say, I never really do ‘cause it doesn’t change my management. In terms of all that, A&E have already done it, psych are coming after; so if I go into it to, it doesn’t really add anything.” [8b]

Laura and Charles hint at a division of labour that warrants their focus on merely the physical side of patients who have taken an overdose; if the psychiatry team are coming afterwards anyway, then there is no need to tend to the mental side of things as well.

This division of the physical and the mental is made explicit by another trainee doctor, Ken. Ken was bent down on one knee before a young woman as he proposed. What he proposed was a series of questions for a young woman called Suzie, who had taken a paracetamol overdose. Her face was red and puffy, as if from crying a few moments ago. She seemed visibly upset during their short conversation, curled up in the armchair beside her bed as if she didn’t want to be there.

Ken posed short, closed questions in a thick Chinese accent, which generally demanded a “yes” or “no” answer: “you know taking paracetamol overdose is bad for you, yeah? You know it can cause the liver failure, yeah?” Suzie would often sigh before answering, as if to indicate that this conversation is a waste of time. I found it remarkable that, despite Suzie being clearly upset and having tried to kill herself, Ken’s questions related purely to the physical details of what had happened without any attention given to *why* she wanted

to harm or kill herself [7a]. Ken confirmed this intentional division, explaining it to me immediately afterwards:

I see it as my job's to treat them medically and the psychiatry team to try treat in terms of her mental health issue... The paracetamol overdose is a medical - in my mind – issue, in my mind. The depression and the trigger that makes her wants to take the paracetamol overdose would be from the psychiatry point of view, in my mind. [Ken, 107-118]

Like Charles and Laura, Ken's focus on the physical side of Suzie is in view of his place in the professional sequence. He is the episode before the psychiatry team; tending to "the depression and the trigger" of this overdose would thus be an unnecessary duplication of labour. When speaking with a patient who has taken an overdose, Harriet, Laura, Charles and Ken all concentrate on the physical side as opposed to the mental side of the patient.

The anatomy of a patient within the AMS is therefore not simple. A patient has many sides. Patients are divisible. The component parts into which they are divided may be a reflection of the division of labour of the professionals sequentially reviewing patients. As a result, patients can have as many component parts as there are uniforms visiting them. Patients can have a medical side, a mobility side, a lifestyle side, a physical side, a mental side. And perhaps many other sides.

Within the AMS, a patient can be figuratively understood in terms of anatomy, whiteboard or journey. Insofar as a patient's component parts relate to different tasks, their anatomy is equivalent to the whiteboard. Insofar as the whiteboard charts a patient's progress from admission to discharge, the whiteboard is equivalent to their journey. And insofar as their journey from doors to doors features a multidisciplinary series of consultations, their journey is equivalent to their anatomy.

Patients do not arrive in the AMS out of habit or curiosity; they have problems that need to be addressed. In what follows, I present three different kinds of problem that I encountered within an AMS, which help to characterise the overall aim of the work of an AMS.

6.2 What is the problem?

6.2.1 Deviation

In order to enter the doors, a patient must have a problem. Without a problem, a patient would not make it past the triage point of the junior doctor in A&E. As a result, patients arrive in the AMS with an already-identified problem. Often this problem is identified by the patient themselves. As a patient called Brigitte recalls:

Well, I was getting on grand after my operation, my breathing was a lot better until Friday morning and as I got out of bed my husband just caught us as I was going to the bathroom. That's was more or less... I would have collapsed. And I was sweating. Clammy, you know. I thought "oh dear me!", and of course I phoned my daughter. [Brigitte, 7-10]

Brigitte recognised that her near-collapse, sweatiness and clamminess meant that there was a problem. This disturbance in ordinary home life was recognised immediately, seemingly without any need for deliberation or measurement.

Mike describes, in contrast, how he knows he does *not* have a problem. In hospital with a chest infection, we speak about his past. Mike lies on his side as we talk, with his head propped up on his hand. He acknowledges that he used to have a problem with alcohol but feels clear that it is not a problem anymore:

I divin't get like I used to get. I used to get intoxicated and wake me up and it's like "what have I been doing now?" I'm not like that anymore, you na?... For it to become a total problem when you cannot pull yoursel' out of it at five o'clock tea-time, d'you na what I mean? And you're not eating proper and stuff like that. Where now, I'm eating again and I'm getting up at like seven eight o'clock and gan deeing things. [Mike, 62-69]

For Mike, whether or not his alcohol consumption is an alcohol 'problem' is determined by whether there is impairment of his ability to lead a normal life. A normal life for Mike features regular meals and daytime activities and, without deviation in these, his alcohol intake is not deemed problematic.

Like Mike, consultant Charles uses a template of a normal life in order to assess how problematic a condition of breathlessness is:

It's a bit about the impact on the patient. You know, how's it actually affecting the patient? Generally, if a patient has come to you, if you're in heart failure for example, if 3 months ago they were able to, you know, walk to the shop and now they have to stop 5 times... then it would be reasonable to treat. [Charles, 356-360]

According to Charles, whether or not a patient should be treated for a problem with breathlessness requires contextualising the symptom within that particular patient's life and considering whether their normal life is impeded. Sometimes this reference point of a patient's normal function is referred to as their 'baseline'.

Consultant Harriet refers to a patient called Harold's baseline in considering whether to let him go home. Harold is a frail-looking, disorientated man who is wearing the standard white and green hospital gown but it remains untied at the back, exposing his lack of underwear. Consultant Harriet is speaking with nurses

nearby when they observe Harold walking assisted across a section of the ward and defaecating in the process.

Harriet: "If that's baseline then I'm happy for him to go home. Would you [nurse] give a call to the [care] home and see if that's baseline function?" [3d]

Comparison with "baseline function" strikes me as an unusual way to respond to this event. It refers to what normal living is for this patient. If there is deterioration in Harold's continence, then there may be a problem that the AMS staff need to address. In the absence of deviation, however, such behaviour is not deemed medically problematic.

A fellow consultant, Dr Morrison, also emphasises the importance of comparing the patient's current state to their baseline function. She stands reading through a new patient's medical notes before attending them. In the hospital's 'clerking proforma' (the paperwork on which a patient's first full clinical assessment is recorded, typically in A&E) features a section entitled 'social history'. Dr Morrison turns to me and her accompanying doctor in order to express her frustration with this clerking, and emphasise the importance of a thorough social history:

She has noticed that the social history in the clerking often fails to document the patient's "baseline". This was important because, as Dr Morrison put it, "how do you get someone home if you don't have a baseline?" [4b]

Like Harriet, Dr Morrison considers baseline function to be an essential reference point by which to evaluate a patient's clinical need and readiness for discharge. A patient's impairment in function is not seen as a problem, in terms of requiring in-patient medical care, if it is their baseline. As such, the recognition of a problem seems intimately related to the patient's ability to lead their *normal* life.

However, there are also times when a patient is recognised to have a problem in the absence of any obvious interruption in their ability to live a normal life. Audrey is a lady who has no family nearby and dislikes coming to hospital. She speaks with me at her bedside about how she ended up being admitted, starting with routine health-check blood tests:

Yesterday morning, the nurse came, took another blood sample. And then last night, half past nine at night, I had a phone-call from the people who check the blood. Some hospital or whatever it is, and she said "are you on your own?" She said "it's very serious." [laughs] She said "can you get somebody?" I said "no!" [laughs]. So she said "you mustn't be on your own", she said. I said "look, if I feel ill I'll call 999." She said "well we're going to speak to a kidney specialist, and we'll come back to you." [Audrey, 12-17]

Audrey resisted coming to hospital, saying to the doctor who called later:

“But I’m alright. I don’t feel ill or anything!” [Audrey, 23]

When she was told that, according to the blood tests, her kidneys were failing and that it was serious, Audrey was worried and conceded to come to hospital:

You panic, you know, which I did more or less. [Audrey, 65]

Here, the recognition of a problem occurred without any impairment in Audrey’s ability to live a normal life. Purely as a result of measurement of blood tests, a problem was recognised by health professionals and, to some degree, by Audrey herself. Whilst this was not an impairment of her day-to-day behaviour, it was arguably still a case of *deviation* from her normal functioning: the baseline function of her kidneys.

Deviation from normal kidney function is also the reason another patient, Maureen, is on the ward. Fergus emerges from Maureen’s cubicle having restarted many of her medications, which were suspended in light of her kidney failure. Fergus has reserved a nearby computer by leaving her paperwork beside the keyboard. He explains to me why he checks kidney function blood tests on the computer before seeing the patient:

I was able to kind of piece together more of the story and actually go “actually, yes it is this result, which is bad in most people but actually it’s her normal”. There’s this obsession with numbers- I find numbers very interesting because especially with numbers we don’t think about normal. Everyone’s normal’s different. We should be working with whatever their normal is. [Fergus, 76-81]

The story that the blood results tell Fergus is what Maureen’s normal is; specifically, her kidney baseline function. This enables Fergus to evaluate to what extent Maureen’s current state is a deviation from normal and thereby problematic.

Whether speaking of breathlessness, activity levels, mobility, continence, social dependence or kidney function, then, such things are evaluated within an AMS by reference to baseline function. A patient has a problem when their function has *deviated* from what is normal for them.

6.2.2 Distress

However, it is not quite so simple. There is another kind of problem that is evident within the AMS, such as in the following light-hearted interaction between Heidi and Charles.

Heidi has been a patient in the AMS for 3 days now. She looks up eagerly at consultant Charles, who stands beside her cubicle bed. They have been speaking about the headache she has been experiencing and the results of the MRI scan. Previous doctors have mentioned the possible need for Heidi to have a lumbar puncture, which is a procedure that obtains a sample of cerebro-spinal fluid, for diagnostic purposes. Over

the past 3 days, Heidi has received mixed messages regarding how much longer she will need to be in hospital:

I was still none the wiser... I was just being tossed between one and the other and the other.
[Heidi, 22-26]

As a result of a doctor mentioning a possible diagnosis of 'meningitis', Heidi has told her family not to visit, in case she infects them [Heidi, 85-86].

After a brief clinical examination of Heidi, Charles takes a step backwards, as if to indicate a change of tack from receiving information to now providing it. Charles explains that Heidi has not had infective meningitis. She continues to look up at him, waiting for something more. Charles adds that it is now perfectly safe for Heidi to re-join her family: "I think we can send you home" [8b].

The mention of home seemed to light up Heidi's face: "Today?! Eeh, you're my favourite – you're a very good doctor, you know! What a lovely doctor!" she joked. Charles laughed as he turned to walk out. As we left the cubicle, he joked that perhaps the ward should direct Patient Experience (who take a survey of patients to assess how well the ward is doing) to speak with her. [8b]

Heidi's humorous response is filled with relief and delight. Charles's joke, in return, shows that he recognises that being home-bound is a relief for Heidi. What is striking is that her relief was not so much prompted by Charles' assurance that she does not have infective meningitis as by Charles' assurance that she can re-join her family at home. Heidi describes the pain of separation to me as follows:

It just gets your heart because it's like: I've got a granddaughter 'cause me daughter's had another baby so she's got 2 now. But me granddaughter she's 4 and she's a nana's girl. Everywhere I go she goes, you know? Well I'm Maui and she's Moana [characters from a recent Disney production], because that's what she calls me 'cause it's what we are. And she's just rung me up this morning at t' phone crying and saying "where are you, nana?" and "I need you, Maui" and it's like [sighs] you know? [Heidi, 78-83]

Separation from her family, according to Heidi, "gets your heart", and hearing how much her granddaughter misses her is a cause of distress. In her eyes, it is a problem. It is a problem that is not characterised by abnormal functional deviation but by relational dislocation. It is a problem that is relieved by the words "I think we can send you home".

Not all patients make it home, however. Deanne is sat in a dark room beside her partner, John, who remains in a coma from meningo-encephalitis. He occasionally rolls across the bed but does not respond to her presence. Deanne speaks to him but he does not respond. She tries to hold his hand but it does not grasp

her. Deanne looks into the lids of John's eyes as she leans over the bed rails, intermittently stroking his head [9c].

After a brief introduction, consultant Nick sits down to speak with Deanne in the ward's Quiet Room. Deanne sits awkwardly on a squeaky leather-bound sofa, leaning forward to hear what Nick has to say. There are three other empty seats in the room. After a summary of the course of events, Nick pauses before stating "it could go one of two ways" [9c]. Unable to reassure Deanne of the likelihood of recovery, she appreciates the frank conversation. As soon as Nick turns the corner to walk along the corridor, Deanne reaches for her mobile phone.

Clearly upset by her partner's illness, Deanne also describes another hurt at the moment: the empty seats. She calls John's brother to give him an update and then turns to me with tear-glazed eyes:

"The thing is, his family, right, they're very nice, they are. They're lovely. But if it were my brother, I'd be here! You know? That's what matters now, ya know?" [9c]

What matters is being together, being here, caring *for* John by being *with* John. The pain of her partner's critical illness turns out to be a double-pain, multiplied by the absence of family. The problem of meningo-encephalitis (an abnormal *deviation*) is coupled with the problem of relational *distress*.

A patient's relationships, and any relational distress, can be hard to see in a cubicle. This is significant within this AMS because the majority of patients are in their own cubicle. The large window of each room is positioned to the side of an armchair and the bed, with a blank wall opposite. As a result, a lot of time can be spent looking straight ahead, staring at a wall.

Mr Whitehead was staring at the wall ahead as the palliative care nurse (Kylie) came to see him to speak about his "terminal metastatic disease and... difficult home set-up" [6b]:

Mr Whitehead was an elderly, frail-looking man who was extremely thin. He had long, wiry, white hair which was un-combed, which gave me the impression he did not care much what he looked like. Perhaps out of weakness, he was slumped to his right-hand side and seemed unable to hold his head up vertically. [6b]

Kylie sat on a plastic chair close beside Mr Whitehead as he spoke about his circumstances at home. Since the death of his son, he has been living with his two teenage grandsons.

After a long pause, he looked to the far wall and uttered "I think it was 'cause his wife left him". Hearing this news made me feel extremely heavy-hearted for this man, and his grandchildren, whose pain was far deeper than I realised initially. [6b]

Mr Whitehead turned from the wall back to Kylie as the conversation continued:

Kylie then clarified the frequency and timing of the visits from a carer that Mr Whitehead receives. He resumed eye contact with Kylie as he recalled this information. It seemed to me that, whilst this information was urgent to make a plan for Mr Whitehead's discharge, it was not what was on his mind. [6b]

The conversation between them alternated between logistical issues, such as the number of carer visits and how often the grandchildren are around, and psychological issues, such as the pain of losing his son and how Mr Whitehead feels about dying.

Mr Whitehead maintained a concerned expression, with lowered eyebrows and a creased forehead, throughout the conversation... "I've been in 4 days. It's like a lifetime." [6b]

Perhaps four days in the AMS feels like a lifetime because Mr Whitehead has been re-living a lifetime of memories as he stares at the wall. Perhaps four days is a lifetime because his awareness of dying is accompanied by contemplation of eternity. Perhaps it feels like a lifetime because of the pain of being so separated from home and his loved ones. It is not clear what Mr Whitehead means by this phrase. What is perhaps clearer is that his focus is alternating. Switching between the wall ahead and the palliative care nurse beside, Mr Whitehead is switching from considering the 'there and then' of life-related memories and the 'here and now' of dying-related tasks.

Kylie had met Mr Whitehead before and seemed to have a very close rapport with him. She would listen for long stretches, allowing Mr Whitehead to pause and reflect as he looked ahead at the wall. She feels this gave her insight into what the biggest problem was:

He was referred to me for some pain. control issues.... But when I went to see him, pain wasn't his biggest problem, and then it was more about his social situation and his desire and want to be at home if he was dying. [Kylie, 17-20]

Kylie incorporated this conception of the problem into her role in looking after him:

It felt like, based on the conversations that I'd had over the two days previous, that home was very important to him – to die at home... I felt that I should help to move things forward as quick as possible. [Kylie, 30-32]

Following their conversation, Kylie then wrote a summary of it in the medical notes, with a concluding action plan:

Three times a day care from a care agency, with two visits from a district nursing service, a telephone contact to rapid response from palliative care, and someone there all night every night.

[Kylie, 107-109]

Thus whilst physical pain was associated with Mr Whitehead's illness, what seemed to be the biggest problem was in fact existential.

This problem was explored in two modes. In the first mode, Mr Whitehead would share his story whilst staring ahead at the wall, reflecting the 'there and then': "I think it was because his wife left him". In the second mode, Mr Whitehead would make a plan whilst looking across to Kylie, reflecting the 'here and now': "his desire... to be at home". Overall, his lifetime-in-four-days is translated from stories and desires into a list of tasks to be completed in order for Mr Whitehead's existential concerns – the problem of distress - to be met.

The problems that Heidi, Deanne and Mr Whitehead encounter are not of the same sort as a *deviation* in kidney function. Their experience also exhibits a relational, emotional, existential dimension. That is, they experience a problem of not being with loved ones and not being home, with its accompanying *distress*.

6.2.3 Disruption

Besides deviation and distress, Kylie alludes to a third kind of problem which she was conscious of in her dealings with Mr Whitehead:

Sometimes it's easier to move it forward before you start getting the bed pressures, which you do get from acute medicine unfortunately, which is "what are we doing? Do we need to be here in Middleton?" *[Kylie, 44-45]*

Kylie started preparing the practicalities of Mr Whitehead's discharge early and swiftly, in anticipation of the mounting pressure to reclaim the ward bed. She hints that it would be problematic to do otherwise; this approach is "easier" in some way.

Consultant Tony helps to shed light on this third kind of problem. As mentioned earlier, the pressure to discharge a patient is a major element in the 'insanity' feel of the AMS. There are times when this experience of pressure is more pronounced:

[Wednesday] was one of the worst days in terms of patient flow through the emergency department that this Trust has ever had. And I know that - it felt like that at the time. But I know that subsequently having talked to people yesterday about how severely strained the system was on Wednesday.

[Tony, 112-115]

Tony was conscious of this system strain which contextualised the assessment of a new patient (Stuart) coming through the doors:

And in the middle of that this patient arrived who is a cancer patient, on chemotherapy, who has a temperature. [Tony, 116-118]

Tony explains how the strain of the system affects the assessment of a patient:

I think there's a palpable sense sometimes, which there was on Wednesday, a palpable sense of 'this place is really under strain', and 'if we don't need to admit this man to a bed overnight then that would be a good thing for everybody'. [Tony, 136-139]

Immediately after assessing Stuart, Tony returned to the whiteboard to update it with plans. He spoke with me as he wrote:

"A&E is full, and it's full of frail elderly, which puts a lot of pressure on us, as you can imagine, because a lot of them will need to come in. And that has an impact on decision-making. Just now I sent a cancer patient home. He was febrile, but not neutropenic. To be honest, if there were beds I probably would have kept him in and kept an eye. But as it is, I had to send him home". [6d]

Thus the pressure that is felt when the system is "under strain" is pressure with a direction: out the doors.

Sophie is a trainee doctor who is working alongside Tony that same day. I greeted her near the central work station as she walked past energetically in order to prepare the medical notes for Tony's next patient. She sighed and smiled with resignation, saying:

"The hospital's in crisis. No beds!" [6d]

A lack of available beds causes disruption across the hospital as an organisation. Here is consultant Dr Taylor speaking of a man who was in the AMS with brain injury after taking an insulin overdose:

He was very complicated socially and I kept him at Middleton purely because I think if he goes to a base site [general hospital within the Trust] he will just get stuck forever. [Dr Taylor, 529-530]

"Getting stuck forever" is not only a problem for the patient; it is a problem for the hospital trust. A lack of beds is a "crisis" (Sophie) because it impedes "flow through the emergency department" and puts the system "under strain" (Tony). Specifically, it impacts decision-making in such a way as to raise the bar required to justify admission. This results in mounting pressure on Kylie to discharge Mr Whitehead on whatever social care plan is available soonest, and pressure on Tony to deny admission to a cancer patient because it might be "a good thing for everybody". In order to prevent the problem of a hospital in a bed crisis, staff strive to

maintain the flow of patients back out the doors. In addition to the problems of *deviation* and *distress*, there is thus a third kind of problem: organisational *disruption*.

6.3 What is the point?

6.3.1 Problems and pathways

It's eight o'clock in the morning and two trainee doctors, Faisal and Laura, are gathered at computers around the central work station, discussing whether a patient called Tina needs any more treatment. They have a rushed demeanour, as if eager to discover this before the morning handover with the consultant. Tina is in the AMS because she took an overdose of paracetamol and was admitted overnight. While Faisal looks up Tina's liver tests, Laura looks up some guidance online.

Having eventually found the King's College Transplant Score online, Laura seems amused and frustrated that the score leaves it indeterminate whether Tina would be eligible for transplant because she has not had a phosphate blood test done. [8b]

Faisal and Laura are joined by a more senior trainee doctor, Jackie. Jackie is specialising in Acute Medicine and arrives looking serious, clutching a flask of coffee.

Jackie opens the 'Toxbase guidelines' on a computer. As she does so, she surmises that Tina probably needs another 16-hour bag of intravenous treatment. Toxbase guidelines appear to be an algorithm which guides what treatment to give, and when a patient who has overdosed is safe for discharge. Reading through the text, Jackie declares loudly: "ALT [a liver test] still high but INR [a clotting test] 1.1, so she's not for more NAC [an intravenous treatment]; medically fit for discharge!" [8b]

In order to progress from blood results to this conclusion, the doctors were in search of a pathway, which Jackie was first to find.

As she said this, she sat back in the office chair and crossed her arms, in a confident and satisfied manner. To me this moment was quite striking; it was as if a significant milestone had been reached by arriving at the conclusion 'medically fit for discharge'. The loud declaration and accompanying satisfied posture change was reminiscent of somebody playing 'bingo', whose numbers had come up. "So she's not for more NAC?", checks Laura. "Nope, she's medically fit, medically fit for discharge!", repeats Jackie. [8b]

This episode of algorithm bingo was reminiscent of a quick-fire game in which the winner is the first one to say the slogan "medically fit for discharge."

Laura turns to me and remarks how many pathways there are. "There's one for everything!"
[8b]

Just adjacent to Laura as she speaks, there is a cabinet of approximately 30 drawers, in which staff can find printouts of pathways in the form of algorithms, "bundles", protocols and proformas. Each relates to a particular situation, such as 'Acute Kidney Injury' or the completion of a clinical procedure [8b]. In addition, there are clinical guidelines on the hospital intranet, such as for management of Giant Cell Arteritis headache [3d], and many more available on the worldwide web.

Laura remarks that there are more pathways in this hospital than she has ever seen in previous hospitals. "In a way it makes it easy but I don't know how good it is in the long run. What do we do when the computer breaks?" She shrugs her shoulders as if to suggest that doctors may be stumped without computer access to pathway guidance. [8b]

At first glance, there seemed to be an enthusiastic uptake of pathways by these three trainee doctors, all of whom were participating in the algorithmic rush to declare Tina "medically fit for discharge". The problem was protocolised; in the absence of significant physiological deviation (on blood tests), Tina is to be discharged. However, the enthusiasm for pathways is a qualified one. Laura expresses concerns that the plethora of computer-based pathways, which is particularly pronounced here in Middleton hospital, may not be good "in the long run". Such mixed feelings about pathways is shared by Laura's consultant colleague, Dr Taylor.

6.3.2 Pathways and cul-de-sacs

Consultant Dr Taylor describes when knowing what to do for a patient is obvious:

I think things are obvious when they fit that guideline or protocol, aren't they? So that SHO-level [senior house officer, a rank of trainee doctor such as Laura] of: take history, you have a diagnosis, there is a test to confirm it, there is a treatment that I know, it's the right treatment, and there is a known, understood way of following you up or discharging you. And that's easy, isn't it? [Dr Taylor, 558-561]

She contrasts "easy, pathway-driven things" [Dr Taylor, 566-567] with situations in which knowing what to do is more complicated:

And I think increasingly, what comes into hospital is not single organ, single disease, single diagnosis driven. I think it's multifactorial and complex. In terms of its medical disease origin but also in terms of its social context... It's "Mmmm, you've got a bit of COPD [chronic obstructive pulmonary disease] and a bit of heart failure, and you're struggling on the stairs and you daughter's really worried about

your breathlessness, and she's going away to Australia for a month"... There's no pathway that says "this is how you fix this". [Dr Taylor, 567-579]

On Dr Taylor's ward round, she prepares to meet the next patient, Albert Jenkins, by reading through medical notes in a red folder and looking up previous clinical notes on the computer system. Albert Jenkins is a man in his 70s with frequent journeys through this AMS with the same problem: more breathless than normal. Dr Taylor noted the same course of events each time: oxygen, CTPA [computed tomography pulmonary angiogram] scan, discharged. Dr Taylor crouched down at the bedside to hear his story.

Mr Jenkins narrated the run of events prior to his admission. He started by describing his routine every Tuesday afternoon, when he visits his wife's grave site "without fail". On this occasion, he began to feel breathless and thought "something was up". [6c]

On this occasion, Dr Taylor explained that oxygen and a CTPA scan were not required, to Mr Jenkins' relief. Reflecting with me as she walked away, Dr Taylor said:

"I sometimes think we've got to break this cycle that patients have in their heads: 'I go to hospital, I get a CTPA, I feel better, I go home'. And similarly with us as doctors, we work by algorithm in acute medicine. We just tend to think: 'it's a PE, we fix it, then they go home'". [6c]

She describes the trigger for needing to change tack:

She pointed out that it's when she stepped back and saw in the correspondence that Mr Jenkins keeps coming in and having this cycle reinforced, that she realised the medical team need to think differently about his care. "We're so busy excluding a PE [pulmonary embolus], but after all a PE might not be a bad thing for him. You've got to die of something". [6c]

Dr Taylor thus portrays the mindset of both the patient and the doctor as pathway-like. However, in view of the broader picture of Mr Jenkins' life (and mortality), she recognised that such scanning and PE-excluding might be a pointless way to go. Sometimes, these pathways become a pointless cycle which needs to be broken because what is being pursued, such as the exclusion of a PE, is futile: "you've got to die of something" [6c].

Dr Taylor's colleague, Harriet, is having a conversation with some family members in the ward sister's office which also involved a change of direction.

Gloria is an elderly, frail lady with dementia whose son (Bill) and his wife (Jenny) have been asked to come in "for a chat" with Harriet, the consultant. Once they are each seated, Harriet describes the "difficult

situation” [3d]: Gloria needs blood-thinning medication to prevent further clots, but also needs to *avoid* blood-thinning medication to prevent harm from falls. Jenny appears too tearful for words, but Bill responds:

“Can I be blunt with you? I do – that’s what I’m like, I like to just say things, don’t I? [glancing across to Jenny]. Me mam’s got no quality of life. If it was our dog, I would have no hesitation in putting it down, and that’s what I’d do. I don’t mean to be heartless, because I’m not – I’m like this when I’m with her but when I leave I cry me eyes out – I think you should do nothing. [3d]

At this, Jenny looks to the floor as tears start to roll down her cheeks and Bill rests a hand on her to comfort her. Harriet explores the specifics of this suggestion:

Harriet: ...as I say, I’ll do what causes her least distress and illness. It might be that the best thing for her is a blood clot

Bill: ...or a massive heart attack

Harriet: Hearing what you’re saying, it sounds like we should...

Bill: ...let nature take its course

Harriet: ...exactly; you could put it like that.

Bill: Thank you for speaking with us. We feel a lot better [wife nodding].

Harriet: Nee bother. [3d]

The daughter-in-law remains tearful as the couple leave the room and hug each other, distressed at coming to terms with the dying phase of Gloria’s life.

Following Bill’s statement “if it was our dog...”, there seemed to be consensus between him and Harriet that blood-thinning medication for Gloria would be futile: she’s “got no quality of life”. This encounter could also be described as veering off a pointless pathway. The standard pathway for treating a blood clot would be with blood-thinning medication. However, in this case the prevention of a blood clot is considered pointless or futile (in view of Gloria’s perceived poor quality of life).

However, there are times when such agreement on where to draw the line and break from a pathway is not forthcoming. These decisions can feel more complicated. As consultant Tony says:

An example of a more complex decision would be, for example, a patient with what is perceived to be end-stage organ failure, such as end-stage heart failure, in a discussion regarding resuscitation for the patient who has capacity and in clear consciousness asks us to do everything that we can do,

including making sure we do CPR [cardio-pulmonary resuscitation] and put them on a life-support machine if it comes to that. [Tony, 324-328]

Tony expands on what makes this situation difficult:

Because we would be potentially be subjecting that patient to treatment, to CPR, ventilation, whatever it comes to, that a reasonable body of medical opinion would say is inappropriate, unnecessarily aggressive and futile. [Tony, 329-331]

I ask for clarification on what futile means in this context, which Tony illustrates:

If there isn't a plan for the next stage... if it's a cul-de-sac you're going to, basically, with this. If the heart rhythm comes back to normal and the heart starts pumping again, but the patient is likely to have a similar problem arise imminently again, then you kind of need a way out. And if the road is blocked because we're not able to offer that patient inotropes or organ support, then what is the value in putting that patient and their family through another episode of that if it's predictably gonna end in a similar or even worse condition for the patient to be in at the end of that?

[Tony, 355-361]

Thus if a treatment is not offering a way out, it ceases to be a pathway and becomes a “cul-de-sac”. Rather than simply continuing down a blocked road, Tony suggests a change of direction.

Laura’s mixed feelings about pathways have been supported by Dr Taylor, Harriet, Tony and Gloria’s family. Whilst able to guide Jackie to a declaration of “medically fit for discharge”, pathways have been less satisfactory at other times. Sometimes the situation is complicated and multifactorial and there is no pathway that can say “this is how you fix this” (Dr Taylor). Sometimes the pathway⁴⁶ assumes that lethal conditions should be prevented as much as possible but in reality “you’ve got to die of something” (Dr Taylor). Sometimes the pathway assumes that life should be extended wherever possible whereas in reality a patient’s life may not be considered worth extending if they’ve “got no quality of life” (Bill). In such instances, when following a pathway is seen as futile, the pathway is deemed to be a “cul-de-sac”; the “road is blocked” and “you need a way out” (Tony), prompting a change of approach.

6.3.3 Cul-de-sacs and futility

However, futility is not simply one thing. In what follows, I try to show that futility comes in three forms within this AMS. Futility is, in fact, a set of three *futilities*.

⁴⁶ By ‘pathway’ here I mean to include the pathway-*mindset* that Dr Taylor attributes to doctors and patients.

One person's futile is not the same as another's; one person's pathway may be another person's cul-de-sac. This is illustrated by Tony, in his description of a patient "who asks us to do everything" despite the fact that such treatment, in the eyes of medical professionals, would be "inappropriate, unnecessarily aggressive and futile" [Tony, 331]. Unanimity at times can be hard to come by, resulting in three kinds of situation. In some situations, a pathway can be followed until the patient be declared "medically fit for discharge" (Jackie). In other situations, a pathway can be rejected because the clinical scenario is too complicated or because the pathway is deemed a cul-de-sac. In yet other situations, however, the clinical scenario may prompt *both* the following *and* the rejection of a treatment pathway; what is futile to one party may not be futile in the eyes of another.

This chapter began by considering what a *patient* is and what a *problem* is, within this AMS. This laid some of the groundwork for considering what the *point* is of work within this AMS: *to restore order by addressing problems*. This is enacted by sometimes following pathways and sometimes changing direction when following the pathway is deemed futile. In what follows, I explore the notion of futility a little further, connecting it explicitly with the three kinds of problem described above (*deviation, distress and disruption*).

6.3.3.1 Distress futility

First, I turn attention back to the conversation between Harriet and Gloria's family: Bill and Jenny. A turning point in the discussion ("if it was our dog...") was recognising the futility of life-extending treatment. This futility was not because of any indication that the treatment would be ineffective in re-establishing baseline function and extending life. Rather, this treatment was considered futile because Gloria's *experience* of life would not be helped: "she's got no quality of life" (Bill). Whilst possibly addressing *deviation*, in physiological terms, giving life-extending medication would fail to alleviate Gloria's *distress*, in existential terms.

Let us consider a nurse's perspective on this kind of scenario. Nurse Ryan was speaking with me about when withdrawing treatment might actually be good for someone:

They've got cancer and they're in so much pain. And they are, like, the best thing possibly is for them to die because, if that's what they want. And there's no way they're gonna come back from it. There's no way they're gonna improve. There's no way they're gonna get better. You know, if they're in that much pain then sometimes it is in best interests, yeah. [Ryan, 127-132]

"If they're in that much pain", then extending life may be futile; even if successful at stabilising functional *deviation*, such action would fail to address the problem of *distress*.

Whilst Ryan described dying as possibly “the best thing” for a hypothetical cancer patient, he takes a different approach with regard to a young, suicidal patient called Emily⁴⁷. Ryan had found Emily in the hospital canteen. She had left the ward without permission and was escorted back under the assistance of security personnel. Emily is a teenage girl who has tried repeatedly to end her life and, when admitted, the AMU is her usual ward. In contrast to letting the hypothetical cancer patient die, Ryan is not so approving of letting Emily die. He speaks of what might happen if staff did not intervene:

...then she would end up, yeah, probably dying. It's not what you want, especially for just a young girl as well. [Ryan, 124-125]

Looking after Emily is a team effort; all ward staff seem to be aware of her and the need to keep an eye out for her likely attempt to leave the ward. For example, Sharon is a healthcare assistant who knows Emily well from previous admissions, and has spent hours with her to “make sure she’s not self-harming and that kind of thing” [Sharon, 20]. Sharon is likely a similar age to Emily’s mother. She describes how Emily used to live a different life before a traumatic relationship breakdown:

Before that she was normal. Going to work, going out with her friends, driving her car. [Sharon, 79-80]

Sharon describes the reason for wanting to intervene to treat Emily:

Well just to protect her really, isn't it? She is a young girl. I think that if she got the support that she needs... maybe she could turn her life back around. [Sharon, 97-99]

Emily is a “young girl” with the potential to “turn life back around” and enjoy it again, so treatment is not futile; it is to protect her. The treatment pathway is not seen as a blocked road. Treating Emily, even if against her wishes, has the potential to improve Emily’s *deviation* (from the normal life she used to lead) and possibly her *distress* (so that she could turn her life around and enjoy socialising with others again).

In contrast, the patient with cancer is in pain and “there’s no way they’re gonna improve” (Ryan). “The best thing probably is for them to die” (Ryan). Their road map is different. Their life-extending treatment, like Gloria’s, is futile because they’ve “got no quality of life” (Bill). Thus one kind of futility is an irredeemably poor quality of life, when the problem of *distress* is not going to improve.

6.3.3.2 Deviation futility

I return to the case of Albert Jenkins, (who visits his wife’s grave without fail). Dr Taylor reflects with me afterwards:

⁴⁷ Emily’s stay in hospital will be explored in more detail in Chapter 8 *What’s best*.

My aim for [Mr Jenkins] would be to start to explain to him and the team treating him that this needs a much more holistic, realistic approach and that should be led by him. And that he should be at the centre of it, and not just do what doctors tell him is the 'right' thing. [Dr Taylor, 159-161]

Dr Taylor had crouched low down at Mr Jenkins' bedside, submissively sitting on her heels, as she listened to him tell his story [6c]. In contrast, she shares her approach to deciding about to cardio-pulmonary resuscitation (CPR):

It sounds awful but I'm not sure I go to seek agreement, I go to seek understanding. You know, it's the clinician's, it's a consultant's choice. I can't put people on critical care if it's the wrong thing to do... It's a treatment that we're offering and it's not right to offer a treatment if it's not the right thing to do to somebody... I think responsibly, ethically, morally, that's the right thing. So I don't go to say "let's all sit down and agree this together". I go to say "this is what's happening and this is why, and let's understand the why". [Dr Taylor, 345-352]

Whilst adopting a submissive posture whilst listening to Mr Jenkins tell his story, Dr Taylor adopts a more assertive posture towards making CPR decisions: "it's a consultant's choice". She expands on this with an illustration:

If you are a frail, older person with a downward trajectory of your functional status with lots of co-morbidities, who are deteriorating in hospital with a rising NEWS score [a measure of systemic physiological instability] because of your pneumonia, your COPD [chronic obstructive pulmonary disease], your heart attack, pulmonary oedema, whatever it is, then we know that resuscitation is not going to be a successful exercise, that it's futile and that most of those people are going to die of physiological problems. And the rest we may withdraw because of brain damage. And the few that survive the brief intubation are not gonna make it out of that acute hospital stay. [Dr Taylor, 389-395]

Dr Taylor unpacks what futile means with regard to CPR by asking herself two questions:

It's a treatment where you say "what am I trying to achieve here? Am I just prolonging death?" [Dr Taylor, 414-415]

As Dr Taylor describes, a treatment can be deemed futile even it is wanted by the patient, on the grounds that it will not restore biological function. The problem of baseline deviation cannot be fixed; the therapeutic road is blocked and thus the CPR pathway is deemed a cul-de-sac. Rather than existential distress, here the futility is of a second kind: CPR would fail to improve functional *deviation*.

6.3.3.3 Disruption futility

To identify a third kind of futility, I return now to the situation in which consultant Tony is assessing whether a patient with cancer (Stuart) needs to stay in hospital at a time when “this place is really under strain” [Tony, 137-138] for lack of beds. Tony describes his approach like this:

My decision-making was to decide whether or not to offer the patient the opportunity of going home, essentially. And then I left that decision to him. [Tony, 129-130]

The process of deciding whether to offer the opportunity of going home involved clinical data:

I knew that he wasn't neutropenic. I also knew he felt well in himself. And that his physiological early warning score, (so there's national early warning score calculated on his blood pressure, heart rate, temperature et cetera) was not ringing any alarm bells. It was near normal. [Tony, 124-127]

In addition, this decision-making process involved consideration of other, non-clinical factors:

[Stuart] was very happy to be at home... And he happened to live around the corner from Northside Hospital, and his mum happened to live next-door to him, and he had good social support. So he's a great example of someone who's in the right place if things go wrong. So if he became unwell overnight, you know, he's right next to where he needs to be. And he can ring for help. And he's a sensible chap who's got capacity and coherent and stuff. [Tony, 143-149]

Putting the clinical and other factors together, a decision was reached with the patient in the driving seat:

And he made that decision, I suppose with me and his mum, about going home. [Tony, 149-150]

During interview, I asked Tony to describe how he would have responded if Stuart had desired, even insisted, to be in hospital.

On Wednesday, the way things were, I think I would have gently challenged him about that. [Tony, 156-157]

This challenging involved ascertaining the reason for wanting to stay in hospital:

If the reasons for him wanting to stay in hospital were perhaps less objective and more along the lines of “well, to be honest, erm I've got a relative staying with me who I really dislike and I need to be out the house tonight” or something less kind of clinically relevant, I suppose. Then I would be tempted to say “I'm afraid that is not, you know, it's not a reasonable use of the NHS. For us to keep you in a bed overnight and be your hotel overnight”. Because [pause] the infrastructure of this place is a hugely complex business, and is a hugely costly business. [Tony, 164-171]

Tony expands on this in terms of resource allocation:

If he doesn't like his aunty and they fall out, well, that's not really society's problem. And we don't really need to be ploughing the very finite and stretched resources of the healthcare system into that personal issue that he has. [Tony, 194-196]

To Tony, keeping Stuart in hospital is not an acceptable pathway because it would cause *disruption* to the healthcare organisation. Sensing the futility of this, Tony describes a psychological gear shift from 'leaving the decision to Stuart' to "gently challenging him".

Dr Taylor also encountered a patient who was reluctant to go home during her ward round:

Dr Taylor crouched beside the next patient, Brandon, who was a man with grey hair, sat on his bed in his own clothes with his arms crossed. They spoke about his reason for admission, and how much better he feels now. Dr Taylor mentioned that, following pneumonia, it takes many weeks to recover strength, emphasising the need for rest. At this moment he became tearful and said he's been having a lot of "trouble with the neighbours". He described it as escalating recently, and now the "police are involved". [6c]

Brandon raised this issue with a troubled, downcast expression once the plan for discharge was mentioned. As it happened, he did not put up resistance to going home other than describing this reluctance to be near to his neighbours. I explored this further with Dr Taylor, supposing Brandon had insisted on staying in hospital:

"Before, I would have just sent him home. But now I wouldn't. He'd only re-present to A&E, which creates a load more work. So I tend to just let them stay another night." [6c]

Where Tony would have challenged Stuart to persuade him to go home, Dr Taylor describes conceding. Both, however, share a similar motivation: to avoid overloading the hospital. Dr Taylor describes how it feels to negotiate this:

I think this is really hard, isn't it?... And I think it's a real balance between how much you force somebody out and say "no, you are going." [Dr Taylor, 480-486]

Dr Taylor gives a pragmatic justification for prolonging admission:

I suspect you'd have bed manager and management of the Trust saying "he just has to go". But I suppose the counter-argument to that is "well if he comes back later, he gets another X-ray, another set of bloods, another A&E clerk, another 8-hour trolley wait, then he comes in, another post-take

ward round. And actually, if we keep him at Middleton Hospital, he'll go home tomorrow. [Dr Taylor, 511-515]

To Tony, keeping a patient in to be their “hotel overnight” is futile because it is expending finite resources on something which is not “society’s problem”, so a change of approach⁴⁸ to “challenging” is seen as appropriate. To Dr Taylor, forcing someone to go home is futile because it “creates a load more work”, so a change of approach to conceding is appropriate. To both, the indication that the pathway is in fact a cul-de-sac is futility of a third kind: the futility of a course of action which does not ease the workload of the hospital; it fails to address the problem of organisational *disruption*.

6.4 Conclusion: goals and futility

In this chapter, I presented my ethnographic and interview findings in relation to the theme of restoring order. This theme has featured three variations: the *patient*, the *problem* and the *point*. Each of the three variations has not been as simple as it first seemed.

An AMS is a place where patients are admitted, 30-at-a-time. However, the category of ‘patient’ is not simple. A patient can be construed in a variety of ways. For instance, a patient can be construed *experientially* as someone on a journey from doors to doors. A patient can be construed *organisationally* as a named row on the whiteboard which is a few tasks away from discharge. A patient can be construed *professionally* as a series of component parts with which different uniformed people are concerned. These different construals also reflect the environment of an AMS, which is characterised by pressure and pace.

An AMS is a workplace where problems are addressed and these problems are acute medical problems. Addressing these problems could be described as *restoring order*. However, like ‘patient’, ‘problem’ is not a simple category. I encountered and presented three kinds of problem. The single aim of restoring order can thus be described as a set of three goals: to address the problems of *deviation*, *distress* and *disruption*.

The point of an AMS, to restore order, is achieved by a range of courses of action. Sometimes these courses of action take the form of following a pathway; at other times a pathway is seen as a cul-de-sac because the course of action it endorses is futile. However, the category of ‘futility’ is complex. A course of action is deemed futile insofar as it fails to address a problem (and thereby fails to restore order). Given there are three kinds of problem to be addressed within the AMS, there are thus three kinds of futility: *deviation futility*, *distress futility* and *disruption futility*.

In a sense, then, my first impressions of Middleton Hospital were an adumbration of what I would encounter within the world of the AMS. The hospital was a place where there are clear, simple categories: staff and

⁴⁸ This change of approach is similar to what I describe as a psychological gear change in Chapter 8.

public, healthy and sick. However, the relation between these categories was complex, even paradoxical: people are smoking outside yet the hospital is purportedly smoke-free. This relation of simple and complex would prove a persistent feature of my time in the field. This will also become evident in the next chapter, in which I explore how people work together within the AMS.

Chapter 7. Working Together

In the previous chapter, I described the aim of the work of an AMS as to restore order. Order is restored by addressing three kinds of problem: deviation, distress and disruption. A course of action is deemed futile when it fails to address one of these problems. In Chapter 8, I will present an account of how people within an AMS figure out what course of action is best and the values that are involved in this process.

In this chapter, I focus on the relationships between people within an AMS as they work together to alleviate needs⁴⁹. I present this in four steps. Firstly, I illustrate the contrasting kinds of interaction within the AMS. Secondly, I describe different ways in which people interact in harmony within the AMS. Thirdly, I describe the opposite: different ways in which people interact in cacophony within the AMS. The fourth and final step is a metaphorical one. I portray the way people interact within the AMS as a peculiar kind of dance.

7.1 Culture of contrasts

7.1.1 Morning huddle

“Huddle!” shouts Emma, the nurse in charge for today, projecting her voice through the doorway. “Huddle!”, she repeats into the next doorway. She has a stern, frowning expression, and is walking briskly with a sense of urgency about her, before coming to a standstill near the central work station. Her standstill is not a case of standing still, however. She agitatedly stands on the spot, changing weight between feet, looking around and glancing up at the wall clock intermittently, which is positioned prominently at the centre of the central wall beside the central work station. Emma stands opposite the clock and seems to become more anxious with each look at it [1a, 4d].

The team emerges out of various sections of the ward to form a circle. Apart from the nervous gap either side of Emma, staff stand side by side and evenly spaced. The heavy, sound-proof double doors to the patient areas are closed so that the announcements can begin. This is staff time now.

“We’re understaffed today; can we please be strict on visiting hours. I don’t want anyone staying over visiting hours today.” [4d]

After a couple of notices, staff introduce themselves to the rest of the staff in the huddle circle, proceeding clockwise. There is a uniform structure to it: state your name, role and shift duration. This is usually done without verbs in shorthand: “Mark, staff nurse, long day” [1a].

The huddle circle is large, featuring 16 people, and for some it is the only time in their shift that they will be standing upright and still. The strict formality of this interaction, the uniformity of staff members in the circle

⁴⁹ I describe the relation between needs and problems in the next chapter (see: Chapter 8 *Problems and needs*).

and the exclusion of patients give a sense of togetherness. As such, 'huddle', with its connotations of a sports manager gathering, organising and uniting his or her team, seems a fitting term.

7.1.2 Afternoon visiting

After lunch, senior nurse Victoria is standing at the notes trolley. Like Emma during the huddle, she also stands agitatedly, shifting weight between her feet.

Victoria was tall and stocky, and had trainers for footwear... She stood centrally along the side of the trolley where notes would be drawn out, with her back to the central work station. This way, she could look along the main corridor to the ward entrance as well as easily look sideways into a patient's cubicle, all of which were visible from her standpoint. [6b]

Where Emma had had her back to the main entrance in order to face the main work station, Victoria has her back to the main work station in order to face the main entrance. Where Emma was agitatedly waiting to speak to staff, Victoria is agitatedly waiting to be spoken to by relatives:

I'm checking through the plans from the doctors and making sure all me notes are here", tapping on a red folder of patient notes which was resting under her left hand on the trolley as if she was guarding it in some way. "It's almost visiting time, see, and that's when all the relatives will be askin'." [6b]

Visiting hours officially start in ten minutes' time, at 2:30pm. In the meantime, straight ahead of Victoria can be seen the visitors to the ward, who are also standing still, preparing for action:

Outside the ward entrance doors could be seen a small crowd of visitors, who lined up along the wall, either side of the doors. At 2:30pm, a member of staff left the ward. Before the door closed, one visitor held the door and entered, and then the rest quickly followed. The visitors walked one- or two-at-a-time down the corridor. [6b]

The main entrance double doors have a glass inset, through which the visitors can be seen gathering and intermittently peering through. As the clock strikes 2:30pm, their quiet standstill becomes a linear march; exclusion converts to inclusion, inaction converts to action:

Having previously found this unremarkable when I worked as a clinician, I now found this slightly amusing: such obedience to the 'visiting hours' rule, such an orderly march down the corridor, prompted by the clock striking such a precise time; this reminded me of a military march, which felt like an absurd comparison, given that we are talking about family members who are coming to comfort their loved ones. Seeing my amusement, Victoria remarked to me "the floodgates have opened!" [6b]

Now it is the nursing staff and ward clerk who become quiet and motionless. The visitors walk onto the ward briskly, hands still wet from the alcohol handwash dispensed at the entrance. Visitors are friends and relatives of patients, wearing their own clothes, talking informally and without introducing themselves first. Victoria stands with her hand still resting on the pile of red files of medical notes, as if expecting a question from any visitor about any patient at any moment [6b].

The opening of the “floodgates” strikes me as a stark contrast to the calling of the huddle. Where the huddle separated patients and staff in different places (and visitors in no place), visiting time brings patients, staff and visitors together in the same place. Where the huddle was formalised by hierarchy, ritual and codified language, visiting time is relatively unstructured, unpredictable and conversational.

In the AMS, there is a time for huddling and a time for visiting. Whilst both these moments bring people together, the manner in which they do so are remarkably different. As such, the culture of the AMS is one which involves contrasting forms of interaction. I will explore some of these varieties within two categories: *harmony* and *cacophony*.

7.2 Harmony

I categorise an interaction as harmonious if the relationship does not overtly frustrate the needs of an involved party. This loose definition will become clearer after a consideration of a range of different harmonious interactions within the AMS.

7.2.1 Relying

Fergus the pharmacist steps out of a patient’s cubicle clutching a file to his chest, followed by a trainee pharmacist. As they search for an available computer to use, Fergus greets me and says they have “just done a medication review with bed 3” which was complicated because “she’s an ITU step-down, renal patient”, he says with a smile.

In cubicle 3 is woman in her 70s called Maureen, who is seated on her armchair beside the window, where she had been sat whilst the pharmacist was with her. The room feels quiet because her bedside TV is off, probably turned off during her conversation with Fergus. She also describes her medication issues as complicated because of her kidney problems (including a kidney transplant). I ask her how the medication changes happened:

Basically “we’re not giving you this, we’re not giving you this, we’re not giving you this, and you will take that.” And I just do it. Because they’ve been in touch with the Lighthouse [regional specialist hospital] so I know that the renal team are the ones that are sorta like leading the way. So and I mean

they're the ones I rely on to keep me fit and well. So I was quite happy to go along with things.

[Maureen, 88-91]

During our conversation, she spoke fondly of the renal medicine team at Lighthouse. She continued:

I trust the Lighthouse and I trust that- I mean, they are the specialists in the kidney unit. So, if I can't trust them to tell me the right drugs to take, is there any point in me going to the doctor's at all?

You've gotta put your faith in someone. [Maureen, 116-118]

Maureen's trust in the Lighthouse is related to knowledge:

Well I can't tell how my rejection tablets are doing. And the Lighthouse only know because I get the blood tests. And they can tell from that what they need to up and down. [Maureen, 127-128]

Maureen is content to do as she is told by Fergus and others here in the AMS because she knows they are being led by the renal team at Lighthouse, whom she trusts because they have the expertise to know what she needs. Her trust in expertise yields reliance on medical advice.

Brian is another patient who spoke to me about trust, and is also sat in his armchair beside the window. Compared to the drilling, moving and hammering sounds of the construction work outside, his cubicle felt peaceful and he seemed pleased as he finished giving an update to his wife over his mobile phone. Brian describes the doctors as facing a "difficult balance" [8b]: Brian has an injured, bleeding spleen as well as a recent blood clot on the lungs. The former needs the avoidance of blood-thinning medication; the latter needs the administration of blood-thinning medication. I asked how he is going to approach this difficult situation:

"I trust the doctors. They know what they're doing. I know my body, but they know the medications 'n that, ya na?" [8b]

An hour later, the consultant, Charles, returned with his junior doctor colleague, Laura, to see Brian:

By this stage, Brian was lying on his bed. After a brief greeting and introduction, Charles then summarised the situation: "so your wife's going to administer the tinzaparin. Your chest's better; kidneys are better; diarrhoea's better. I think we can send you home today." The structure of this summary sounded to me like it matched the 'problem list' of a medical notes entry, and what Laura is likely to write down. Brian appeared delighted to hear this and thanked them both, as they promised to sort out the final "paperwork", which presumably meant the discharge letter and prescription for take-out medications. [8b]

Like Maureen, Brian trusts the doctors to make a plan for him to follow. He expands on this trust during interview:

I trust them 'cause, you na, past experiences. And the fact that, ya na, they're the experts and I'm not, ya na? So... yeah, not a problem there like... Well obviously there's a training structure thing where they have to go through, ya know, it's not just any Tom Dick or Harry that becomes a doctor. It's a profession and I think it's not just a profession, it's a – what's the word- a vocation, ya na? And I think they're all interested in their job and I know they work long hours and all this 'n that 'n the other but you know, the better the thing for them is to get the patient better, ya na? That's their focus. So it's in their interests to be as, ya na, up to date with all the procedures and things, ya na? So... ya na, you don't become a hospital doctor without being, ya na, clever. [Brian, 49-59]

This perceived cleverness of doctors translates to trust:

If it's a medical thing you wanna trust the doctors. Because they know the facts 'n figures. They've got all the data, all the experience. [Brian, 74-75]

Brian's trust in doctors cannot be reduced to mere cleverness, however:

They ooze confidence, ya na? And that gives me confidence, ya na... it's the whole lifestyle isn't it? It's dedicating, that's what it is. It's dedication to their job, ya na? And it's not gonna be what a life you get, ya na? In the hours I do in my job, I do it the best of me ability 'n I'm dedicated when I'm there. But when I go home I switch off, ya na? These people are working away after, ya na, daft shifts... So they have to be dedicated to do that. [Brian, 61-68]

To Brian, the difficult balance between avoiding blood-thinning medication and administering blood-thinning medication is best managed by doctors, whose cleverness, confidence and dedication has established his trust. His respect *for* them and his trust *in* them yields his reliance *on* them.

7.2.2 Complying

Finlay is a tall, thin Scotsman who has been admitted to the AMS after taking an overdose of paracetamol which left him in pain. Like Brian, Finlay displayed, and spoke of, a level of trust in professional expertise. Having been seen by the doctors on the morning ward round, he is considered 'medically fit for discharge' on the condition that the psychiatry liaison team agree with this [7c]. Today the psychiatry liaison team consists of a doctor and a psychiatric nurse who are currently speaking with Finlay in the quiet room:

Finlay was sat in the 2-person chair in the corner of the room, whilst the two women from the psych liaison team sat opposite him. One of them, Meghan, sat confidently with her legs crossed and back upright, and asked the majority of questions, which Finlay was answering. The other of psych liaison,

Amber, sat cross-legged on her chair but was hunched over her notes; she was making minimal eye contact but instead was making notes to each of Finlay's answers. [7c]

On questioning, Finlay reluctantly recounted the order of events before his overdose: after an argument with his mother and brother, he left his dog with his brother, went home, left the door unlocked, overdosed on paracetamol, jumped in the car and drove away. Having responded to these initial questions, Meghan continued to probe further:

Does he often argue with his family? Has he ever overdosed before? Was this planned? Are his family searching for a 'missing person'? ...Meghan continued, asking questions about Finlay's living circumstances, his dog, his relationship with his brother, his work as a street sweeper. She then asked about any "mental health history". [7c]

Finlay felt embarrassed talking about his overdose, describing his reason for being here as "'cause I done somethin' stupid" [Finlay, 69]. This was reflected in the way his conversation with the psychiatry liaison team proceeded:

Meghan directed the conversation. Finlay seemed content to answer the questions she asked, but did not seem to be particularly concerned, as if he was really just doing this for her. He answered in a matter-of-fact way, without expanding. At times he seemed surprised that she was asking so many questions and tried to wrap things up by phrases such as "that's it really. Simple as that." [7c]

It occurred to me that Finlay may not have wanted to have this interview to begin with. He recounted how this interview was arranged:

Just one of the doctors decided... just said "somebody's coming in t' assess you" [Finlay, 73-77]

I asked Finlay if he had been involved in any decisions during his hospital stay:

Aye, whether you drink tea or coffee [laughs]! I think the doctors and nurses ken what they're doin'... they ken what they're doin', so leave it to th' experts I say... You might know or think you've got a clue but, at th' end of the day, they ken what they're- they've done it for long enough to know what they're doin'. [Finlay, 83-93]

This deferential attitude perhaps contributed to the tone of the interaction between Finlay and the psychiatry liaison team:

Then Meghan asserted "so you're to going contact your family, contact your work, contact the GP if you need to or the Crisis Team if it's urgent. Okay?" She counted these points out on her fingers, and raised her eyes and voice as she asked "okay?" I noticed the tone that she used reminded me of a

teacher at school towards a naughty pupil, who was to promise good behaviour in response to her correction. Finlay responded with a nod and “Right.” [7c]

Like Maureen and Brian, Finlay also trusts the expertise of medical staff. This results in his “leave it to th’ experts” attitude, reflected in a passive, deferential role in his interaction with the psychiatry liaison team.

This whole interaction struck me as both tragic and comic. Tragic, in that this man has had an awful time and feels a fool. But nevertheless there was something comic about the conversation, which I found hard to pin down. Perhaps it was the reduction of a complex, messy situation into a simple process, a bit like a proforma. Perhaps it was that the doctor acted like she was doing this for the patient’s sake, and the patient acted like he was really just doing this for the doctor’s sake!

[7c]

Given Finlay’s trust in the expertise of healthcare staff, it was unclear whether he was *relying* on them to meet his needs or whether he was *complying* with them to meet other needs, such as the needs of the psychiatry liaison team to complete their enquiry. When a patient speaks with the psychiatry team, are other needs involved besides the patient’s health needs?

I spoke with the psychiatric nurse, Amber, immediately after this interaction with Finlay in the quiet room. Amber had documented a summary of the conversation and spoke with me about the reason the psychiatry liaison team ask Finlay so many questions:

A lot of kind of the questions what we ask about sort of family- personal history and family history do bear some sort of significance into sort of current risk. It does kind of feed into current risk. Which is why that we ask the questions. It’s not just that we’re trying to be nosey and find out more about what’s going on [smiles]. [Amber, 12-16]

She unpacks what kind of “risk” they are trying to assess:

Risk of further acts of suicide and self-harm. Risks of further deterioration in mental state... So that’s kind of the picture we try and get. And sort of the information we sift out is to kinda sort of look mostly around risk and capture. Is this person at risk of harming themselves, harming others? [Amber, 34-45]

The language used here is reminiscent of the legal framework within which the psychiatry liaison team operates. Sections 2 and 3 of the Mental Health Act (2007) permit the involuntary admission of a patient for assessment and treatment, on the condition that a deterioration in mental state leaves the patient at risk of harming themselves or harming others (Pattinson, 2014: 182–183).

Amber says:

The gentleman that we were seeing was unknown to our service. So, when somebody is unknown, we have to do a, you know, a full history of somebody? And that includes just finding out a bit more about, you know, where we're going, where they grew up... what kind of childhood they had, what kind of family dynamics is there going on. Is there any family history of psychiatric, sort of, mental illness or physical illness. And again a lot of that is because that kind of informs some of the risk, current risk and things, in families. [Amber, 5-10]

A “full history” here is performed by the psychiatry liaison team in order to gain information about risk. There is a hint here that it is not only Finlay’s needs that are in play, given that it is “we”, the psychiatry liaison service, who “have to do” it. This sense of obligation may be a professional obligation, in order to have done a good job; it may also be a legal obligation, in order to have abided by the guidance of the Mental Health Act to which she alluded earlier.

Alison is another member of the psychiatry liaison team. She is an experienced psychiatric nurse who has been doing the job for many years. Having been speaking with a young woman who had also taken a paracetamol overdose, she described the reason for this conversation was to assess the “safety of getting her home” [Alison, 39].

Is she considering taking a further overdose? Has she got any imminent thoughts of self-harm or suicide? And she doesn't. So those would indicate that at the moment it's safe to send her home... [Alison, 46-48]

Alison describes a situation in which the risks are suitably low for discharge from hospital:

A lot of people still have ongoing suicidal thoughts and we send them home but that's because often there's evidence of some forward planning so they're not imminently thinking about doing something it's just that they live with chronic suicidal thoughts... if they're willing to work with their regular care team about those issues then that would be something that we'd be happy then to send that person home if there's evidence of some forward planning. [Alison, 51-57]

Forward planning [making arrangements for future activities] and co-operation with a regular care team render the risk low enough for discharge from hospital to be deemed safe. Notably, it is the psychiatry liaison team who must deem it safe and who have a need to be “happy” with the plan.

If we felt that somebody was high risk and we didn't feel happy to send them home and discharge them, we would make a referral to Crisis Team. [Alison, 126-128]

Sometimes a different assessment can bring out different things and there might be that the patient didn't give us any sort of safety things that made us feel happy about letting them go... [Alison, 139-140]

Like Amber, the safety of the patient features prominently in Alison's mind. In addition to the need of the patient to be safe at home, there is a hint of an additional need here: *she* needs to be happy with her decision to 'let them go' or else she would perform the less risky act of referring to Crisis Team. Thus there is ambiguity here as to whether it is the patient or the psychiatry liaison team whose need to be safe is being addressed.

The stories that people have to tell are quite emotional and can be very upsetting. And there are some circumstances where, you know, we've all felt it was a really difficult assessment or that you've been a bit torn with what to do with somebody, unsure about what to do with somebody, whether you do feel okay sending somebody home or what's the best place to signpost somebody to. [Alison, 150-155]

The visceral terms in which Alison describes her response to patients indicate that the concerns of the patient and the concerns of the psychiatry liaison team are not easily separated. Given a patient's trust in the psychiatry team and their concern for the patient, the needs of both parties appear entangled. Patients *rely* on the professionals to be trustworthy and they *comply* with their questions and advice; the professionals *rely* on the patients to be truthful and they *comply* with relevant professional and legal standards.

With regard to Maureen and Brian, the needs of the patient seem centre stage and professionals are entrusted with providing sound advice. With regard to Finlay, there is an indication that the needs of the professionals may also be involved in an unclear, entangled way. I now present some interactions with nursing staff in order to further characterise what the needs of members of staff might be.

7.2.3 Resisting

Sarah is a staff nurse who has spent the morning busily to-ing and fro-ing between patient cubicles and the lab room, where medications are prepared. She is barely 5 foot tall but manages to scurry across the ward rapidly with the help of her sporty black trainers. Around 4 hours into her shift, I find her standing still. Her section of the ward, "section one", feels somehow quieter. There is no longer the sound of patient bedside buzzers, beeping infusion pumps, ward clerk telephone conversation or the squeaking of the cleaner's oil-deprived bucket.

Sarah, an alcohol nurse and a healthcare assistant are gathered around the notes trolley, leaning in with their backs facing outward. Whilst looking down at their respective pieces of paper (and the healthcare assistant without a piece of paper but looking down anyway), they are chatting about baby names, nurseries

and child care. The ward clerk, Jane, is within ear shot and joins in intermittently as she piles up folders on the floor beside her desk. I find something amusing about this scene: it would be impossible to guess the topic of conversation if someone, such as the modern matron or Trust management, were to peer into the ward from the main entrance.

Sarah explains to me that she is completing all of her “routine documentation”, which consists of “breakfasts, washes, toileting and any assistance required” [3c]. She states this with a tone that suggests it is uninteresting work and so I ask her why she does it. Whom is she writing for?

“Management really. It’s just in case there are any problems. Covering my back basically” [3c]

Shortly afterwards, a new patient is wheeled into a cubicle of Sarah’s section by porters. Sarah announces to herself “right, better do the admission”, as she picks up a proforma. Turning to me for a second, she points to the proforma and exclaims with a sigh “look, so many boxes!” [3c]. Detecting a note of reluctance to complete such a proforma, I ask Sarah why she is completing this form:

“Covering my back again! ...there’s more and more covering your back. So many forms now!” [3c]

As Sarah’s black trainers are kicked into action again, I am left wondering in what way nurses feel the need to cover their back from “management... in case there are problems”. Sarah’s colleague, Rachel, is an experienced nurse who helps to shed light on this through her interaction with Nick.

Nick is a new consultant who is about to return a phone call to bed management, who have asked to know how soon beds on the ward will become available for new admissions. Rachel is seated close by as Nick picks up a telephone handset at the central workstation.

Picking up on his slightly nervous demeanour and extensive preparation before the phone call, Rachel sought to encourage him: “just smile when they ask you, but at the end of the day you’ve gotta do what you think is right.” [9c]

She clarified the reason a defensive approach is needed:

Bed management, right, what gets me about them is that all they care is about bums on beds. Or bums off beds more like!” She chuckled for a moment, as Nick affirmed this. Rachel continued: “if owt [anything] goes wrong it’s your registration, that’s what you’ve gotta remember. It’s your registration that’s on the line.” She seemed to grow in emotional intensity as she described this, as if she had had bad experiences of struggling with bed management in the past. [9c]

Rachel is aware of her vulnerability as a professional; she fears she may lose her licence to practise as a nurse “if owt goes wrong”. The organisation’s need for beds must, from Rachel’s point of view, be balanced against the professional’s need to practise safely.

On one occasion Rachel had adopted a similar posture to how Sarah had appeared earlier: in the same section of the ward, Rachel was gathered with two other colleagues around the notes trolley, leaning forward, with their backs exposed outwards. They were discussing a trust policy which had recently been taped to the surface of the trolley. Rachel explained to me that this is a “falls policy” [3b], instructing what level of vigilance is required by the nurse for patients with different levels of falls risk. One level of vigilance was described as ‘within line of sight using cohorting’. She explained to me what that means:

If you’ve got two patients who need watching, you put them both together so that you can watch them both, and that’s your cohort. But obviously if you go in to help one, you can’t keep an eye on the other one. So he could fall and it’s not your fault, but they’d say the patient weren’t line of sight. So it’s just ridiculous, it’s not practical, and I tell’d them that.” [3b]

Rachel thus identifies with Sarah’s felt need to ‘cover her back’, and she recognises unsafe discharges (which risk her professional registration) and impossible policies as two examples of situations in which she is aware of her vulnerability. Using paperwork to ‘cover her back’ is a means of Rachel ensuring her professional needs are recognised, despite the pressure of the situation.

Besides management, Rachel identifies an additional source of her vulnerability. During night shift at 11:30pm, Rachel and a colleague were again gathered around the notes trolley, leaning forward, in backs-exposed position. They seemed anxious and Rachel explained why:

“They’re coming thick and fast at the minute. Had 4 patients in 10 minutes! ...But we haven’t got any more beds.” [2a]

She identifies an additional stressor:

“Plus I’ve got a horrible patient in bed 8. He’s proper horrible... He’s withdrawing from alcohol, but he’s also really scary. He’s got the blind down now [points] and I’m like ‘I don’t want to go in there. He’s so intimidating’”. The healthcare assistant, still seated a few feet away, joined in: “he is very intimidating. And big. Aggressive. He’s already threatened us once.” [2a]

Rachel highlighted that the physically intimidating patient is ex-military and as a result she feels extremely vulnerable: “I’m not going in; I’m terrified!” [2a].

As Rachel said this, Rosemary approached to comfort her. Rosemary is an experienced staff nurse who works bank shifts on this ward and at other hospitals. She shared with me immediately afterwards that it is moments like this that make her want to leave nursing:

I'm gonna have to leave nursing altogether. I don't enjoy it at all. And it upsets us. It stresses us out... I could just come and sit in the toilet, and have a good cry. Because you just can't do your job. And it's people shouting for their tablets, shouting for- and you just can't because your workload's so heavy.

[Rosemary, 24-30]

Speaking in general about the vulnerability of nurses:

Lots of violence. And relatives are also quite aggressive and violent with you sometimes as well. Rude. You know what I mean? I think we're easy targets. [Rosemary, 138-140]

As Sarah, Rachel and Rosemary have shown, nurses also have needs. Their felt vulnerability reflects their risk of losing their professional licence, risk of reprimand from hospital management and risk of aggression from patients and relatives. The gathering of nursing staff around the notes trolley, exposing their backs as they complete documentation, could thus also be read figuratively; nurses complete pieces of paper in order to 'cover their backs'. As nurses with registrations to protect, documenting pertinent details of the situation is a means of self-defence; it ensures their professional needs are met.

It could be argued that such defensiveness does not appear particularly harmonious. Nevertheless I have categorised these interactions as harmonious because, whilst 'covering your back' is a form of resistance, it is done to help protect a nurse's registration. Whilst Rachel herself may be understandably and overtly frustrated, her professional *needs* are not overtly frustrated. There are some instances in which needs are more overtly frustrated, which will be discussed below (see: *Cacophony*). Before turning to consider cacophonous interactions within the AMS, I pause to reflect on the notion of *needs* and what kinds of need there are. Specifically, *whose* are the needs?

7.2.4 Whose needs?

As has been shown, many patients exhibit trust in the expertise of professionals. Maureen pointed out that "you've gotta put your faith in someone". As Finlay said: "they ken what they're doin', so leave it to th' experts I say". This trust is based on cleverness and dedication, according to Brian. The deferential attitude that accompanies this trust at times can introduce ambiguity: it is unclear whether patients such as Finlay are *relying* on professionals in order to meet his needs or *complying* in order to meet the professionals' own needs.

My interpretation of the psychiatry team identifies their need to be 'happy' with the degree of risk associated with a decision and a need to be acting in accordance with professional and legal guidance. This suggestion of a professional's need is made more explicit by nurses such as Sarah, Rachel and Rosemary, who feel vulnerable to reprimand and patient aggression. Gathered around the notes trolley with backs exposed but pen in hand, nurses exhibit defensive behaviour as a means of resisting the threat to their professional registration.

Within an AMS, then, whose needs are being met? As we have seen, this is not a straightforward question to answer; any answer is ambiguous because there appears to be a multiplicity of needs going on simultaneously between patients and healthcare professionals. This ambiguity is exemplified by a routine action during a doctor's ward round in the AMS: the knock at the door.

7.2.4.1 *The knock at the door*

Dr Morrison, the consultant on this evening, has been building up to knocking on the next patient's door for 25 minutes:

Dr Morrison was standing at a notes trolley, sifting through the preceding entries in the red folder of medical notes, and writing a bullet-point summary on the post-take ward round page, which has a box for the consultant to sign at the bottom. She stopped to check the patient's "obs" [observations] on her handset. She mostly continued in silence until she came across something surprising: the patient is taking a tablet called 'clopidogrel'. "Why are they on clopidogrel? There's no mention of-" Her speech tailed off as she again sifted back through the previous notes entries to clarify previous medical diagnoses that this patient had received. [4b]

She then suffered a series of urgent interruptions: a phone call from A&E about another patient, then documenting this telephone conversation, a phone call from psychiatry liaison team, then documenting that telephone conversation, followed by a series of alert notifications on her hospital handset. After this:

As Dr Morrison walked along the corridor to resume documenting, the ward clerk approached and asked loudly: "have you had anything to do with the patient in 26?", to which Dr Morrison replied: "ask one of the juniors." Before getting to the central work station, she noticed an elderly patient losing her balance as she walked. Dr Morrison came to her side quickly and just caught her to break the patient's fall. With a sigh, she finally sat down at the central work station, where the red folder of medical notes remained open, and said aloud "Right, better carry on or I'll never get this done." [4b]

Dr Morrison was then interrupted by the ward sister who was asking about another patient. She wrote a few words before having to leave to attend the on-call handover meeting down the corridor. Upon her return, with a tone of rushed exasperation, she vocalised a mental list of the issues to assess during this consultation:

“AKI [acute kidney injury], sepsis, vomiting, ketosis, from critical care” [4b]

Dr Morrison knocked on the door with her right hand whilst opening it with her left, describing her reason for visiting as “to see how you’re getting on” [4b].

Whereas in a General Practice surgery or an out-patient clinic the patient walks to the doctor’s room and knocks, in the AMS these roles are reversed; the consultant knocks on the door of the patient’s room. I am used to a knock on the door signifying a request for permission to enter, which is granted or denied by the person on the interior. However, here there is no pause for permission to be ascertained. A knock on the door is justified by the vocalised list of clinical needs to address, but also enacted briskly according to the needs of Dr Morrison to get on with seeing the next patient without further delay. As such, the routine of knocking-on-entering captures something of the ambiguous multiplicity of needs interacting in the AMS: the *patient* needs to see the doctor in order to get on, and the *doctor* needs to get on with seeing the patient. Arguably, there is a third set of needs in play here that so far is only implicit: the needs of the *hospital*.

Dr Morrison’s consultant colleague, Dr Williams, was walking quickly out of the door of a patient’s cubicle during his morning ward round. Still rubbing his hands with alcohol gel, he held the door open with his foot to confirm the plan with Sophie, his accompanying junior doctor. Dr Williams, like staff nurse Sarah, is wearing sporty trainers and puts them to good use as he walks briskly from one place to the next, clearly eager to get on with the ward round quickly:

If you can rattle through quickly then you allow time for those patients where you need to stop and spend 20 even 30 minutes with them. You know, a standard COPD [chronic obstructive pulmonary disease] exacerbation you can see in 2-3 minutes... You can’t spend 20-30 minutes on each one or you’re talking about 10-hour ward rounds! [leaning over trolley where Sophie has opened another red folder of medical notes] Right, who’s next? [4d]

The disruption that would be caused by “ten-hour ward rounds” is something that evidently could not be entertained in an AMS. As such, there is a need to “rattle through”. Whose need is this? It is a need which considers ‘time’ a limited resource which needs to be allocated effectively, appreciating the patients collectively and the ward round as a whole. The need is thus a collective need: the hospital needs the ward round to be quick to prevent organisational *disruption*.

As fellow consultant, Nick, puts it:

“being really thorough and going into depth with one patient might reduce risk for that one patient, but then there’s a knock-on risk for the patient load, the rest of the department. You’re not just managing one patient; you’re managing a department... It’s a real source of stress that I think you feel most when you’re a consultant.” [8a]

Thus perhaps Dr Morrison’s sense of frustrated urgency, which warrants the hasty entrance to finally see the next patient, is as a result of her duty to not just manage the patient but manage the department. Like Dr Williams and Nick, she embodies the need of the *hospital* to maintain procedural efficiency.

7.2.4.2 The transfer of needs

During another busy ward round, a phlebotomist (Brenda) arrives with her trolley of equipment in order to take some blood tests from a series of patients: a ‘ward round’ of her own. She is wearing white, like laboratory staff. Brenda picks up a pile of printed requests beside the ward printer and sets to work. Evidently, she is not well acquainted with the patients she sees, as she consults the whiteboard in order to locate them. Like Dr Morrison, she knocks on entering:

“I’ve just come to get a blood sample from you...” [1b]

It strikes me that the phlebotomist’s introduction is purely functional, without exchanging names or conversation regarding the patient’s illness. The patient puts down her magazine. There is quiet for 2-3 minutes whilst the blood samples are collected. With the ‘ping’ of a released tourniquet and the clunk of blood sample vials placed on her plastic trolley, Brenda’s work is done. As she reverses out her trolley, she smiles to the patient and says “Thank you!”, to which the patient replies “alright” and returns to her magazine.

This mundane, routine interaction immediately struck me as surprising. As I reflected at the time:

Who is doing whom a service? [1b]

According to the doctor’s printed request, the patient is the one who needs a blood test. The phlebotomist arrives to provide help to meet that need. However, this interaction sounded as though the phlebotomist was doing the needing and the patient was doing the helping, by allowing the Brenda in, suspending her leisure activity and donating a blood sample.

7.2.4.3 The plurality of needs

Let us retrace our steps briefly. Patients arrive at the A&E Department in need of healthcare. Patients arrive in the AMS having had their need affirmed by the doctor in A&E. Once in the AMS, however, who it is that is in need becomes less clear. The plurality of needs can make it ambiguous whose needs are being met in a given encounter. In some encounters, the needs of staff are more prominent, such as nurse Rachel who is

afraid of her intimidating patient and phlebotomist Brenda who apologises for interrupting her patient's leisure time.

Thus patients have needs and professionals have needs. A third source of needs is also evident in the data, however. Dr Morrison's knock on the door was rushed because she had a whole ward of patients to get through. As consultant Nick comments, "You're not just managing one patient; you're managing a department" [8a]. The hospital needs the department to maintain effective patient flow in order to prevent a bed crisis. This need of the organisation is also evident in the vulnerability expressed by Rachel. The "thick and fast" patient admission rate as well as the policies which are "just ridiculous" and "not practical" (Rachel) are a reflection of the hospital's need to maximise patient flow through the AMS and to function on a stretched workforce. Patients have needs. Professionals have needs. Even *hospitals* have needs.

However, such needs are not easily separable. Indeed, the very fact that participants find managing multiple needs to be such a source of "stress" (Nick) is an indication that the needs are not independent but entangled, pulling a person in multiple directions at once. A single person can embody a plurality of needs. For instance, Rachel (as a person) feels intimidated by an aggressive patient, whilst (as a professional) feeling her professional registration is under threat unless she covers her back, whilst (as an employee of the organisation) feeling obliged to admit and discharge patients rapidly. It is perhaps more accurate to speak not of sources or locations of need (patient, professional, hospital) but rather to speak of different kinds of need: *personal* need, *professional* need and *organisational* need.

In what follows, I present an account of how these three kinds of need can contrast in ways that are not harmonious; one kind of need clashes with another and so the interaction could be described as *cacophonous*.

7.3 Cacophony

7.3.1 Organisational vs. professional

Nick is a new consultant who, above, described the tension between managing an individual patient and managing the department as "a real source of stress that I think you feel most when you're a consultant" [8a]. I notice a pattern in how he conducts his interaction with his trainee doctor colleague (Sophie): after a moment of cheerful talking with Sophie, Nick's facial expression would return to one of frowning concern. With this silent cue, Sophie would start presenting the information relevant to the next patient, in a standardised order:

Medical notes, blood results (on computer screen at central work station), imaging, observations (on mobile phone handset)... [8a]

Nick explained this habit to me:

“I tend to have the same routine for each patient: notes – blood results – imaging – obs. [observations]. And actually, I think you kind of have to do that to be systematic. It’s really important to be systematic. To make sure you don’t miss things.” [8a]

Being thorough and systematic is not the only priority, however:

“At some point you’ve gotta draw a line when you’ve read enough.” Nick illustrated this by describing a consultant colleague of his in a previous hospital, who was from an African country and gained most of his medical experience there. “He’s incredibly fast. He’ll see literally 30 patients in an hour! And yeah, he makes mistakes. But the department manages. I’m certainly not as fast as him, and I’m more risk averse, but I do think there’s something to be said for that.” [8a]

Nick recognises the need to look after the individual patient well to “make sure you don’t miss things”. This could result in harm to the patient and professional repercussions. At the same time, he recognises the need of the organisation for the whole department to manage. He describes something of a spectrum of risk aversion along which a consultant is placed, which affects where the line is drawn to say “enough” attention has been given to one patient. I asked how much risk aversion is about right, or how to know where to draw this line:

Good question! I dunno, it’s really difficult to know isn’t it?! I guess from looking at your outcomes. Right... [8a]

And, with that, the frowning expression returned, kicking the trainee doctor into action. The tension between looking after the individual patient thoroughly, as a doctor in the *profession*, and looking after the department, as a consultant in the *organisation*, is arguably not eliminated by “looking at your outcomes”, however. This is because it remains unclear whether this is the outcome of the individual or the department, and how much weight to render to each.

The dissonance that comes with looking after patients both individually and collectively is also described by Helen, who is an experienced staff nurse at the start of a 12-hour shift. Helen intermittently stands with her hands on her hips and vocalises to herself “right, what was I doing now then?” [6a] before walking hastily to the next task. It is the morning and she is busy doing her ‘drug round’. Each patient has a Kardex, which is a tabulated display of the prescriptions the doctors have authorised for each day. Some of her patients also have an infusion chart, which is a tabulated display of the intravenous drips that doctors have authorised for each day. She is rushing back and forth between her patients and the Lab Room, in which the Kardexes and infusion charts are laid out in a line on the counter [6a]. She reflects on this shift:

This shift today has been steady but busy; there's been a great variation of different patients in. Quite heavy⁵⁰ patients that need double attention. Quite a lot of infusions going, so it's just trying to catch up and trying to chase everybody just to see what is needed. [Helen, 5-7]

“Chasing everybody” consists of noticing something about the prescription which needs clarification, correction or collaboration. The next step is to locate the relevant colleague, which entails hunting the likely area of the ward to find them. Doctors could be at the notes trolley or behind a curtain or behind a cubicle door. Staff nurses and healthcare assistants could also be in the Lab Room, clean utility room or sluice (which is a room for the cleaning or disposal of dirty things). The pharmacist could be at the computer, with a patient, or off the ward. For anyone else, there is a telephone.

For Helen, she usually performs this chase under pressure:

It hasn't been too bad today compared to other days where it's really, really busy. Because I've been lucky I haven't had a lot of discharges. Because when you've got your discharges on top of looking after really poorly patients, it adds a lot of pressure. [Helen, 9-12]

The priority of discharging patients, as I described in the previous chapter, is to free up beds and maintain ‘flow’ of patients through the AMS. “Poorly patients”, however, require Helen to spend more time on them individually; they are the “heavy patients” that need “double attention”. As such, Helen is caught between the *organisational* need to maintain flow, by arranging discharges of well patients, and the *professional* need to deliver good care, by spending time looking after sick patients

Today, Helen is managing to progress through her line of Kardexes and infusion charts swiftly, despite all of the “chasing” she has to do. She recalls a shift recently when one of her patients needed painkillers. This resulted in a stressful kind of chasing:

[The patient] was a lady who was in a lot of pain. She had multiple things. Fibromyalgia. She was on so many medications but the doctor wanted to give more paracetamol, and it was over the dosage of the 4 milligrams in 24 hours? And I said I wasn't very happy in doing that. And he said they do do it in resuss [resuscitation bay in A&E] and I was like “well I'm not in resuss”. And you're not allowed to have that. [Helen, 86-90]

This confrontation led to further chasing:

So I went and spoke to pharmacy because – I did go to a sister first but the sister didn't do much so I went to pharmacy and asked them – and they said “no, they can't”. So I went back and relayed and

⁵⁰ Helen uses “heavy” figuratively here, to refer to clinical demand rather than patient physique.

he said “no, well I think they should”. So I asked the pharmacist to go and speak to the doctor.

[Helen, 90-93]

Helen’s concerns were vindicated:

And then the doctor did come back and apologise and said he was wrong ...And sorry that he had put us in that situation. [Helen, 95-97]

She identified what was threatened by the doctor’s prescription:

Everybody can be under stress... but, as I had explained, it’s my registration. Even though it’s prescribed, if I give it, it’s my registration that’s on the line. So you’ve got to be able to stand up and say “no”, or when you see certain drugs that are written up you think “that doesn’t seem the right dose for that” so I will go and double check and I will ask another doctor just to make sure.

[Helen, 101-105]

Whilst Helen senses the need to discharge patients and get through tasks rapidly, such as administering painkillers which have been prescribed, she also senses another need: to work according to professional standards. Helen needs to complete her tasks efficiently, for the hospital’s sake, but also appropriately, for her professional licence’s sake. The one is clashing with the other. The dissonant “stress” that she experienced was thus caused by an irreconcilable conflict in the plurality of needs: the *organisational* versus the *professional*. This is not the only kind of clash, however.

7.3.2 Professional vs. personal

A second way in which relationships can feature cacophony within the AMS is when there is a clash between professional need and personal need. To explore this, we return to Dr Taylor and her interaction with Mr Jenkins.

Dr Taylor is the consultant on today, and she is in the middle of her morning ward round. She is preparing to see Mr Jenkins, and goes through the same preparatory routine as Nick, her consultant colleague: medical notes (including clinical correspondence), blood results, scan images, nursing observations.

Mr Jenkins was a man in his 70s, who was wearing the standard white-with-green-pattern hospital gown. He had an oxygen mask over his face, which was making a quiet hissing noise, and was sat up against his bed, which was tilted up at the back. He smiled and looked across as Dr Taylor walked towards his bedside and crouched down, sitting on her heels. [6c]

With an opening greeting, the conversation started:

Mr Jenkins narrated the run of events prior to his admission. He started by describing his routine every Tuesday afternoon, when he visits his wife's grave site "without fail". On this occasion, he began to feel breathless and thought "something was up". [6c]

Following more conversation about how Mr Jenkins has been feeling, Dr Taylor examined him, which included listening to his chest with her stethoscope.

After this, Dr Taylor sat on the edge of Mr Jenkins' bed and said "I think we need to be open and honest with you: I can't fix your chest. I wish I had a better magic wand, but I don't." ...Mr Jenkins nodded and listened as Dr Taylor continued: "it's about your quality of life. It's about how you feel about your breathing and getting you feeling better."

Dr Taylor said she doesn't think that a CTPA [a scan of lung arteries looking for a blood clot] scan is going to be useful; like the previous ones on two recent similar admissions, it would probably "not show anything". [6c]

In interview, Dr Taylor recounted how reading the medical notes had helped to provide some direction for this ward round consultation:

The interesting thing with him was to spend a bit of time looking at a computer before we saw him. Because that gave you a real flavour for this man who's had multiple admissions, he's getting multiple scans every time he comes in, we just go straight for a CT scanner. They never show anything. He's gone onto oxygen. He's hypoxic in clinic ...And to me that is a really bad combination of factors.

[Dr Taylor, 89-94]

Dr Taylor characterised the significance of this bad combination of factors:

Because I just felt in a way, whatever our diagnosis and whatever our management, he is probably heading towards the end of his life. He was very anxious. It was anxiety a lot, I think, that was distressing him. And I think we just need to be a bit more holistic and a bit more realistic. [Dr Taylor, 104-107]

After Dr Taylor explained the plan for the physiotherapist and the palliative care nurse to see him, Mr Jenkins gave a smile and said "right-oh!" [6c]. As we walked back to the central work station, Dr Taylor describes how doctors habitually approach this kind of situation:

"As doctors, we work by algorithm in acute medicine. We just tend to think: 'it's a PE [pulmonary embolus], we fix it, then they go home'". She pointed out that it's when she stepped back and saw in the correspondence that Mr Jenkins keeps coming in and having this cycle reinforced, that she realised

the medical team need to think differently about his care. “We’re so busy excluding a PE, but after all a PE might not be a bad thing for him. You’ve got to die of something”. [6c]

Dr Taylor draws a link between this algorithmic approach, which responds to diagnostic categories such as ‘PE’, and the way doctors are trained:

We’re taught a very paternalistic, kind of protocol guideline-driven way, and every time there’s a new patient safety incident there’s a new guideline or protocol! And I think we have to understand that they’re really good, evidence-based guidelines but that patient in front of you is not the same as that 10,000 patients that went into that trial. And so, you know, you and them have to have some wiggle room on what’s right. [Dr Taylor, 228-233]

Dr Taylor recognises a limit to the usefulness of clinical evidence: this patient is a unique individual. She expands on this with an illustration of how doctors customarily approach the treatment of DVT [deep vein thrombosis]:

You’re in your own little pathway “oh DVT, must treat. Here, have tinz [blood thinning medication]”. But you’re not actually saying to the patient “in the last part of your life remaining, how do you want to live? Do you want the district nurse to come in every day? Do you want to go to Costa Rica next week as your last thing before you die of your breast cancer or whatever? Do you want to try and get sharps through customs or would you prefer to take the risk and die of PE and you don’t have medical insurance anyway?” [Dr Taylor, 200-206]

Dr Taylor summarises the connection between these illustrative examples:

I just think we’re very paternalistic to assume that we know the answer to this. So I think we have to explain the pros and the cons, the risks and benefits, and then I think patients have to try and have some input into that decision. And a lot of people probably aren’t able to wholly make that decision because they maybe can’t quite understand or – a lot of people would still say “what would you do?” But I think it’s important that we at least show people that it’s not black and white. [Dr Taylor, 206-211]

With regard to Mr Jenkins, Dr Taylor says:

My aim for him would be to start to explain to him and the team treating him that this needs a much more holistic, realistic approach and that should be led by him. And that he should be at the centre of it, and not just do what doctors tell him is the ‘right’ thing. [Dr Taylor, 159-161]

Whilst doctors may feel a professional need to follow evidence-based guidelines, treat diagnoses and to have “ticked the box” [Dr Taylor, 164], Dr Taylor recognises an additional need here. This additional need involves patient input and shades of grey. She continues:

As human beings we're not stupid. We can all feel that we're getting weaker, or we're getting tired-er, or that we're struggling more or that we're coming in more, and I don't think we allow patients to tell us that story. Or to accept that, or to say "well okay, that is getting more difficult. Doing all these tests isn't going to change that. What's important to you?" [Dr Taylor, 257-261]

As well as assessing need in terms of professional diagnostic categories, Dr Taylor urges the assessment of need in terms of a patient's life story:

You can sit there and you can take a history and do some tests and prescribe some- but if it doesn't really fit with what the patient wants to get out of that consultation then actually what have you achieved? [Dr Taylor, 223-225]

Dr Taylor's frustration with what she sees as the traditional medical approach is expressed in terms of neglect of the additional need to cater for the patient as a unique person with a life story. The professional (perceived) need to medicate a diagnosis clashes with the personal need for individual self-expression and avoidance of over-medicalisation.

The juxtaposition of Dr Taylor's approach with the expectations of her traditionalist colleagues could be described as cacophony, due to the conflict in these instances between a multiplicity of needs: the *professional* versus the *personal*.

However, as well as conflict between her approach and that of her more paternalist colleagues (*interpersonal* conflict), there appears to be a conflict *within* Dr Taylor herself (*intrapersonal* conflict).

Each patient in the AMS is expected to have a 'Treatment escalation plan' (TEP). This is a proforma, which is usually completed by the consultant, which describes what limits to healthcare are relevant to this particular patient. In addition to a TEP, many patients in the AMS also have a 'Do not attempt resuscitation' (DNAR) form. This is also usually completed by the consultant, and the presence of the form in a patient's medical notes prevents the initiation of cardio-pulmonary resuscitation (CPR) on that particular patient in the event of a cardiac arrest.

Consultant Tony summarises the process:

In theory it's black and white... for the nursing staff and other clinicians looking after the patient because they either have a valid DNAR form in which case you don't start CPR, or they don't in which case you do. [Tony, 334-337]

However, Tony recognises the situation as less black and white once the practical details are considered:

An example of a more complex decision would be, for example, a patient with what is perceived to be end-stage organ failure, such as end-stage heart failure, in a discussion regarding resuscitation for the patient who has capacity and in clear consciousness asks us to do everything that we can do, including making sure we do CPR and put them on a life-support machine if it comes to that. ...the way things are legally, that can be quite a tricky business. [Tony, 324-329]

Returning to Dr Taylor, she describes how she approaches such conversations:

I think a lot of the times that's about listening – sitting down with the family – and listening to their concerns and their... and getting them to tell you the story. [Dr Taylor, 285-287]

Dr Taylor sheds light on her intention in such moments:

...you get them to tell you the story first, and then try and explore the frailty and the downward trajectory and the fact maybe they are getting a bit weaker and "you said they used to go to the supermarket; you said the last time was six weeks ago" and, you know, picking out bits. So that before you say "as the doctor I think this, and this is black and white, and this is my decision and that's it; hard luck", you've actually got them to start to come to terms with some of that. [Dr Taylor, 287-292]

Both Tony and Dr Taylor recognise that the situation, in reality, is not black and white. Dr Taylor suggests that the problem with a black-and-white construal is primarily rhetorical; it is an ineffective way of "getting them to start to come to terms" with it. As Dr Taylor continues:

Sometimes getting people to acknowledge that it has been at the back of their minds but they've just not wanted to come to terms with it, is quite helpful. What isn't helpful, certainly, is to be really busy and to blast in and say "I'm the critical care consultant. No. Goodbye!" [Dr Taylor, 299-302]

Compared to chemotherapy or surgical laparotomy, Dr Taylor observes that CPR and subsequent intensive care is relatively misunderstood:

I think people don't understand what resuscitation is. "Is it CPR?" And actually when, you know, you have to spell it out in black and white what it is, families are like "I never knew. I never realised".

[Dr Taylor, 330-332]

This difference in understanding is addressed in conversation:

And I think sometimes it's just about exploring their vision of what you're talking about because it can be very different to your black and white knowledge, factual knowledge. And what they've seen on Casualty or ER or something. [Dr Taylor, 338-341]

Dr Taylor summarises her approach to CPR discussions:

It sounds awful but I'm not sure I go to seek agreement, I go to seek understanding. You know, it's the clinician's- it's a consultant's choice. I can't put people on critical care if it's the wrong thing to do... It's a treatment that we're offering and it's not right to offer a treatment if it's not the right thing to do to somebody. And I think as a clinician I think we're legally, that's our position. I think responsibly, ethically, morally, that's the right thing. So I don't go to say "let's all sit down and agree this together". I go to say "this is what's happening and this is why, and let's understand the why". [Dr Taylor, 345-352]

In her interaction with Mr Jenkins, Dr Taylor emphasised being "open and honest", "holistic and realistic" in a way which prioritises his personal needs. In her depiction of CPR discussions, however, she seems to take a different approach. Regarding Mr Jenkins, care should be led by him with his input and him at the centre; regarding CPR, it's a consultant's choice. Regarding Mr Jenkins, a doctor should avoid protocolised black-and-white knowledge; regarding CPR, the public's television-induced misconceptions contrast with a doctor's black-and-white factual knowledge. Regarding Mr Jenkins, there needs to be "some wiggle room on what's right" and he should not merely go along with what the doctors say is the right thing to do; regarding CPR, there is a morally right thing to do which provides the basis for a doctor saying "this is what's happening and this is why."

Perhaps this can be interpreted in terms of a clash between *personal* and *professional* need. With regard to Mr Jenkins, the need to respect his personal autonomy and unique life-story trumps the professional need to medicate a diagnosis. With regard to CPR, the professional need to avoid administering putatively futile treatment trumps the personal preferences and wishes an individual or family may express. Thus Dr Taylor enacts two conflicting approaches to weighing up needs in these two different sets of circumstances.

7.3.3 Personal vs. organisational

A third way in which there can be cacophony within the AMS is when organisational need clashes with personal need. We return to Tony and continue the topic of DNAR decisions and escalation plans.

Tony, wearing his consultant uniform of grey scrubs, has just begun his morning ward round. Accompanied by a trainee doctor, Ling, they are preparing to see “the gentleman in room 3” [6d]. A more junior doctor, who had introduced herself as “the F1” [6d] is seated beside them, writing down salient points in the medical notes on a proforma entitled ‘Post-take ward round’. Tony highlights these salient points by announcing them in a higher pitch and volume, with a subtle turn of the head towards her.

Tony sits down beside the F1 doctor, who has laid out the notes for patient 3 and X-ray images on computer. “Lung cancer patient” he reads aloud. “But no cancer clinic letters. We find this a lot [turning to LM], that cancer patients arrive and we have no clinic letters, which would really be quite helpful, to know what the overall picture is. They might say something like ‘radiotherapy, if doesn’t work then palliate only’. But we don’t know that for sure – until acute cancer nurse comes tomorrow”.

[6d]

After viewing clinical information on the computer and in the medical notes, Tony reflects to Ling that there are “still a few pieces of the puzzle missing” which would be useful to know in order to figure out the “ceiling of care”. Patient 3 is Mr Johnson, who is sat in the bedside armchair in the far corner of the room. Mr Johnson is wearing the standard green-and-white hospital gown, with his own slippers over his feet. A few feet away from him are his son and daughter-in-law, seated in the corner on standard plastic chairs for visitors.

Tony knocks and enters the room, which is dimly lit by the glow of sunlight through the blind. He stands in front of Mr Johnson, with intermittent looks towards Mr Johnson’s family. Ling and the F1 doctor stand on the far side of the bed, nodding and writing respectively. After an initial greeting, Mr Johnson describes to Tony his usual day-to-day activities and then cuts to the chase:

Mr Johnson: I’m ten times worse, breathing-wise

Tony: It’s not clear what’s made it worse, so we’ll give you antibiotics. We’re treating you in case you’ve got an infection. My guess is that we’re not gonna be able to cure this problem.

After a brief discussion about the home environment, Tony then changes the focus of conversation:

Tony: If and when things take a turn for the worse, I think we shouldn’t be trying to restart your heart.

Mr Johnson: “Shouldn’t?”

Tony: It wouldn’t work.

Mr Johnson: That's nice to know. [smiles – unclear if being sarcastic or relieved]

Tony [turning to son and daughter-in-law]: I've only just met you. I'm just trying to piece together the puzzle, the picture.

Daughter-in-law: So are we just keeping him comfortable then, sort of thing?

Tony: We are still actively treating him with antibiotics for an infection. We've just got to be realistic as well that we might not be able to cure everything here. [Turning to son] Is your brother coming in later?

Son: Aye.

Tony: We can have a word with him too [looking at Ling], when he comes in [Ling nods]

Mr Johnson: I hope you win!

Tony: [amused] me too!

Closing the cubicle door, the medical team stand around the notes trolley, as Tony documents in addition to what F1 has written: "poor exercise tolerance even on a good day". Tony turns to Ling: "We should expect the other son might disagree with that DNAR"

Ling: I'll have a word with him. When he comes in, I'll talk with him.

Both consultant and Ling complete DNAR form for Mr Johnson, stating he is not for resuscitation.

[6d]

Tony described what was going through his mind as he entered the room to meet Mr Johnson:

Walking into that room, I know that the man has had a diagnosis of quite advanced squamous cell lung cancer. And he hasn't had surgery. And he hasn't had chemotherapy. And he was judged not fit for chemotherapy at the time of his diagnosis. So immediately I am thinking the trajectory for this gentleman, no matter what we find when we walk in the room, unfortunately the trajectory for this gentleman is not going to be that he is cured from lung cancer. And probably all the treatment he's had is aiming to keep it at bay, and reduce the symptom burden, and give him the best quality of life.

[Tony, 225-232]

This downward trajectory has implications for resuscitation:

In my view it would not be appropriate to put him on a life support machine to try and get him through that. And that's based on my experience that patients with significant symptom burden from their

lung disease, which he had, because he's breathless walking a couple of yards. That if he became so poorly that he needed organ support on a high dependency or intensive care unit. If it got to that point, the chance of him recovering to have what most patients would consider a meaningful existence – quality of life at home – the chance of him recovering would be pretty slim. [Tony, 269-276]

With regard to what a “meaningful existence” for Mr Johnson would be, Tony said:

I guess many patients, you have that conversation with them and they would say: “being in 24 hour care and unable to... communicate, or unable to feed myself or toilet myself would be unacceptable to me. Many patients you have that discussion with them and that's the type of level at which they think that's not really an acceptable quality of life for them. And if he had a cardiopulmonary arrest, given that background and given that his right lung was essentially gone with his cancer, then the chance of him surviving and not ending up in 24 hour care of some kind would be next to zero. [Tony, 286-292]

However, Tony recognised a limitation to this assessment of Mr Johnson specifically:

For him I don't know because I didn't ask him. I didn't ask him “what to you, Mr Johnson, is an acceptable quality of life?” [Tony, 280-281]

Tony expands on this:

Some patients have – some people have – massively different priorities to others. So for example, I've met patients who leave, take off their oxygen in a clear state of mind, clear consciousness, walk out the hospital, get a bus home to make sure their dog is fed. You know, with what to us, we perceive to be terrible pneumonia and respiratory failure. But for that particular person the priority is making sure the pet they love is not being neglected, and that they see them every day. So that's their priority. I don't know if I really gave that particular patient that we're talking about, I don't know if I really gave him the opportunity to voice what his main priorities are. [Tony, 296-304]

Giving Mr Johnson this opportunity, to describe what a “meaningful existence” is for him, is something Tony could have done “if we had a lot more time” [Tony, 281]. In Tony's view, the way the workload is divided addresses this to some extent:

But I'm almost certain that he had that discussion the following day with the palliative care nurses. ...That is typically the type of thing they would choose to spend some of their time discussing with patients: what their priorities are. [Tony, 304-309]

Due to time pressures, Tony is unable to give Mr Johnson the opportunity to “voice what his main priorities are”. As a result, Tony must make an assessment of whether resuscitation is worthwhile based on what “many patients” in similar circumstances would consider a “meaningful existence”. Although he recognises that people have “massively different priorities”, he is unable to appreciate Mr Johnson’s uniqueness in this regard; in the interests of time, Tony must consider Mr Johnson as a category of ‘patients with incurable lung cancer and significant symptom burden’. The difference between seeing Mr Johnson as a *category* and seeing Mr Johnson as an *individual* is captured in the juxtaposition of Mr Johnson’s standard hospital gown with his unique homely slippers. This difference could be described as a clash between *organisational* need and *personal* need.

One more instance of a clash between the organisational and the personal will bring our exploration of cacophony to a close: visiting hours.

Maureen, the lady in her 70s who trusts expert professionals with her kidney tablets (“you’ve gotta put your faith in someone”), feels strongly about visiting hours:

Obviously you’ve got to limit as to how many people come in at a time ‘cause it can be disruptive. And I think when you’re in a cubicle on your own, does it matter if you’ve got a visitor or not? Because it’s different if you’re on a ward and there’s lots and lots a people with visitors, it can be mayhem. So, you know, I think you should- a bit of discretion if you don’t actually live local. [Maureen, 15-19]

With a deflated sadness in her tone of voice, she describes her partner’s struggle with visiting hours. He lives in a town many miles away and his journey requires two bus journeys. Maureen says:

He doesn’t drive, so it’s horrendous for him to get here. And the first time he came to visit he sat down here waiting for us, I was still in intensive care but he didn’t know that. And he was sat here and missed quite a bit of the visiting time. And he had said, you know, “I’ve only got one hour in that visiting time between buses.” ... But he just- he’s a little puppy really. He doesn’t complain about anything! You know? He just gets on with it. [Maureen, 31-45]

When her family members were asked to leave by nursing staff on two occasions, Maureen explains why they were compliant:

‘Cause they don’t like confrontation. You just go. ‘Cause you think, you know, what’s the knock-on effects if you upset the nurse? Is the nurse then gonna be in a bit of a strop because your family were like that? And then they would maybe treat you that little bit different. [Maureen, 52-56]

Lamenting the rigidity of impersonal rule-following, Maureen comments:

Everybody's different. We all have different reasons for needing other people outside of being in here.

[Maureen, 76-77]

As Maureen describes it, everybody is different and everybody's need for visitors is different. This matters very much to Maureen and her partner. Yet, on the ward whose welcoming poster reads "if it matters to you, it matters to us" [2a], visiting hours are standardised. The tension between these two facts is experienced by the nursing staff, who are responsible for enforcing visiting hours restrictions:

At the section 1 work station, I was standing chatting with two nurses. Amanda was at the computer and Rachel was writing in notes on top of the notes trolley. The topic of conversation was visiting hours, and when to "stretch" them. Amanda said she would stretch visiting hours sometimes "if they were really sick". When I asked how sick, she replied "you just use your judgment. Definitely if they're palliative." I was aware that 'they're palliative' is a shorthand way of describing a patient on the ward who is terminally ill and often likely to die within a few days. [9c]

Perhaps the "discretion" that Maureen wished for is in fact exercised by Amanda's "judgment". However, where Maureen had in mind the degree of travel inconvenience for her partner, Amanda has in mind the degree of sickness of the patient. Rachel pauses her writing and lifts her head to join in:

Rachel overheard this response and mostly agreed, but added a little extra: "plus, I dunno if I should say this, but you're definitely more lenient if the family are nice! And like if they're elderly or they've come from far or whatever. Not if it's just like their 17 year-old boyfriend!" She went on to describe an occasion when a teenage boyfriend of a patient had wanted to stay overnight with the patient, even sharing her bed. "No way! I wouldn't let that; my dad would never have let my boyfriend stay over when I was 17 like. That's not happening!" [9c]

The clinical emphasis of Amanda's judgment is complemented by the lenience of Rachel, who incorporates the kind of concerns that Maureen expressed. In addition, Rachel is prepared to interpret the relational significance of particular requests, such as the impropriety of a 17 year-old boyfriend staying overnight.

In stark contrast to this, Amanda and Rachel's colleague, Emma, sees visiting hours differently. Behind the sound-proof doors of the Lab Room, Emma is preparing an infusion before the morning huddle. She has a jittery, impatient demeanour, to which the other nurse in the room (Mark) responds with silence.

"Look, we've got to put an end to this. It's getting ridiculous. [turning to me] It's impossible to get anything done when you've got relatives there thinking they can stay as long as they like asking idiotic questions. ...They expect you to drop everything, whatever you're doing. ...Especially when we're understaffed, we've got to get on." [leaves room hurriedly with medications to give] [4d]

Mark looks embarrassed at the way Emma spoke and adds:

“Emma gets quite stressed about it. It’s so variable but she takes it really seriously. I sometimes think it’s okay as long as the relatives aren’t getting in your way. It’s only the ones that get in the way that are a problem.” [4d]

Within the nursing team, there are evidently different interpretations of visiting hours policy. Some are lenient and emphasise the uniqueness of patients, clinically, relationally and circumstantially. This leniency is from a *personal* perspective, recognising that patients each have “different reasons for needing people” (Maureen). Some instead emphasise standardisation, considering patients as a single category. The push towards standardisation is from an *organisational* perspective: the department needs to run efficiently and this is impeded by relatives who “get in the way” (Mark). The simultaneous different interpretations clash with one another; they are a cacophony because there is an irreconcilable clash between *personal* need and *organisational* need.

“Huddle!” shouts Emma, the nurse in charge for today, projecting her voice through the doorway. “Huddle!”, she repeats into the next doorway. She has a stern, frowning expression, and is walking briskly with a sense of urgency about her, before coming to a standstill near the central work station. As ward staff complete their introductions in a clockwise fashion, we too have come full circle [1a, 4d].

7.4 Conclusion: contrast and cacophony

7.4.1 An AMS is a dance

What follows is an allegorical ethnographic account of how people in the AMS work together: the AMS is a dance⁵¹. It is an unusual dance because, as we shall see, people are dancing to two sources of music.

At one end of the dancefloor, there is a small stage with a piano on it. The piano is strikingly colourful. As I approach it to make out the unique pattern, it becomes clear that what gives this striking appearance is that it is autographed all over. Names have been painted on it, each in a different colour. As I walk round it, I can make out only those which have been painted on recently: *Maureen, Finlay, Brian, Mr Jenkins, Mr Johnson*. The closer I look, the more names I see, each painted on in their own style. Each name contrasts with the others; no two are quite the same. I start to wonder what colour the piano was to begin with. Was it black, originally? Or perhaps white? Or is it colours all the way down?

Seated at this piano is a pianist who is dressed in a formal grey suit. She is seated with a straight, motionless back, as is expected of pianists within the classical tradition. Her straight back contrasts with the elegance and rapidity of her fingers as they traverse the keyboard. She is wearing a name badge on her lapel, which I

⁵¹ I unpack this allegorical account in Chapter 9 (see: *Back to the dancefloor*)

struggle to read due to the number of awards which she has pinned beside it. As I peer in to get a closer look at her name, she glances across to me as if to indicate that looking there is not appropriate. She caresses the keys expressively and sensitively, yet her facial expression is intermittently stern as she keeps looking across to something.

As I trace the pianist's gaze, I notice that something to be an electronic metronome, beeping with insistent regularity. The metronome is only small, almost invisible. In fact, were it not for its effect on the pianist I might have never discovered it. As I reach to touch it, I find it to be cemented onto the piano, rotated away so that the pianist cannot change the settings. The metronome is white. Nobody's name is written on it but it does feature a plain blue logo on the front. I wonder who made it? Who cemented it that way around? Who set the tempo? Isn't this a bit fast?

The dancefloor is a circle. In fact, it is a white circle, with that same blue logo in the middle of it. An alarm is set off when too many people step on it. People round the edges are wearing white and green and move cautiously. Curiously, they have paint on their hands and a look of anxiety on their faces. People in the middle wear grey, pyjama-like outfits whether it is day or night. All pyjamas have the same blue-and-white embroidery. They dance energetically and always have clean hands. This must be a ballroom dance, as people pair up for a few moments, holding hands, and then move on to a new partner. People in green and white only dance when the pyjama people arrive and initiate. The dancers in pyjamas seem concerned for dancing to be done properly; they are quick to spot when someone's dancing is out of step. Once dancing together, though, it becomes unclear who is the 'lead' and who is keeping in step.

At the other side of the dancefloor, people are dancing in a very different fashion. Rather than holding onto each other's hands, they are facing opposite each other. Rather than dancing to the pianist's music, each dancer is wearing a headset. This must be a silent disco, in which each dancer is tuned in to one of three music channels playing through their headset. What music is best to dance to? Each channel is selected by pressing a button of a different colour: blue-and-white, grey or multicoloured. However, each channel's music is playing to a different beat! As a result, the dancing on this side is chaotic and unpleasant.

On the piano side of the dancefloor, the contrasts were co-ordinated and reconcilable. On the headphone side, though, the contrasts are clashing and irreconcilable. The way people dance together on this dancefloor is either in noisy harmony or silent cacophony.

7.4.2 Working together to alleviate need

In the previous chapter, I described the aim of an AMS as to restore order. In this chapter, I have described how people relate to one another in the pursuit of this aim: people work together to alleviate need. Just as the aim of an AMS turned out to be a complex of three goals, so the notion of 'need' has turned out to be a

complex of three kinds of need: *professional*, *personal* and *organisational*. Sometimes these needs are contrasting but harmonious; they can be reconciled. At other times these needs are contrasting but cacophonous; they clash and a need is overtly frustrated. It is within this context that people within an AMS figure out what course of action is best, which is the subject of the following chapter.

Chapter 8. *What's Best*

In the previous two chapters, I presented data organised around two themes. In *Restoring order*, I portrayed the aim of an AMS as to restore order by addressing three kinds of *problem* (deviation, distress, disruption). A course of action is sensed to be futile if it fails to address one of these kinds of problem.

In *Working together*, I described the relational aspect of the work of an AMS. Specifically, people within an AMS work together to alleviate *need*. Three kinds of need were identified (professional, personal, organisational). The contrasting forms of interaction are usually harmonious but can be experienced as cacophonous when a course of action overtly frustrates one of these kinds of need.

The findings of these two chapters provide the background for the focus of this present chapter: *how do people figure out what course of action is best?* In this chapter I present data organised around the theme *what's best*. It is in this chapter that values become more apparent and, specifically, what their role is in decision-making within this AMS. I progress towards this point in four steps.

Firstly, I consider the connections between the key concepts in the previous two chapters: *problems, futility, need* and *cacophony*. Secondly, I describe moments of conflict in decision-making and characterise this as a conflict between two values. Thirdly, I identify a third value which is also in play albeit less conspicuously. Fourthly, I use these three values as a model to explain the difference between *obvious* and *negotiated* decisions.

8.1 From problems and needs to values

8.1.1 Problems and needs

Problems and needs have come in threes. In *Restoring order*, I presented three kinds of problem: deviation, distress and disruption. These three formed a triad of problems which ought to be put back in order to avoid futility. In other words, problems are things that *need* to be corrected. More precisely, perhaps, problems are things that *people need* to correct.

In *Working together*, I presented three kinds of need: professional, personal and organisational. These three formed a triad of needs that ought to be alleviated in order to avoid cacophony. In other words, a need is something which poses a *problem*. More precisely, needs are things that *people experience as problems*. Just as a problem without correction is in need; a need without correction is problematic. Problems are needs and needs are problems; both are things that ought to be corrected.

Before claiming absolute synonymy, I concede that the two terms nevertheless may have a difference in emphasis. Chapter 5's 'problem' emphasises the circumstantial aspect of an uncorrected need: a situation which is disordered. Chapter 6's 'need' emphasises the phenomenological aspect of an uncorrected

problem: an experience which people work together to alleviate. Perhaps it is most accurate to consider the two terms to be relatively synonymous in that they are two perspectives on a very similar thing: something that ought to be corrected.

If this is so, then it comes as no surprise that both problems and needs have come in threes. With two different emphases, the themes of *restoring order* and *working together* have overlapped by both describing things-that-ought-to-be-corrected within this AMS.

8.1.2 Futility and cacophony

In similar fashion, it comes as no surprise that ‘futility’ and ‘cacophony’ have come in threes. Futility is sensed when there is unavoidable conflict between problems. Cacophony is sensed when there is irreconcilable clash between needs. If problems and needs are perspectives on things-that-ought-to-be-corrected, then the three kinds of futility are relatively synonymous with the three kinds of cacophony, albeit with a difference of emphasis. Just as needs are problematic, so cacophony is futile.

8.1.3 Things-that-ought-to-be-corrected and values

As things-that-ought-to-be-corrected, problems and needs are therefore value judgments in the negative tone of voice. The thematic exploration of *restoring order* and *working together* has thus been an exploration of negatively valued things, made more prominent in conflicting moments of futility and cacophony. But how do people know what to do about these negatively valued things, such as problems and needs? Building on the previous two chapters, we can pose the question as follows: *how do people figure out what course of action is the best way of working together to restore order?*

This question is a question about values. It concerns how people judge what is *good* (and even *best*). In such a goal-oriented environment as the AMS, these judgments may relate to problems: perhaps what is best is what restores order? In such an interactive, collaborative environment as the AMS, these judgments may relate to needs: perhaps what is best is what alleviates need? However, both these questions presuppose some kind of evaluative standard or criterion: a means of discerning whether a course of action restores order or alleviates need *the best*. This search for evaluative criteria, or values, will be the ultimate focus of this chapter. *What is the role of values in how people figure out what course of action is the best way of working together to restore order?*

8.2 Tension in decision-making

Moments of tension in decision-making can bring values to the fore⁵². In the following section, I describe five types of tension in decision-making which can be characterised as a conflict between two recurring values.

⁵² This phenomenon has come to be known as the ‘squeaky wheel principle’ (Fulford, 2004: 206).

8.2.1 Paternalism vs. advocacy

Kylie is a very experienced palliative care nurse, who visits the AMS to offer a liaison palliative care service. Whilst any patients she sees remain under the responsibility of the acute medical team, she is there “to liaise and there to advise” [Kylie, 222]. Kylie walks briskly onto the ward with a cheerful demeanour and places her notepad on top of the notes trolley [6b]. Turning to me, she explains that she’s here “to see the gentleman in room 3, Mr Whitehead⁵³, who’s a man with terminal metastatic disease and a difficult home set-up” [6b]. In interview, Kylie described the events leading up to her coming to see Mr Whitehead:

He’d been known to the palliative care team back in November, when he was initially diagnosed with a radiological diagnosis of a likely lung cancer with mets [metastases]... he’d come in with increased shortness of breath and looked very frail and cachectic. Acute medicine team had given him antibiotics and some oxygen and he was feeling a little bit better on the first day when I met him. He was referred to me for some pain control issues. [Kylie, 6-18]

Before entering Mr Whitehead’s room, however, Kylie indicated to me that there might be other issues going on. There was not yet a plan for where Mr Whitehead would go after hospital “and I’m just a bit worried; he looks like he’s dying” [6b]. She sensed that going home might be a complicated arrangement:

Unfortunately his son, who had moved in with him, he had died at Christmas... He didn’t die at home; he died at hospital. But that had been a very rapid deterioration. And there were still two teenage grandchildren living at home with their grandad. [Kylie, 21-26]

“Now Mr Whitehead lives with his grandsons, two of them, with a package of care that maybe isn’t that suitable”. [6b]

We walk into Mr Whitehead’s room, where the sunrise is glowing through the long vertical blinds. Mr Whitehead himself is sitting on his bed: one foot in, one foot out.

Mr Whitehead was an elderly, frail-looking man who was extremely thin. He had long, wiry, white hair which was un-combed, which gave me the impression he did not care much what he looked like. Perhaps out of weakness, he was slumped to his right-hand side and seemed unable to hold his head up vertically. He wore a white vest, clearly visible as his gown was undone at the front. [6b]

As she placed her plastic chair beside Mr Whitehead’s bed, Kylie opened the conversation with a friendly tone:

“I’ve come to have a bit more of a chat with you” [6b]

⁵³ Kylie and Mr Whitehead’s interaction was presented previously (see: Chapter 6 *Distress and Disruption*).

As Kylie had left the topic of conversation fairly open, Mr Whitehead started talking about his family circumstances, and his sadness at losing his son. Mr Whitehead had a fentanyl patch in place, to treat his severe and chronic pain. Despite being asked to tend to pain control, Kylie described a shift in priorities:

When I went to see him, pain wasn't his biggest problem, and then it was more about his social situation and his desire and want to be at home if he was dying. [Kylie, 18-20]

Kylie continues:

The patient himself wanted to be at home... The day that we went to see him, he looked just like he was not improving. He was in bed, he was frail... It felt like, based on the conversations that I'd had... that home was very important to him – to die at home. He had capacity and we felt that – I felt that I should help to move things forward as quick as possible... It was more based on the fact that he was clearly not improving and we knew what his expressed wish to die at home – and looking at him looked like things could deteriorate quite quickly. [Kylie, 27-38]

As Kylie recounts, Mr Whitehead expressed a wish to be at home when he dies. From this moment on, Kylie felt that she should “move things forward” to arrange this. This involved expressing her concerns to the AMS ward team:

My concern was that he would run out of time... what are we keeping him in hospital for if home is where he wants to be? That's when it was our priority. [Kylie, 69-71]

Towards the end of their conversation, the priority of discharge destination over further acute care was clarified:

“Are you the kind of person who wants us to just be open and honest with you?”, Kylie asked. Mr Whitehead replied “Sometimes.” Kylie followed this by describing the outlook of his metastatic cancer, closing with “it's unlikely that we're gonna get you any better.” This seemed to trigger a moment of energy from Mr Whitehead, who immediately replied “I don't want to get better; I want to die!” [6b]

Rather than continuing intravenous therapy and other acute care in hospital, Kylie considered the priority in this situation to be to ensure Mr Whitehead is discharged quickly so that he is at home when he dies. This is an urgent priority because Mr Whitehead's health is deteriorating rapidly and he wants to die; he is one foot in, one foot out. The reason for this being so important is because it was “very important to him to die at home” and his “expressed wish”. In this way the priority of treatment in this instance was to reflect Mr Whitehead's wishes.

However, when it came to arranging a package of care for Mr Whitehead, Kylie's approach was slightly different.

I negotiated with him what would be appropriate. [Kylie, 98]

Kylie sat on the plastic chair, leaning forward with interest as Mr Whitehead described the circumstances and rhythm of his household.

He said night times were very important because he felt that that's what had led to this admission to hospital, because he didn't have a carer overnight, he'd got more breathless and he couldn't summons help from the family members who were in the house. So that's what he felt. So to him, that's what was important to him. So he wanted overnight help. [Kylie, 99-103]

Kylie, however, felt that daytime was more of a concern than night-time; Mr Whitehead's grandsons were around at night. She knew the logistical restrictions that would accompany Mr Whitehead's wishes, thanks to having "twenty-something years of experience and [knowing] the systems" [Kylie, 95]:

I said "well, if you have overnight help we probably won't be able to get you care all day through the day. We could probably put in three times a day care, with some gaps in-between that." [Kylie, 103-105]

After some further discussion, they came to an agreement. As Kylie says:

So I negotiated with him: three times a day care from a care agency, with two visits from a district nursing service, a telephone contact to rapid response from palliative care, and someone there all night every night. He was happy with that. He felt that was maybes a bit too much, when I asked him. He said "well [sigh]". I said "well let's go with that, and we can reduce it if need be." [Kylie, 107-111]

Here was an instance of Mr Whitehead's wishes being both directive and subject to *negotiation*: directive with regard to location, and negotiable with regard to the package of care. Kylie describes some occasions when location of death is also open to negotiation:

We often... try to guide people. If we think that home is gonna be difficult, whether that's because of their uncontrolled symptoms or the lack of resources to be able to give them 24 hour care or because their family aren't gonna cope- are gonna find it really really difficult because there's a high chance they're gonna have an awful death based on what's going on. We might really try to steer them towards home not being the right place, and offer them the other options up. And we do that quite creatively! [laughs]. [Kylie 142-150]

This 'steering' involves painting a mental picture for patients:

By "home will be like this [gestures demonstratively with hands], and it might be – and at the minute you can ring a bell and someone's with you within a couple of minutes. You would make a telephone call or ring a care call alarm and someone might get to you within two hours. Your family members might observe you in pain or distress, or die in the time waiting for somebody to come to see you. Would you want your family to see that?"... I talk about being open and transparent but, I don't know, I think sometimes we use it to try and guide people as to what's right for them. [Kylie, 150-158]

Kylie's account of figuring out what's best for patients involves both advocating for what's important to them as well as guiding them towards "what's right for them." She explains:

It comes down to your own beliefs about what you would want, what you would want for your loved ones, what you would want. I think you build up some of that. I've got staff in our team who are total patient advocates and no matter what the scenario is, they will be 100% patient advocate... So they will just: patient says they want to be at home, they'll do anything possible to get them home. [Kylie, 168-175]

The desire to ensure patients' wishes are realised and the desire to do what's right for them are two desires which can pose a dilemma:

It does give you a dichotomy... advocacy is probably the first value that we try to instil in our palliative care team members, and then paternalism come in a bit later on! [laughs] [Kylie, 181-183]

Whilst Mr Whitehead's interaction with Kylie teases out an important conflict in the decision-making process. As she puts it, it is a tension between "advocacy" and "paternalism". On the one hand, the advocacy approach seeks to respect Mr Whitehead's wishes; if it is important to him to die at home, then it is important to the team that Mr Whitehead dies at home. "If it matters to you, it matters to us", as the poster puts it [1a].

On the other hand, the paternalism approach seeks to do what is *right* and, where this conflicts with a patient's wishes, it is the patient's wishes that the paternalist tries to change: "to try and guide people as to what's right for them" [Kylie, 158].

In times when there is a conflict between what course of action the patient thinks is best and what course of action the clinician thinks is best, advocacy and paternalism bifurcate. According to an advocacy approach, the clinician's opinion yields to the patient's wishes, which are paramount. According to a paternalist approach, the patient's wishes are to be negotiated towards the clinician's knowledge of what is right.

The conflict between advocacy and paternalism, here, can be characterised as a conflict between bioethical principles. According to an advocacy approach, 'respect for autonomy' trumps 'beneficence' or 'non-maleficence'. According to a paternalist approach, however, the order is reversed. Likewise, the tension that Kylie exhibits and articulates can be characterised as a conflict between values. An advocacy approach cherishes the value of *choice*; getting what you want is a good thing. A paternalist approach cherishes the value of *welfare*; getting what helps you flourish is a good thing.

How Kylie selects what the priority of treatment is and how she arranges carers for Mr Whitehead at home are two conflicting approaches. This conflict is similar to that between the decision-making of younger and more experienced palliative care team members. It is the conflict of advocacy versus paternalism. In terms of values, it is a conflict between *choice* and *welfare*.

8.2.2 Wellness vs. wishes

The tension between what is important to the patient and what the professional says is right is experienced, from a patient's perspective, by Mike. Yesterday, Mike came to hospital short of breath and hypothermic, and is being treated for a chest infection. He is lying in bed attached to a drip for intravenous antibiotics. The consultant-led ward round has just passed. Despite having hopes of being back home today, Mike was told that he is not fit for discharge today. Immediately afterwards, he shared with me what he was thinking. He gazes down to the floor as we talk, looking bored and despondent.

I'm not stopping in much longer like. I've had enough, oh aye. [Mike, 35-37]

Mike describes a limit to how long he would wait in hospital under medical advice:

Well it's me birthday for a start on Saturday. I'm not sitting in here, you na what I mean, when it's me birthday. [Mike, 39-40]

I could gan yem [go home] now if I want. You na what I mean? They can't stop us. I'll discharge meself but I cannot see the point. [Mike, 97-98]

Mike summarises his plan:

I'm gonna sit and listen to what their advice is... see what they've got to say... God knows when I'm gonna get yem like... [Mike, 108-112]

I've got a choice, ya na what I mean? They're not forcing us or anything like that, you na what I mean? But I mean, even tomorrow, if it boils down to it, I'll just have to walk yem. [Mike, 118-120]

On the other side of the ward, Heidi is also frustrated that her admission has lasted longer than expected. She fidgets as she speaks, anxiously awaiting the consultant-led ward round to tell her whether she can be discharged home today:

Because I'm not a doctor 'n that and even if I looked at the scan results I wouldn't know what's going on, so I have to have the faith and the trust in the doctors that are specialising in what they're doing. So more they're gonna you know tell me what's best and what's not best. Obviously I've got to tek that into consideration and listen because even if you showed me the scan results I wouldn't be able to read it and know. So I just tek it as face value that what I'm being told is what's being told.

[Heidi, 136-141]

Whilst Heidi has faith in the doctors to tell her “what’s best and what’s not best”, she also takes what they say “into consideration” and exercises a degree of choice:

Well I could [go home] because I'm an adult and I could discharge meself if I wanted to. But then if I'm at home with me daughter and owt goes wrong, that falls back on a 12 year-old and I can't do that. [Heidi, 70-74]

Both Mike and Heidi recognise their right as adults to self-discharge but are following medical advice for the moment instead. In considering whether to stay or go, they both are balancing their wishes with concerns for their wellness. This balance is not clear-cut, however. Whilst both Mike and Heidi desire to go home, they also desire to be well. Thus, it is not a simple balancing act of wishes-against-wellness. There is an indication in both accounts, however, that their autonomy, as adult patients, cannot be undone by medical authority: “They can’t stop us”, says Mike; “I’m an adult and I could discharge meself if I wanted to”, says Heidi. They can accommodate medical advice for the present time, taking it into consideration. However, if their patience is stretched too far, Mike and Heidi’s *choice* would trump medical concern for their *welfare*: “if it boils down to it, I’ll just have to walk yem [home]” (Mike).

8.2.3 Safety vs. preference

I have so far presented the conflict between *choice* and *welfare* in two manifestations: advocacy or paternalism, wishes or wellness. I now turn to a third way this conflict manifests: preference or safety.

Maureen has been sitting in her cubicle since Fergus the pharmacist and his assistant left. She is waiting for visiting time, when she can finally spend time with her family and partner, who live far away. Although it is her preference for visiting hours to be extended for her family, her preference is not accommodated. She describes a similar pattern occurring with regard to her medications:

I do feel frustrated when I look in my pot [for medications] and I think well, I don't even know what I've got anymore. Because I do like to know. But there has been times when I've thought "well I am not takin' that!" [thumps table, laughs]. [Maureen, 95-98]

Maureen describes how she wants to be in control of her laxative medications, and is frustrated if she cannot administer them according to her own judgment:

[The tablet] softens things up a bit. And I had had enough, d'you know?! I was like "no, I don't need it anymore!" But [the nurses] still give you it. They don't ask if you want it. You still get given it. And I thought "well, I don't want it, I don't need it." [Maureen, 103-105]

However, there are other medications which Maureen is quite happy to be administered or denied without any accommodation of her preference. She describes what happened with regard to some kidney-related medications:

Basically "we're not giving you this, we're not giving you this, we're not giving you this, and you will take that." And I just do it. Because they've been in touch with the Lighthouse so I know that the renal team are the ones that are sorta like leading the way. So and I mean they're the ones I rely on to keep me fit and well. So I was quite happy to go along with things. [Maureen, 88-91]

The Lighthouse Hospital is the specialist hospital which is responsible for the management of Maureen's renal transplant. From Maureen's point of view, there are two different types of tablets: laxative-type tablets, about which she "would like to know" and use her discretion, and renal-type tablets, about which she "is happy to go along with things".

Fergus the pharmacist spoke with me afterwards about his interaction with Maureen, in which medications were reviewed and changed.

Laxatives patients refuse all t' time. T' nurses will tell "oh it's a laxative" and they'll go "well I don't want to take that." If you see refusals for drugs, if you ever look at drug charts and what patients refuse: painkillers 'n laxatives! [Fergus, 351-353]

Fergus goes on to describe how staff respond to this:

So a nurse will usually encourage more heavily to take normal meds than they would laxatives or painkillers. So you do see that, I don't know if that affects it. Also from a pharmacy perspective, laxatives aren't [whispers] something you really care about! They're something you buy over t' counter. They're not high-risk meds. [Fergus, 355-358]

Like Maureen, Fergus indicates two types of medications:

So from a nurse's perspective, they don't really care about "oh they're not taking their laxatives, they're not on any paracetamol but they do need their antibiotics." And how you come about a patient, especially elderly patients, how you come to them and how you talk about medication is very different. So for example, a good example is tablet size. Patients hate- a lot of antibiotics are huge tablets. Patients hate them. So they're very quick to go, if the nurse thinks they're in any way struggling or would take a liquid easier, they'll come to you and ask for liquid very quickly. Because in- because they're part of a critical meds list, because they're deemed important treatment, by nursing staff by everyone, you don't want patients refusing antibiotics, so you want to encourage differently. [Fergus, 372-380]

Whereas laxatives are a type of drug which nurses reportedly "don't really care about", antibiotics are a type of drug which is "important treatment" on a "critical meds list". Fergus goes on to describe the process of figuring out what is best for medicating patients:

There's a default for safety. So if your kidneys aren't working, literally [pharmacists] will slash and burn. They will. Sorta like "no no no, that's off limits". And that's never almost never discussed with a patient because they are just made. Look at t' drugs, a decision is just made. [Fergus, 254-256]

A decision is made immediately to cross off kidney-harming medications in circumstances of kidney failure. On the basis of safety, such drugs become "off limits." Fergus describes what happens if a patient would like painkillers which are harmful to kidneys:

So if you had... NSAIDs [non-steroidal anti-inflammatory drugs]. Because they're ones that are very nasty for- very nephrotoxic [harmful to kidneys], but patients quite like it for the painkiller effect. And they are automatically default stopped because they're so nephrotoxic. [Fergus, 269-272]

Despite a patient's wishes or preference for a medication, if it is harmful then the medication is "automatically default stopped". Fergus continues to describe how this is enacted in practice by pharmacists:

I'll be honest, if it's me I'm usually having a conversation. I'm telling them "it's because it's damaging your kidneys. We will not be giving it." Usually, from my perspective, I think pharmacy is very much so much more cut 'n dry. Usually if we're telling a patient, we're telling them "it's stopped for this reason." And it's usually a discussion of "there are other painkillers we can use and we'll look at them." So say for example, it will be "we'll try 'n give you other painkillers instead." But if you're kidneys are damaged, certain drugs are pretty cut 'n dry. However much you like them! [Fergus, 275-281]

Fergus summarises his approach to this conflict in terms of value judgments:

Patient safety always beats patient choice. However much they like their opiates [a class of painkillers], if your kidneys aren't working you actually need to change your opiates and that's it.
[Fergus, 284-286]

From Fergus' perspective, a patient's request for a painkiller or laxative medication is of secondary importance compared to protecting their kidney function. Their wish for laxative-type drugs is a matter of choice; the damage to their kidneys is a matter of safety. "Patient safety always beats patient choice."

With regard to communication, Maureen's priorities are the inverse of Fergus' priorities. The laxatives that he "[doesn't] really care about" are precisely the drugs she wants to know about. With regard to values, however, it seems Maureen's priorities match up with Fergus's priorities. When it comes to drugs which are a matter of her *welfare* (described in terms of safety), she is willing to forgo her involvement; her preferences concede to the higher priority of needing to be kept "fit and well" by the Lighthouse hospital's renal medication. Just as "patient safety always beats patient choice", so the value of *welfare* in this instance beats the value of *choice*.

8.2.4 Best interests vs. capacity

So far, I have characterised three decision-making tensions as manifestations of a conflict between two values: *choice* and *welfare*. The next tension I describe is one which relates closely to the experience and management of patients who are classed as mentally ill within an AMS.

At 4 o'clock in the afternoon, I walked onto the ward and observed an interaction which struck me as both comic and tragic. The door of cubicle 15 was open but guarded. The guard was the smallest person on the ward: a healthcare assistant called Kerry. Kerry is a short, thin, middle aged woman who is seated on a little plastic chair at the doorway. She is wearing the typical brown top and trousers of healthcare assistants and facing away from the cubicle. What is remarkable about her appearance, however, is her posture. One of her skinny legs is extended horizontally across cubicle 15's door and resting on a plastic chair which is positioned at the other side of the doorway.

As such, her little leg was functioning as a barrier. She was leaning against the back of her plastic chair in a relaxed posture, checking her hospital handset at the same time. [7d]

Inside the cubicle, a teenage girl was pacing up and down agitatedly. She intermittently muttered something to the healthcare assistant which I couldn't quite hear. But the little healthcare assistant's voice boomed back, speaking over her shoulder:

"Well you can't. It's for your own good." [7d]

Whilst it seemed tragic that this teenage girl was trapped in the cubicle, the manner in which she was enclosed seemed to me to be a little amusing in its absurdity:

This tiny healthcare assistant with her leg extended across two plastic chairs was a symbol of power: [the teenage girl] was not free to leave across this psychological barrier. It struck me as a surprising way to symbolise power. [7d]

What events have led to this teenage girl entering this enclosure and not able to exit the barrier?

Another healthcare assistant called Sharon is giving me a who's-who of all the patients in her section of the ward, pointing at their door as she starts the patient summary. She pauses as she points to cubicle 15:

Actually, we've got one of our annual attenders in. Sorry, I mean weekly. She's a regular attender. Knows all the staff. We all know her. Comes in with overdose. Paracetamol. She even took more on the ward once. Nice girl. In all the time. She's currently off the ward with Ryan I think, dunno why. [7d]

Sharon is in her 50s and thickly built. She speaks with confidence, holding a nurse handover sheet in one hand. The short sentences with which she speaks reflect the punctuated pattern of speech during handover, as if she may be passing on the messages that launched the day into action.

I soon accidentally discovered where "bed 15" was, as I left the ward for lunch:

As I walked along the corridor, I saw nurse Ryan. He was walking along, smiled at me and said hello. Two steps behind him walked a young woman, who appeared around 18-20 in age. She was wearing her own clothes: a baggy green top over white pyjama bottoms with a dotted pattern. She was very thin and quite small; I would guess just over 5 foot. She walked along with her arms crossed, as if reluctant to be here, and resentful of the company. She seemed upset, with her head directed down towards the floor, eyes looking up and eyebrows lowered. I didn't say hello to her although we made eye contact and I guessed immediately that she must be the patient from cubicle 15. [7d]

The procession continued:

Two steps behind her walked two security staff. They were both men, tall and big-built. They were dressed mostly in black and wore thick vests, which looked a bit like bullet-proof vests. They walked in a very relaxed fashion, almost dawdling. I found the contrast between the physique and posture of the woman ("bed 15") and the security staff quite dramatic, almost amusing, were it not for the

serious and tragic nature of what was going on. I supposed that she was being escorted back to the AMS from the canteen. [7d]

Once “bed 15” was back on the ward, I learned her name was Emily and went to see her:

Emily was sat cross-legged on her bed, wearing her own pyjamas with a baggy green top... She sat upright with her back against the wall. Opposite her was a blank green wall, at which she was staring when I entered. In the corner of the room was an intravenous drip stand, with a partially used bag of fluid at the top. The drip was not attached, as if it had been started and then stopped. [7d]

As Emily spoke with me in her cubicle, I viewed the ward from the other side of the door:

The door was closed, and every few minutes the face of a staff member could be seen looking through the window and then walking on: healthcare assistant Sharon, nurse Ryan, consultant Dr Taylor. This I found distracting at first and looked out each time someone looked in, and then I found I just got used to it. I noticed that Emily would not find it as distracting as me, and would continue talking, seemingly familiar with being monitored in this way. [7d]

As we started talking, Emily quickly cut to the chase:

On Wednesday night I took an overdose of paracetamol and I live in supported living, so I was found by the staff. The staff then rang an ambulance. Didn't want to come to hospital because then I'd have to have treatment, so then the police were called and they brought me here. And now that I'm here I can't leave. The doctors have decided that I don't have the capacity to make my own decisions anymore. Because I would like to leave and I don't want the treatment. So it isn't up to me anymore. I don't really have a choice, which isn't very nice. [Emily, 6-11]

She describes her understanding of “capacity” and how she has responded:

The doctor said my mental health is affecting my ability to make decisions so therefore I don't have the capacity... I think that's what it is. They have told me a few times. I can't remember... [I'm] upset, because I know that I can't leave here. I've tried to leave and the security bring me back, which isn't nice. Like last night, when I was forced to have treatment, I was sedated. That wasn't very nice. But they say that they're doing it in my best interest. [Emily, 14-21]

Over the course of the afternoon, nurse Ryan has been busily going back and forth between patient bedsides, the notes trolley and the Lab room where medications are stored and prepared. Even during his lunchbreak, Ryan spotted Emily “absconding” [7d], called security and escorted her back to the AMS. He describes his involvement with Emily also in terms of capacity and bests interests:

Well, for capacity as well. Because, I mean... we get quite a lot of patients who come in with overdoses. We get one regular attender who comes in with the same kind of paracetamol overdose every other week she comes in. And she'll go through the same thing. She'll come in, she'll refuse treatment. And then her bloods get taken and her bloods are getting worse and worse and worse and it's obviously affecting her kidneys and things like that. And her liver. And for her best interests, I speak to the doctor and we try and, as best as we can, to try and guide her to getting her to try have the treatment.

[Ryan, 27-33]

“Guiding” Emily to try treatment is often not an easy process:

She has a lot of mental health issues going on. So it's quite hard to engage with her sometimes because one minute she'll be fine and she'll be willing to accept the help. And the next she'll be pulling her cannula out, and then that's the treatment gone. And then she'll be absconding off the ward, and you have to go and, like, try and find her. And then she's also been found in the toilets to be slitting her wrists and things like that with a tiny little blade that she's got. It looks like a pencil sharpener blade? Slitting her wrists in the toilet, trying to hang herself in the bathroom and things like that.

[Ryan, 35-43]

Ryan describes how the clinical team work together:

So we have to just make the decision to- as a team, as a multidisciplinary team, to kind of put best for patient interest in. So she can't maybe refuse the treatment because it's in her best interests. So we've got the psych team in, we've got the doctors on board. And basically it's, it's “you're having your treatment, otherwise you'll be in critical care.” So, yeah. [Ryan, 43-47]

Ryan explains the justification for this approach:

So to let her to walk off the ward would be unsafe because we know the damage that would come. And it'll probably end up killing her. So, to let her walk off the ward without treatment, it's not in her best interests. So yeah, you've always got the patient's best interests first thing to do. So to let her to walk off without treatment would be, yeah, just wouldn't be right. [Ryan, 115-119]

Thus, from Ryan's point of view, letting Emily walk off the ward would not be right nor in her best interests because it risks damage and death.

So if we didn't do best interests, then she would end up, yeah, probably dying. It's not what you want, especially for just a young girl as well. [Ryan, 124-125]

Sharon, like Ryan, recognises that Emily is just a young girl and justifies the clinical team's actions in reference to this:

Well just to protect her really, isn't it? She is a young girl. I think that if she got the support that she needs, which is – I don't know what it is; I'm not a mental health specialist – maybe she could turn her life back around. She's just young. Far too young for his. 'cause she does seem like a nice girl.

[Sharon, 97-100]

Like Ryan, Sharon sees Emily as a young girl who needs support; the clinical team, amongst others, work together to restore order, which she conceives as follows:

So before that [traumatic incident] she was normal. Going to work, going out with her friends, driving her car. This is all from that. Since she came back she just feels the support's not there.

[Sharon, 79-80]

Staff on the AMS work together to restore order to Emily's life. This involves protecting her by not permitting her to leave, which is conceived as in her best interests. Emily's choice is not directive in this situation because her mental health is interfering with her ability to make decisions properly. Plus, her walking off the ward and risking death simply "wouldn't be right."

From the interior side of Emily's cubicle door, many things are the other way around. Firstly, security is scary:

I don't have a choice. And it's that, not having the control over yourself, that's scary. Like security coming in and holding you down. That's scary.

[Emily, 148-149]

Secondly, living is worse than dying:

I was once asked "are you scared of dying?" I was like "no. I'm actually scared of living!" I'm afraid of trying to survive. It's hard. It's really hard.

[Emily, 259-260]

Thirdly, help is an impediment:

Now I'm at the point where I don't want them to help me anymore. I hope [my liver] does fail... I hope it – yeah, because I'll die. I think I'll die. If it fails, I think I will die. I don't know too much about it but I'm pretty sure you need your liver... And then if I die, I die. If I don't then I'll just keep taking stuff.

[Emily, 59-67]

Fourthly, to care is to let go:

At the time I was like "you aren't listening. If yous [sic] cared about us, you wouldn't give us that drip". And they're like "no, we're giving you it because we do care about you". That's kind of how it's been

the last few days. I was like “you mustn’t care about us because you’re forcing us to have that”. And they’re like “no, we do care about you. We’re trying to help you” ... It’s nice. It’s nice that people care. But I just get upset because I don’t want them to care. I don’t want them to care. I want them to just let me go. [Emily, 324-337]

What is the best course of action: to let Emily go without treatment, in keeping with her *choice*, or to retain Emily for treatment, in a manner in keeping with her *welfare*? From Emily’s perspective, people ought to work together in order to restore her to a less-scared state by letting her go or letting her die. This is because what is important is being nice to her by letting her have a choice. Emily would like her choice to be respected – if only she were deemed to have capacity.

From the perspective of staff like Ryan and Sharon, people ought to work together in order to restore Emily back to a normal life. Whilst some of this may not be attainable until she gets “the support that she needs” (Sharon), the clinical team can at least keep her alive; letting her go and risking her dying “just wouldn’t be right” (Ryan). Ryan and Sharon would like Emily’s welfare to be protected – a sentiment which is captured in their use of the term ‘best interests’⁵⁴.

Emily and nursing staff thus figure out what is best according to different, and competing, priorities. Where Emily values *choice*, staff value *welfare*. On this occasion, welfare has triumphed over choice on the grounds that Emily has an impairment of her mind and is deemed to lack capacity to make decisions regarding treatment and discharge. With Emily’s *choice* invalidated on mental health grounds, the value of *welfare* takes pole position in decisions about her care.

This characterisation of best interests requires a final note of clarification. ‘Best interests’ and welfare here relate to what is seen as *good* for Emily, what is seen as *right*; what is in her best interests is “the support she needs” (Sharon) even if she does not want it. Whilst in this instance the pursuit of Emily’s best interests is the pursuit of her survival, this is not always the case. Ryan reflects on occasions when *dying* can be in a patient’s best interests:

It’s a hard one because you’ve got people who are end of life, who are in so much pain. They’ve got cancer and they’re in so much pain. And they are, like- the best thing possibly is for them to die because, if that’s what they want. And there’s no way they’re gonna come back from it. There’s no way they’re gonna improve. There’s no way they’re gonna get better. You know, if they’re in that much pain then sometimes it is in best interests, yeah. So that’s when you withdraw treatment and

⁵⁴ In keeping with ethnographic methodology, I interpret the term ‘best interests’ as it is used within this social context. I recognise that its usage here differs in some respects from the characterisation of ‘best interests’ in legal guidance in England & Wales (MCA, 2005; Department of Health, 2007).

things like that. Yeah, so end of life when you stop doing- giving them medications... You stop doing blood pressure and things like that... It is a tricky one. Because it's- the cancer patient's not- it's not a mental health issue... But with mental health, it's, you know, you're not in the right frame of mind to make the decisions that you want to take your own life. [Ryan, 127-142]

Ryan here is keen to emphasise the *irreversibility* of the cancerous condition, such that survival is an increasingly limited aim. He is also keen to emphasise the *painfulness* of the patient's present state, such that the quality of the patient's life experience is increasingly compromised. Here Ryan's estimation of best interests involves an interplay between the two notions of survival and quality of life. This leads to the fifth and final decision-making tension.

8.2.5 Survival vs. quality of life

Like Emily, Sheila is a young woman in a cubicle who is in the AMS after taking an overdose. She is wearing black and is sat cross-legged and cross-armed on her bed. The lights are turned off, as if she does not want to be seen. Sheila's mother is sat in the armchair beside her, leaning forward anxiously and with her hands together in a prayer-like position [8d].

Sheila is quick to share her concerns with me. She is worried she is "going mad" because thoughts keep "zooming" through her head in a destructive way [8d]. This has blown up recently in an explosive relationship break-down with her girlfriend. She struggles to put it into words at first:

I feel like my thoughts are just- like I run away with- like I get like a small idea and it just like blows into this massive- she's married to- like, she's not even going out with her and I'm already thinking they're gonna be like together for a long time and whatever else. [Sheila, 8-10]

Sheila connects this with her mental health:

I just feel I know what I'm thinking isn't right. And I just can't- I can't like, dunno. Just very like paranoid and I get really anxious all the time and feel like I can't breathe and just don't feel right in my head. Like I'm just so- I just make everything worse all the time. [Sheila, 31-34]

I just feel like there's something wrong with me. Something about the way I go on isn't normal. [Sheila, 52-53]

Sheila and her mother are worried that a pattern is developing of difficult relationships in the family. Sheila's mother, after sharing some of her own troubles, concludes:

I'm not very good in relationships, [to Sheila] am I not? And what Sheila's seen me go through, I feel somehow it's been linked to how she is. Yeah, it's repeating. And it's not healthy... But I don't know what to do. [Sheila's mother, 109-112]

Both Sheila and her mother shed tears as they speak with me, their voices intermittently choking up with sadness. After a moment's pause, Sheila describes what it would be like for her to be well:

I just want to be happy... I just wanna be able to deal with certain situations- I can't deal with things. I can't cope very well. I've got no coping mechanisms. I've been like, sounds stupid, I've been on like YouTube looking at ways to cope in like bad situations. I try and like be really really strong but just something happens and I just- like I'm fine, I'm like laughing and listening to music and then something just like clicks and then I just like I get like really really warm, and like I get really really anxious and like shaky and I feel like I can't breathe. And then I just start like thinking things in my head all the time. And then I have to try and stop myself because I know it's gonna make me ill.

LM: Okay. So to be well would be to be free of that pattern?

Pt: Yeah. To be, like, at peace... I just want to be happy. [Sheila, 61-73]

Outside the door, two doctors are gathered at the notes trolley, preparing to see Sheila. After looking at the red notes folder, the computer screen and the nursing measurements, consultant Dr Morrison takes the red folder and pulls out a pen. "Why don't you see this one and I'll scribe?" [8d] she says to Zoe who looks surprised and a little nervous but agrees nonetheless.

I watch from a corner of the room as the interaction progresses. After a brief introduction, Zoe mentions she understands that Sheila has taken some paracetamol tablets. She checks how many, what time, whether they were consumed all at once, and whether any alcohol had also been consumed at the time. After a moment's pause, Zoe checks for any symptoms since the overdose "like pain or sickness". Sheila and her mother watched in silence as Zoe proceeded to "have a little look at you", which involved Zoe feeling Sheila's pulse, listening to her chest and pressing on her abdomen [8d].

As Zoe stood up straight again, a summary and plan was described: "okay, so from a physical side of things, things seem to be okay. Your bloods are normal and there doesn't seem to be anything to worry about. We'll just wait for the mental health team to come and check they're happy from a mental health side of things and take it from there. Does that sound okay?" Dr Morrison finished writing, closed the red notes folder, nodded approvingly, and the pair left the room [8d].

On reflection, there seemed to be a conspicuous absence of engagement with Sheila's psychological and relational concerns. After all, Sheila is seeking healthcare because she wants to be "at peace" and "happy".

Why the silence in this regard? How does Zoe know there is nothing to worry about? Does she care only for Sheila's physical recovery (survival) rather than Sheila's experience (quality of life)?

This apparent disproportionality is particularly poignant in light of Zoe's professed "ideal":

I think we would all say that the ideal is that all care we provide should be patient-centred. But realistically it probably isn't. So I think patient-centred to me would mean that rather than treating someone with their diabetes or whatever the condition might be, it's about the individual and their set of circumstances, which includes physical, psychological, social. [Zoe, 272-276]

I guess every human is an individual and has their own passions and interests and priorities, so it's taking those into account rather than treating people as a condition. And therefore providing individual care. [Zoe, 282-284]

In interview, Zoe describes the importance of psychological and relational social considerations as part of providing individualised care. However, in consultation, this seems to be decidedly not the case. There is more going on here than first meets the eye, however. For this reason, I will present Zoe's account of how she figures out what is best in other scenarios before returning to this interaction with Sheila.

I saw someone else in the AMS the other week who had sepsis of some sort. And then acute kidney injury and they weren't passing much urine. And they were quite elderly. And the prognosis didn't look good. So they might have pulled through with treatment but we weren't sure. And I sat down with his son and daughter and actually they made it very clear that he didn't want to be here since his wife had died. He didn't enjoy his quality of life as it was at the moment and actually they thought he was ready to die. So, yes, we should treat what we could, but actually if this was the end of his life, then their priority was comfort but they kind of felt like he was at a place when actually he was ready for that. [Zoe, 161-169]

Zoe recognises that life-extending treatments can be unpleasant for patients to experience:

I was sitting there trying to decide: do I cannulate them or not? Because these things, they're not nice. Cannulating people isn't nice. Doing ABGs [arterial blood gases] isn't nice. The things I had to offer are things that aren't nice and I didn't know whether they'd work. And I wished a decision had already been made about that. So it would have been easier to know how far to go. [Zoe, 184-190]

Zoe describes having to weigh things in a balance:

I knew that the things that I could offer would cause some distress. The patient was confused and drowsy and therefore doing things to them that they don't understand what you're doing, it's

unpleasant, it's scary. And they will be painful. They were very shut down [low blood flow to the peripheries] so I thought it's unlikely that we're going to get a cannula in easily, so we're probably going to end up doing several attempts. And all these things aren't nice. So although we could still treat some of his symptoms... doing things was going to cause some level of distress or harm, even if it was also to benefit them. [Zoe, 193-201]

Zoe was able to identify competing priorities by comparing this case to another case she managed recently:

[He] was only 21 but had very severe cerebral palsy. And you do want to have that discussion with the family of "what is your priority?" and "is your priority surviving?" whereas with a fit 21-year-old you wouldn't have thought to have that discussion. [Zoe, 219-222]

In summary, Zoe says:

Unless they've got a life-limiting condition I think we always prioritise survival. [Zoe, 226-227]

Zoe has intimated that, where "surviving" is one priority, "comfort" or "quality of life" is another. She expands on what she means by 'quality of life':

I think it's what it is that is important to a person for them to get joy out of their life and enjoy- yeah, enjoy their life and feel like it is either worth- I guess either worthwhile or getting some kind of joy from it and whatever that might be to them? So that might be being pain-free, or that could be getting to see your granddaughter be born, or it could be living at home and not being in a care home. Like whatever that might be that means that you have some joy in your life and feel like you can fulfil what you want to in your life but I guess there's something about it that's a here-and-now thing rather than a longevity thing, I guess? [Zoe, 256-262]

Zoe manages to summarise the conflict between priorities:

Quality rather than quantity, I guess. So it's different to 'how long have you got?' It's more about 'what's important to you?' Now, with the life that you have now. Rather than in the future. [Zoe, 263-265]

There is thus a potential conflict between extending the quantity of life and improving the quality of life, particularly when life-extending measures are unpleasant. According to Zoe, survival is usually the priority unless the patient is approaching the end of their life, at which point it is a more difficult balance. This balance requires acknowledging the patient as an individual person in a community and what "place" they are in psychologically.

To draw too sharp a contrast between 'survival' and 'quality of life' risks a false dichotomy. After all, if someone does not survive then he or she has no quality of life. Likewise, to hastily translate 'survival' to the prioritisation of *welfare* and 'quality of life' to the prioritisation of *choice* risks is profoundly simplistic. After all, a holistic conception of welfare would ensure the whole person, complete with psychologically and socially situated choices, fares well. Nevertheless, Zoe's depiction of "quality rather than quantity" does permit the characterisation of a tension which results from *choice* and *welfare* in competition with one another.

I return now to Zoe's interaction with Sheila. In the world of an AMS, to prioritise survival is to promote someone's good in the material world, the world made up of breathing lungs and beating hearts. In this world, it does not matter much that Sheila "gets really anxious all the time and feel[s] like [she] can't breathe" because "from a physical side of things, things seem to be okay" (Zoe). If the priority is ensuring Sheila survives this overdose, it is more important to "have a little look at [her]" than to have a long listen to her. *Why* she took the tablets is not as important as *what*, *when* and *how*. What matters more than whether Sheila is an "individual with passions and interests and priorities", is that her "bloods are normal and there doesn't seem to be anything to worry about" [8d].

Survival requires the proper functioning of bodies and body parts, which can be supported to do so by medical interventions. In a patient with sepsis, for Zoe to prioritise survival involves the painful of inserting cannulas because intravenous fluids and antibiotics may be required to restore proper functioning to his body. It's not pleasant for him, it's not nice for him, it may not even have been chosen by him; but it is *good* for him. To prioritise survival is to prioritise the patient's *welfare*.

In contrast, to prioritise quality of life is to promote someone's good in the *life*-world, the world made up of memories, experiences and hopes. Quality of life is not restricted to the currency of physiology. People have a good quality of life when they "get joy out of their life and enjoy their life and feel like it is... worthwhile" (Zoe).

To prioritise Sheila's quality of life is to pay attention to her desire to be "happy" and "at peace" and her wish to be able to "cope" and not "make everything worse all the time" [Sheila, 34]. It is to consider reasons and choices, not just symptoms "like pain or sickness". It is to put a finger on her anxiety rather than a hand on her abdomen. In a patient with sepsis, for Zoe to prioritise quality of life may *avoid* intravenous fluids and antibiotics because the pain of inserting a cannula may compromise the patient's joy and experience of life. Such measures may be 'good' for the physiological normalisation of human organ function but they are not necessarily 'good' for the life of the person and may not be reflective of his wishes. To prioritise quality of life is to prioritise the patient's *choice*.

In interview, Zoe describes her ideal to appreciate a patient's quality of life and thus to offer individualised, patient-centred care. In practice, however, she exhibits a concern for Sheila's survival with relative neglect of Sheila's quality of life. This may be a result of the division of labour and Zoe's awareness that the mental health team will attend the patient after her. Nevertheless, she experiences a tension which is exacerbated in the pressured situation of treating the elderly man with sepsis and the 21 year-old with cerebral palsy. In such situations, Zoe is left unsure how to adjudicate between the competing priorities of survival and quality of life and their associated primary values of *welfare* and *choice*. In Zoe's words, she "wished a decision had already been made about that. So it would have been easier to know how far to go" [Zoe, 184-190].

8.2.6 Conflict and values

I have presented five kinds of decision-making tensions, in which decision-makers are pulled in different directions: *paternalism versus advocacy*, *wellness versus wishes*, *safety versus preference*, *best interests versus capacity*, *survival versus quality of life*. In each of these tensions, I have sought to demonstrate that one side of the dualism prioritises the value of *welfare* and the other prioritises the value of *choice*.

This is not to claim that either 'welfare' or 'choice' fully capture the meaning of any of these terms. Such a reductionism would merge the five tensions into one, neglecting their subtle differences. It is to claim, however, that each side of a tension appeals to an evaluative standard for its justification. The ways that such justifications are enacted within this AMS can be broadly grouped into two: those which assess how good a course of action is by whether it promotes *flourishing* according to what is *best* (objectively), and those which assess how good a course of action is by whether it respects *autonomy* according to what is *wanted*. In shorthand, the former prioritises the value of *welfare*; the latter prioritises the value of *choice*.

It could be tempting, at this point, to conclude that tensions in decision-making are simply due to a conflict between two values: welfare and choice. However, that would be not just simple but simplistic. Further interpretation of the data suggests that there is, in fact, a third value involved in decision-making tensions within the AMS. When it comes to figuring out what course of action is best, this third value is perhaps less conspicuous but equally influential.

8.3 A third value

I return now to the discrepancy between Zoe's ideal of individualised care, which attends to psychological and relational concerns, and Zoe's enacted care which tended only to "the physical side of things" [8d] when she met Sheila and her mother. A second interpretive look at this will disclose a third value which is involved in figuring out what is best: not just welfare and choice, but also *effectiveness*.

8.3.1 'Half an eye on them'

Zoe reflects on the encounter with Sheila:

It was a bit of a different day. So when you turn up on the AMU, often how a day is is quite dependent on what consultant you have on with you because different consultants like to work differently... Dr Morrison wasn't keen for me to see patients on my own... that was really unusual. So I virtually never go with a consultant on a ward round unless we're going to review new patient later in the day. 'Cause usually it's more efficient for me to just go and see patients on my own. So I think actually that was more off-putting and kind of out of my comfort zone because I'm not used to having a consultant watch me see a patient unless it's for an assessment. [Zoe, 10-17]

The presence of Dr Morrison affects Zoe's manner:

I'm better when I'm not being watched. Because then I can just be more normal and myself. [Zoe, 28-29]

Zoe unpacks what the effect of having a consultant present is like:

I find it quite difficult when you've got consultants because ultimately the patient is theirs and if they disagree with the decision you're making, they can change that and say "I don't want to do that." But you don't want to undermine- you don't want the patient to lose trust in you, I guess. And you don't know whether the consultant is gonna interrupt halfway through and say "actually that's not what I think we should do", or whether they're gonna wait till you get outside, or whether they're not gonna do that at all. [Zoe, 30-35]

The presence of a consultant particularly influences the clinical plan that is made:

And you feel like you're saying "this is what we're going to do" but with half an eye on them, in case they say "actually that's not what we're going to do" and I've certainly been in consultations or assessments before when the consultant's been like "oh actually maybe they could go home." Or have interjected at that moment. [Zoe, 38-41]

As Zoe summarises:

In this [encounter], at any moment [the consultant] could choose to intervene... So you're not in control- I don't feel like I'm as in control of the consultation. And I don't feel like I'm as in control of the decisions. [Zoe, 45-49]

Zoe describes the presence of a consultant, who has the authority to over-rule her at any moment, as a presence which leaves her cross-eyed; as she looks at the patient, she also has "half an eye" on the consultant, who effectively controls the decisions.

Zoe applies her ideal to Sheila's situation:

The overdose is the physical effect that you can see, but in order to provide best patient care you need to understand what's underlying that in order to improve patients' quality of life and stop them taking more overdoses. [Zoe, 455-457]

The division of labour has an influence on Zoe's approach:

I always feel uncomfortable... because I know that they're about to go through it in more depth with the mental health team who are more trained in being able to answer those questions and help with those symptoms and provide appropriate support, whereas often at the end of it I don't have anything to offer and I know they're about to see someone that does. [Zoe, 465-469]

This pragmatic approach is not entirely satisfying for Zoe, however:

But I also feel it feels superficial and odd to not mention the fact that they've taken an overdose, or just to say "are you feeling well this morning? Okay, great, we'll get the mental health team to see you" feels very false. So I'm not sure what the answer is and I don't think I've really found a good middle ground. [Zoe, 475-478]

Thus, in Zoe's eyes, "go[ing] through it" may be ineffective; she is not well-trained for the conversation, has little to offer at the end, and Sheila will only end up going through psychological and relational issues again with the mental health team anyway. At the same time, Zoe recognises that this pragmatic approach, which reflects how the workload is divided up in the AMS, feels "superficial and odd". Whilst this structuring of the workload is influential, it is Zoe's perception of the consultant's wishes that is ultimately determinative:

It's difficult when you're being watched by a consultant because you don't know what they expect of you. [Zoe, 462-463]

I didn't know what that consultant, who was watching me, was expecting. Some consultants are like "why are you bothering going into it?" and some would come out and say "you didn't go into at all why they took the overdose." So I guess probably I was also trying to do somewhere in-between. [Zoe, 479-482]

Positioned beside the authoritative figure of the consultant, Zoe feels she is not "as in control of the decisions". There is no point in her doing something that goes against the consultant's wishes because she may be over-ruled, which may cause the patient to "lose trust" in the clinical team. Thus, the most effective approach is to speak to the patient with "half an eye" on Dr Morrison, echoing what she expects.

Despite Zoe's ideal of patient-centred, individualised care which tends to psychological and relational concerns, she has not spoken with Sheila about her distressing circumstances on the grounds of

effectiveness: it is not effective for her to duplicate the work that the mental health team will manage more effectively, and it is not effective for her to diverge from her consultant's expectations.

8.3.2 Being realistic

Zoe identifies an additional reason why individualised care can be ineffective within the AMS:

I guess every human is an individual and has their own passions and interests and priorities, so it's taking those into account rather than treating people as a condition. And therefore providing individual care. The problem with that is that is more time consuming than providing standard care. So it's easier to be like "you three people have paracetamol overdoses so we're going to give you a NAC [infusion treatment for paracetamol overdose], and you three people are on the DKA [diabetic keto-acidosis] protocol and you're at this stage of it." That's much quicker. Providing individualised care for people is more time-consuming. [Zoe, 282-288]

Time-consuming care can be ineffective:

We are very busy and stretched and often have multiple demands on us at work. So anything that takes more time tends to have a knock-on effect on other things. So it affects the speed you can get to the next patient on the ward round, or how many- how long it takes before you get through the ward round and therefore before you can go to A&E or before you can start discharging patients. [Zoe, 290-294]

The value of exploring psychological and relational concerns and individual circumstances is that it enables the clinician to anticipate or understand a patient's choice. After all, "you don't want to be doing something that the patient doesn't want" [Zoe, 395-396]. However, the value of *choice* needs to be balanced against the value of *effectiveness*, acknowledging that the AMU is a place where staff are "very busy and stretched and often have multiple demands". How about the other side of the welfare versus choice dualism: does the value of *welfare* also need to be balanced against the value of *effectiveness*? To explore this, I return to some encounters that I have presented in earlier sections.

Nick is the new consultant who I introduced in the previous chapter. As I presented then, he describes the importance of being methodical, which was reflected in his practice:

As he opened one red folder to read the medical notes of the next patient, Nick turned to me and said "I tend to have the same routine for each patient: notes – blood results – imaging – obs. [observations]. And actually, I think you kind of have to do that to be systematic. It's really important to be systematic. To make sure you don't miss things." [8a]

Nick's opinion is echoed by his experienced consultant colleague, Charles:

I think my routine's fairly standard for whatever- for whichever patient. I think that's a safety a patient safety thing? ... in fact if I don't do that, I don't feel I've got a good grasp of that patient. ...when the hospital is busy clearly there's pressure on discharge and things like that. But I think they're the times when, you know, it's almost imperative that you do stick to your routine. [Charles, 72-76]

Being methodical minimises the risk of missing important information and is therefore a safer approach.

Being methodical thus is in the interests of a patient's welfare. Returning to Nick's account:

"It's all about judgment and taking risk. Managing risk is an inevitable part of it." [8a]

"[In this hospital] there's lots of letters and you can go through them all one by one. But at some point you've gotta draw a line when you've read enough." [8a]

I wondered, then, why not minimise the risk as much as possible, maximising patient welfare by reading all the available information? Why draw a line at all? Nick responds:

"Again it comes back to risk. There's risk either way." He expanded on this: "being really thorough and going into depth with one patient might reduce risk for that one patient, but then there's a knock-on risk for the patient load, the rest of the department. You're not just managing one patient; you're managing a department." [8a]

The point at which Nick "draw[s] a line" is a negotiated risk assessment. This negotiation is between the welfare of the individual patient and the functioning of the department; Nick ultimately has to do what works; the value of *welfare* needs to be balanced against the value of *effectiveness*.

From a patient's perspective, the tension between these competing priorities (welfare, choice, effectiveness) can also be sensed. Next, I present two instances of this.

Maureen is a lady in her 70s (see: *Safety vs. preference*) whose sons and her partner find it difficult to travel to Middleton hospital and, as a result, the strict visiting hours on the AMU seem to her to be an impediment:

And [in other hospitals] I've found that if you can have visiting times that just that guard doctors' rounds and they guard meal times, but otherwise it's quite flexible. But obviously you've got to limit as to how many people come in at a time 'cause it can be disruptive. And I think when you're in a cubicle on your own, does it matter if you've got a visitor or not? Because it's different if you're on a ward and there's lots and lots a people with visitors, it can be mayhem. So, you know, I think you should- a bit of discretion if you don't actually live local. [Maureen, 13-19]

The priority to maintain the effectiveness of the ward was expressed in powerful terms by nurse Emma in the previous chapter, who insisted that visiting hours be adhered to and that family members are not

permitted to get in the way by “asking idiotic questions” [4d]. Here, Maureen senses that the value of *effectiveness* needs to be tempered by the value of *choice*; she wishes staff would use a little more “discretion” to appreciate the validity of patient preferences, particularly for those with unusual circumstances such as those who “don’t actually live local.”

I now turn to a second instance of value conflict being sensed from a patient perspective.

Sarah the nurse is standing alongside a healthcare assistant, alcohol support worker and the ward clerk in a ring around the notes trolley. Their informal conversation ceases when Sarah suddenly springs into action whilst the others stand in stunned silence. The cause for such change is the arrival of two porters who are wheeling a patient to be placed in cubicle 5. However, there already is a patient in cubicle 5: Gary (see: Chapter 6 *The pressure and the pace*).

Sarah’s healthcare assistant hastily pulls across a 5-foot tall screen between the two patients. The new patient is on a mobile bed. He is a frail-looking, elderly man called Arthur, in his 80s, who is extremely deaf. With a frowning expression of concern and an agitated demeanour, he shouts “I can’t hear you!” when Sarah approaches his bedside [3c].

The current patient in cubicle 5 is a middle-aged man called Gary. He is sat up in his armchair beside the window, looking comfortable and reading a magazine. His T-shirt, shorts and sporty watch give him an appearance of youthfulness. There is no opportunity for the two patients to interact, as the screen is quickly erected and Sarah rushes back with a proforma called “the admission” to start Arthur’s clinical journey, now that he is through the doors [3c].

A few minutes later, once the activity has settled down, I go to speak with Gary.

“I’m very impressed with the staff here. Can’t fault them. Some of them I’ve seen on their feet for 13 hours and then, once they’ve finished, they go round offering teas and coffees! Very impressive. Call you by your first name and everything.” [3c]

Gary continues:

I tell you what is impressive: In the morning I have a shower. Problem is, the whole bathroom gets very wet. Within 5 minutes, the lady comes in and mops it up! I didn’t even know they were watching us! I don’t know even how they knew. You don’t think they’re listening and then the next minute someone comes along with painkillers for you, so they were listening. [3c]

Evidently, Gary has observed the efficiency with which tasks are carried out, in addition to the personable and dedicated nature of the clinical staff. He changes his tone as he points his index finger to make a point:

“Mind, I’ve overstayed my welcome... I’m well now. Better give the bed to somebody else. Arthur has come in; may as well have my bed!” [3c]

Despite only watching in silence from the armchair by the window, Gary has picked up both the name of his room-mate and the pressure upon the ward as a department to make effective use of beds. From Gary’s point of view, his *welfare* is now catered for: “I’m well now”. Now it is time to be realistic; the priority of welfare is seemingly outweighed by another: *effectiveness*.

8.3.3 Decision-making involves a triad of three values

After drawing a conceptual connection between problems, needs, futility and cacophony, the mainstay of this chapter has been describing tensions in decision-making, and teasing out the value conflict which accompanies these moments. Decision-making tensions initially appeared to be manifestations of a conflict between two values: *welfare* and *choice*. However, after further consideration of Zoe, Sheila, Nick, Maureen, Sarah and Gary, I have identified a third value which is in play: *effectiveness*. Rather than simply being a battle between two competing evaluative standards, the conflict in values within the AMS is *triadic*⁵⁵: people work together to restore order by figuring out what is best according to three main values: *welfare*, *choice* and *effectiveness*.

8.4 Obvious and negotiated decisions

I have described an array of situations in which people are figuring out what course of action is best, by a thematically organised interpretive integration of field notes with interview data. These accounts of figuring out “what’s best” [Alison, 15; Heidi 138] have led to the identification of three main values, the triad of which provides a diverse range of potential decision-making conflicts. Decision-making within the AMS involves responding to things-that-ought-to-be-corrected according to the dynamic interplay of three main values: *welfare*, *choice* and *effectiveness*. Having identified a triad of values, I end this chapter by taking a closer look at how these three values conflict: when values conflict, what happens? What does it look like? What does it feel like?

8.4.1 Welfare vs. effectiveness

Many staff in the AMS find it difficult to give examples of ‘decisions’ that they make. For example, nurse Victoria says:

I can’t - because you just do them don’t you? That you don’t actually register that you’re making the decision... The decisions you make can be quite minor... Just how someone would transfer, or them

⁵⁵ A triad is a more fitting framework than a mere group of three for reasons that will be raised in Chapter 9 Discussion: *A trivalent model summarised*.

kind of littler decisions... But even that's still like just following a protocol. It's not particularly, like what you would do off the cuff sort of thing. [Victoria, 49-60]

What I, as researcher, might perceive as a decision may not be experienced or categorised by participants as a decision. Courses of action may not be reached by a deliberative process; "you just do them". Victoria's description of this reflex, unconscious approach to decision-making resonates with the account of a consultant called Kiran.

I struggle to keep pace with Kiran as he walks along the corridor. He has quickly seen the new patients admitted through the doors. As we go, he mentioned that the reason he is so fast in assessing patients is because "it's all automatic" [7a]. I explore this idea with him as he reflects with me in the office, clicking his pen energetically as we speak:

[I do things automatically] almost every day at the moment. I think sometimes ward rounds you just go, you just plough through. It's difficult. It's difficult to deconstruct it... it's been building up a bit. And I've been a consultant for three and half years now. So you do this day-in, day-out and you get- you just- you don't- I can't- I don't think I can deconstruct how I think. [Kiran, 79-84]

Kiran goes on to describe two kinds of case. Firstly:

There was someone who came in with three days' worth of vertigo and GP and one of the other acute physicians had done a Dix-Hallpike manoeuvre because they thought she had Benign Positional Paroxysmal Vertigo. And just reading the notes, I said "you've had a posterior circulation stroke." And the house officer was like "how on earth do you know that?" I was like "I just do because, you know, her vertigo's not getting better." And we did an MRI and it confirmed a posterior circulation stroke and she went off to a stroke unit. And I didn't even examine her or whatever... You know, it just comes. It just comes, I think. Just over time. [Kiran, 87-98]

Secondly:

If you get a complicated case, that's when you have to think about things a lot more. [Kiran, 98-99]

I tend to finish my ward round quite fast when I'm on call anywhere. And I keep in the back of my mind the patients that I need to go back to and think over more. [Kiran, 106-108]

In contrast to the case where he 'just knows' what is going on and what to do, Kiran recognises a second type of case: the complicated case. He gives an example of what he means by a complicated case:

This man here who's got worsening of his kidney function. And the simple things would just be to make sure he's got fluids written up, make sure he's got an ultrasound booked, make sure he's got a catheter. And then... afterwards you can go back and check "is his calcium normal? Does he have myeloma? Is his urine dip normal? Is that- has he had other bits?" You know, you can go back to it.

[Kiran, 114-118]

Kiran gives a justification for his approach:

Because you're running a unit. You need to make sure the ward round is done by eleven, half eleven, so that you know the ward runs rather than being stuck with a patient for an hour, and then you can go back and take your time with that particular patient. [Kiran, 108-111]

In order to make sure the ward runs, Kiran manages patients in two ways. Firstly, he works quickly in autopilot, "plough[ing] through" in a manner that is fast but "difficult to deconstruct". Secondly, he makes a mental note of cases which are complicated. These patients he will go back to "to think about things a lot more", such as checking he has not missed something serious.

The way Kiran figures out what is best for complicated cases is thus a negotiation. The time and consideration required for complicated cases is not set in advance, nor is it independent of other ward factors; instead, the time and consideration required for complicated cases is contingent upon other ward factors such as the needs of other patients and the time left at the end of the 'first lap' of the ward round. The time to "go back and check" on complicated cases is a negotiation between how complicated these individual patients are and the collective burden of other ward patients.

This process can be described in terms of values. The simple cases are ones whose welfare can be managed effectively on auto-pilot; their safety is not compromised by Kiran's efficiency because it does not take long for Kiran to figure out what is going on and what needs to be done. The complicated cases are ones whose safety is in fact compromised by his efficiency. Instead of functioning in auto-pilot, Kiran needs to go back and think about them. This requires a trade-off between welfare and effectiveness.

This distinction between what is figured out automatically and what is figured out deliberately is also drawn by Kiran's consultant colleague, Dr Taylor. She also describes two kinds of case. Firstly:

I think things are obvious when they fit that guideline or protocol, aren't they? So that SHO-level of: take history, you have a diagnosis, there is a test to confirm it, there is a treatment that I know, it's the right treatment, and there is a known, understood way of following you up or discharging you. And that's easy, isn't it? So you have flu, test positive. You have PE [pulmonary embolism], test positive. You have, you know, whatever it is. And then- and that's great, and that's why I did Acute

Medicine because the [AMS] was that. It was make a diagnosis and off you go. [Dr Taylor, 558-565]

[Dr Taylor, 558-565]

And secondly:

I think increasingly, what comes into hospital is not single organ, single disease, single diagnosis driven. I think it's multifactorial and complex. In terms of its medical disease origin but also in terms of its social context. And I think those decisions are much harder to make because they involve time to understand all of that, which we don't have. They involve an MDT [multidisciplinary team] that includes patient and family, which we don't have time to have. And there's no right or wrong. [Dr Taylor, 567-573]

Dr Taylor illustrates this contrast:

You know, it's not "P.E., have NOAC [new oral anti-coagulant medication]. Evidence-based, ten thousand patients so it's the right thing. Off you go". It's "Mmmm, you've got a bit of COPD [chronic obstructive pulmonary disease] and a bit of heart failure, and you're struggling on the stairs and your daughter's really worried about your breathlessness, and she's going away to Australia for a month..." There's no pathway that says "this is how you fix this". [Dr Taylor, 567-579]

This can also be summarised in terms of values. "Obvious" [Dr Taylor, 558] cases, which can be managed according to a ready-made pathway, are quick and simple. The best course of action, in terms of *welfare*, typically coincides with the best course of action in terms of *effectiveness*. However, "complex" [Dr Taylor, 568] cases cannot be managed according to a ready-made pathway; they take time and are multifactorial. The best course of action, in terms of *welfare*, typically contrasts with the best course of action in terms of *effectiveness*; their optimal management requires "time... which we don't have" [Dr Taylor, 571-572]. How Dr Taylor figures out what is best for complex cases is thus a negotiation between maximising individual patients' *welfare* and maximising the collective ward's *effectiveness*.

According to the accounts of Kiran and Dr Taylor, the difference between what is obvious and what is difficult can be articulated in terms of values. Obvious decisions, which can be performed on "automatic", exhibit *value coincidence*; the course of action which is the *best* according to the evaluative standard of welfare is *compatible* with the course of action which is the *best* according to the evaluative standard of effectiveness.

Difficult, complex decisions require a psychological change of gear; instead of being obvious and dealt with in auto-pilot, they are difficult and require deliberation and negotiation. Negotiated decisions, which require further thought and time, exhibit *value conflict*; the course of action which is the *best* according to the

evaluative standard of welfare is *incompatible* with the course of action which is the *best* according to the evaluative standard of effectiveness.

However, the above examples only consider conflict between two of the triad of values, namely: welfare and effectiveness. Does the value of *choice* also contribute to a psychological gear change in decision-making? This becomes apparent as I accompany trainee doctor Sophie.

8.4.2 Choice vs. welfare

During her busy shift assessing patients, answering phone calls, checking results and performing tasks, I notice there are some treatments which Sophie simply initiates and others which she discusses with patients. She sits at the central work station with her “jobs list” [5c]. Her jobs list is a miniature version of the ward whiteboard: a table with a row for each bed, and buzzwords of outstanding tasks which are needed during admission. These tasks include “D/C” [discharge documentation], “IV” [change medication to intravenous] and “anticoag” [anticoagulation medication].

Sophie battles with the interruptions of her alert-ridden hospital handset to progress through her jobs list. She completes a discharge letter rapidly on the computer, fills an empty box on her jobs list and moves onto the next task. She jumps to her feet to collect a Kardex, prescribes an intravenous antibiotic and places it back. That’s two boxes filled in within the space of 5 minutes. However, as she considers the “anticoag” task, Sophie lets out a quiet sigh as she goes to collect a red folder, checks the patient is available and then goes to discuss the matter with her [5c].

As I watched this ordinary behaviour of the completion of ward tasks, it struck me that there are some tasks which are work station tasks, and others which are bedside tasks; the former are generally quick and silent, the latter are generally slow and involve talking. Later in this shift, Sophie reflects with me on when to discuss decisions with patients:

The thing is, we would never say to a patient “oh do you think I should start you on IV antibiotics?” You kind of just- you just would. And I think it’s sort of blurred when we have to discuss these things [gestures with one hand] but we don’t discuss these things [gestures with other hand], because obviously we’ll do that. I think it’s difficult. [Sophie, 115-118]

Thus, according to Sophie, there are two kinds of things. On the one hand, there are things which have to be negotiated with patients; on the other hand, there are things which are obvious and do not require discussion: “you just would”.

In order to further explore this distinction between what is obvious and what is negotiated, consider consultant Tony. Like Kiran, Dr Taylor and Sophie, Tony describes two kinds of decisions. Firstly:

[An] easy decision, for example, would be a patient who has had an unintentional paracetamol overdose. So for example, someone who's taken way too much paracetamol for their dental abscess and who are admitted to hospital, treated with an antidote to paracetamol, and at the point we have their blood tests back, if they are completely normal, it's a very straightforward decision to say "this patient no longer needs to be in hospital. They need advice and we can discharge them safely". That's dead easy. Once we've seen those blood results, we know there's no problem any more. That's dead easy, straightforward. [Tony, 315-323]

This decision to discharge, in the scenario which Tony describes, is considered straightforward. During his ward rounds, Tony adopts a similar preparatory routine to his other consultant colleagues: view the medical notes, the previous clinical correspondence, the laboratory results, the imaging tests, the nursing measurements, then the patient. In this kind of "straightforward" scenario, by the time Tony goes in to see the patient, he has already viewed enough; the decision to discharge is already in view from "the point we have their blood tests back".

However, it is noteworthy that paracetamol overdoses are sometimes considered difficult cases and not obvious. Emily, the "regular attender" (Sharon) I presented above, seems to be extremely demanding for staff. As well as necessitating intervention from security staff, and converting a healthcare assistant's leg into a horizontal instrument of restraint, decisions about Emily's treatment can be experienced by staff as not straightforward but difficult, at least on an emotional level. Ryan says:

All you want to do is help her. And then you feel powerless. And, like, it makes you more upset when you can't help her; when she's refusing. And then you're kinda stuck... trying and trying and trying and trying. You could try all day and it'll still be the same. [Ryan 101-104]

A key difference between Emily's situation and the scenario that Tony is describing is that his conception of a straightforward case is not simply any paracetamol overdose but an "unintentional" one. Someone who has accidentally over-medicated their dental pain and voluntarily presents to hospital can be expected to want to live. The patient typically would want the medical team to minimise harm, prevent death, and aim to restore them back home as soon as it is safe to do so; the healthcare team and the patient are all seeking to restore order and conceive of 'order' similarly.

In contrast, what is best for Emily was construed the other way around in her eyes compared to staff eyes, on the interior of the door compared to the exterior; Emily's construal of restoring order and the staff's construal of restoring order are two very different orders. One key difference between this "straightforward" case and Emily's case is that in the easy case, people are working together towards the same goalposts.

Tony contrasts this easy, straightforward discharge decision with a second kind of decision-making scenario:

An example of a more complex decision would be: so for example, a patient with what is perceived to be end-stage organ failure, such as end-stage heart failure, in a discussion regarding resuscitation for the patient who has capacity and in clear consciousness asks us to do everything that we can do, including making sure we do CPR [cardio-pulmonary resuscitation] and put them on a life-support machine if it comes to that. [Tony, 324-328]

Tony expands on why this is difficult:

The way things are legally, that can be quite a tricky business. Because we would be potentially be subjecting that patient to treatment, to CPR, ventilation, whatever it comes to, that a reasonable body of medical opinion would say is inappropriate, unnecessarily aggressive and futile, for example. But if the patient has capacity to, sort of, effectively request or demand that we give them that opportunity. That doesn't happen very often but it does happen sometimes. [Tony, 328-333]

The friction that this situation can pose between people was anticipated in the exchange between Tony, Mr Johnson and Mr Johnson's family, which I presented earlier (see: Chapter 7 *Professional vs. organisational*). Having sensed that Mr Johnson's other son is likely to be keen for more resuscitative treatment, the conversation closed as follows:

Tony: [To daughter-in-law] We are still actively treating [Mr Johnson] with antibiotics for an infection. We've just got to be realistic as well that we might not be able to cure everything here. [Turning to son] Is your brother coming in later?

Son: Aye.

Tony: We can have a word with him too [looking at Ling], when he comes in [Ling nods]

Mr Johnson: I hope you win!

Tony: [amused] me too! [6d]

In both the scenario which Tony proposes and the scenario which I observed, there is a conflict between what Tony considers to be the best course of action and what the patient or family consider to be the best course of action. The course of action that Tony assesses to be best in terms of the patient's *welfare* is not consistent with the course of action deemed best in terms of the patient or family's *choice*. The resuscitative measures that they see as appropriate, helpful and worthwhile, Tony's professional perspective sees as "inappropriate, unnecessarily aggressive and futile". CPR, in Tony's eyes, does not contribute towards the patient's welfare, given their "end-stage organ failure". However, he experiences this scenario as difficult

because he must balance this with the value of choice: the choice of a patient with capacity “in clear consciousness” or the choice of a close relative.

The values of *welfare* and *choice* can therefore commend incompatible courses of action; this *value conflict* contributes to a psychological gear change: the decision is no longer obvious but negotiated.

I have so far presented two examples of value conflict which contribute towards a psychological gear change: *welfare versus effectiveness*, and *choice versus welfare*. I now turn our attention to the final combination of the triad of values: *effectiveness versus choice*.

8.4.3 Effectiveness vs. choice

Heidi is the mother and grandmother whom I presented in the previous chapter (see: Chapter 7 *Distress*). She has been in the AMU for longer than she expected and there has been a lot of deliberation between doctors about whether she needs to have a lumbar puncture to exclude meningitis. Meanwhile, she is longing to be back with her family but does not want to risk any knock-on effects for her children if she could have infective meningitis. She feels heavily dependent on the doctors:

I have to have the faith and the trust in the doctors that are specialising in what they're doing. So more they're gonna you know tell me what's best and what's not best. [Heidi, 137-139]

After a long period of anxious waiting, consultant Charles confirms to Heidi that she is safe to go home and does not have meningitis. Accordingly, there is no health concern to warrant a lumbar puncture. Instead, Charles proposes Heidi is discharged home later today. This disclosure is met with delight:

The mention of home seemed to light up Heidi's face: "Today?! Eeh, you're my favourite – you're a very good doctor, you know! What a lovely doctor!" she joked. Charles laughed as he turned to walk out. [8b]

In conversation with Heidi afterwards, we reflected on this moment. I asked Heidi how it would have changed things if Charles had said that there is no health concern to warrant a lumbar puncture but nevertheless the hospital has policies which enable it to run effectively, and hospital policy says that she should have a lumbar puncture. Heidi responded:

Well then no I would say "no"! I would, definitely, because if there was no reason to have it that didn't affect anything that was going to happen in later on then I would definitely not have it. Hospital policy is hospital policy. It's not the doctor's policy. [Heidi, 160-164]

Heidi explained why she respects the doctor's advice but not the organisation's advice in this scenario:

Because I think the doctors are like you look up to 'em, you respect 'em. Because of all the medical knowledge that they've got, the years of training that they've had to go through. Whereas someone if it's just an hospital policy someone just sat behind a desk just saying "yeah we can afford this or you've got to have this done"- so I think it's like the trust and the respect that you have for someone that's like that. [Heidi, 167-171]

In this somewhat artificial scenario, two incompatible courses of action are in competition. Heidi could follow the advice of the organisation and have a lumbar puncture or she could leave hospital without one. In this scenario, the former is supported by appeal to the value of *effectiveness*: these policies enable the hospital to run effectively; the latter is justified by appeal to the value of patient *choice*: Heidi would say "no" to a procedure which does not seemingly benefit her. In this imagined scenario, choice beats effectiveness.

Interestingly, I did not observe any real instances of personal choice trumping departmental effectiveness. In such instances, a course of action which preserved departmental effectiveness usually triumphed. However, there were instances of relative equipoise, such as nurse Rachel bending the rules on visiting hours in the interests of patient preferences (see: Chapter 7 *Personal vs. organisational*):

You're definitely more lenient if the family are nice! And like if they're elderly or they've come from far or whatever. [9c]

When there is conflict between the wishes of patients and the policies of the department, it is not obvious what is the best course of action. Instead, the course of action is *negotiated*. I now explore other accounts of how the *effectiveness-versus-choice* conflict contributes to a gear change in decision-making.

In Chapter 6, I presented an interaction between Dr Taylor and Brandon, who was reluctant to go home because of "trouble with the neighbours" [6c] (see: Chapter 6 *Disruption futility*). In the event, he accepted Dr Taylor's advice to go home because he no longer had a clinical need to remain in hospital. If he had persisted, Dr Taylor indicated that she would likely concede to his wishes:

He'd only re-present to A&E, which creates a load more work. So I tend to just let them stay another night. [6c]

Thus, as Dr Taylor sees it, complying with the patient's wishes would in fact be most effective for the hospital as a whole.

However, there are perhaps times when conceding to a patient's wishes to remain hospitalised without clinical need is in fact ineffective for the hospital as an organisation. In Chapter 6, I presented Tony's account of how the "strain" of the organisation has an influence on how he figured out whether to admit Stuart

overnight (see: Chapter 6 *Disruption futility*). As Tony described, during a bed shortage the importance of preventing unnecessary admissions is greater. In view of the reality of this, Tony says:

Sometimes I wonder whether this Trust should literally have a block booking of a local- a motel... a couple of miles away. [Tony, 181-183]

Tony describes to me how he would figure out what is the best course of action with regard to a patient who does not need to be hospitalised for clinical reasons but who requests extended admission nonetheless:

If the reasons for him wanting to stay in hospital were perhaps less objective and more along the lines of “well, to be honest, I’ve got a relative staying with me who I really dislike and I need to be out the house tonight” or something less kind of clinically relevant, I suppose. Then I would be tempted to say “I’m afraid that is not, you know, it’s not a reasonable use of the NHS. For us to keep you in a bed overnight and be your hotel overnight”. [Tony, 164-168]

Tony justifies his over-ruling of a patient’s request:

Because the infrastructure of this place is a hugely complex business, and is a hugely costly business. For every extra patient in a bed overnight in this hospital that involves probably more agency or locum healthcare assistance or healthcare workers, it involves more complex admin for everybody, a burden of things that can go wrong. [Tony, 170-173]

Tony is careful to qualify this principle:

If he’s worried about falling going up the stairs, then it’s clinically relevant and an appropriate use of the healthcare resources, in my mind. Because if he does fall overnight and fractures his hip or tibial plateau or whatever it is, then that’s bad for him and it’s bad for the system and society as a whole. [Tony, 191-194]

However, if there is no concern regarding his medical welfare, things are different:

If he doesn’t like his aunty and they fall out, well, that’s not really society’s problem. And we don’t really need to be ploughing the very finite and stretched resources of the healthcare system into that personal issue that he has. [Tony, 194-196]

This patient’s request to stay in hospital on the grounds of a “personal issue” with his aunty is out-weighted by the need of “the system and society as a whole” to make good use of the “very finite and stretched resources of the healthcare system”.

Had the cancer patient insisted on admission overnight during the hospital’s bed crisis, Tony says:

On Wednesday, the way things were, I think I would have gently challenged him about that.

[Tony, 156-157]

In this scenario, which features a fictional embellishment of the cancer patient insisting on admission, two incompatible courses of action are in competition. Firstly, the cancer patient could be admitted into hospital overnight. This course of action may be appraised as what is best according to the value of *choice*; it is what the patient wants. Secondly, the cancer patient could be denied overnight stay and discharged. This course of action may be appraised as what is best according to the value of *effectiveness*; the hospital cannot afford to plough resources into all of society's problems. This scenario thus features a value conflict. As a result, what course of action is best is not *obvious*, it is figured out by the deliberating and 'gentle challenging' of *negotiation*.

8.5 Conclusion: Conflict and negotiation

This chapter has proceeded in four steps. The first step was to draw connections between key concepts of previous chapters and values. Problems and needs are aspects of things-that-ought-to-be-corrected within the AMS. Things-that-ought-to-be-corrected are things which are evaluated negatively. But by what evaluative standards are such things negatively appraised? The second step identified two of these evaluative standards (or values): welfare and choice. The conflict between these two values was evidenced in various decision-making tensions. There is more to the story, however. The third step identified a third value which is also involved in figuring out what course of action is best: effectiveness.

The fourth step took a psychological turn: some decisions are so obvious to participants that at times they are not even seen as 'decisions'. At other times, decisions are experienced as difficult and enacted by way of negotiation. Difficult, negotiated decisions can be manifestations of conflict between the values *welfare*, *choice* and *effectiveness*.

In conclusion, three values are involved in the way people figure out what course of action is the best way of working together in order to restore order. These values are welfare, choice and effectiveness. The same course of action⁵⁶ can be commended as what is best according to multiple values. These instances I have termed *value coincidence*. In such moments, making a decision is experienced by participants as easy and obvious. However, there are also instances of *value conflict* in decision-making within the AMS; this occurs when different values commend incompatible courses of action as what is best. In such moments, making a decision is experienced by participants as difficult and requires negotiation.

⁵⁶ Or two compatible courses of action, whose amalgamation functions as a single course of action.

As is implied by 'coincidence' and 'conflict', values interact with one another. That is to say, the three values of welfare, choice and effectiveness are not independent criteria; they are operationalised simultaneously as a dynamic ensemble. This conceptual model of the role of values in decision-making within an AMS is developed in the following chapter, with consideration of its theoretical implications.

Chapter 9. Discussion

In the preceding three chapters I presented ethnographic and interview data that were organised around three themes. In *Restoring order*, I described three kinds of problem within an AMS, which can result in three kinds of futility. In *Working together*, I described three kinds of need within an AMS, which can result in three kinds of cacophony. In *What's best*, I described three main values involved in decision-making within an AMS, which can result in three kinds of value conflict.

This chapter progresses in four steps. Firstly, I summarise my empirically-informed interpretation of the role of values in decision-making within this AMS and refer to it as a *trivalent* approach or framework. Secondly, I use this trivalent framework as a means of critically engaging with clinical decision-making models that were explored in Chapter 3. Thirdly, I consider how this trivalent framework relates to conceptual and epistemological issues in the philosophy of medicine that were raised in Chapter 2. Finally, I identify ways in which the 'dance' of decision-making within an AMS can be misunderstood.

9.1 A trivalent approach summarised

In this interpretive account of the role of values in decision-making within an AMS, I have referred to a series of sets of three. I have also described each of these sets of three as a *triad* rather than a mere group. I start this chapter by summarising this model, with the intention of demonstrating that these triads are distinct from a group of one (monism) and distinct from a group of three (pluralism).

9.1.1 Three problems

As I described in *Restoring order*, people respond to different kinds of problem within an AMS. Firstly, there is the problem of *deviation*, which is sensed when patients (or their body parts) are not functioning as normal. This can take such forms as Mike's previous alcoholism⁵⁷:

For it to become a total problem when you cannot pull yourself out of it at five o'clock tea-time, d'you na what I mean? [Mike, 63-68]

And Harold's bowel incontinence:

Harriet: "If that's baseline then I'm happy for him to go home." [3d]

And Audrey's abnormal kidney tests:

"But I'm alright. I don't feel ill or anything!" [Audrey, 23]

⁵⁷ Data excerpts in 9.1 are intended to be illustrative fragments of previously explored material.

In each of these situations, a problem was defined as a deviation from a perceived baseline of proper function.

Secondly, there is the problem of *distress*, when patients (and their relatives) struggle with the psychological and relational impact of sickness. This was evident in Heidi's separation from her grand-daughter :

It just gets your heart... [Heidi, 78]

And Deanne's confusion at the absence of her sick partner's family:

"If it were my brother, I'd be here! That's what matters now" [9c]

And Mr Whitehead's reflections as he stared at the wall:

"I've been in 4 days. It's like a lifetime." [6b]

In each of these situations, people experienced the psychological pain of not being with loved ones and the distress of not feeling at-home.

Thirdly, there is the problem of *disruption*, which is sensed when the flow of patients through the hospital is not working. In this situation, not only are patients sick but the hospital is also sick, suffering a "bed crisis" [6d]. Tony described his awareness of the problem of disruption when, in considering whether to admit a patient with cancer:

There's a palpable sense sometimes of... 'this place is really under strain', and 'if we don't need to admit this man to a bed overnight then that would be a good thing for everybody'.

[Tony, 137-139]

When staff anticipate the problem of disruption, they sense a pressure to discharge patients quickly. For instance, Fergus knows bed management "want the bed 5 minutes ago" [Fergus, 457], Dr Taylor reports "a big push of getting people home" [Dr Taylor, 24]. Even patients, such as Gary, sense the problem of disruption and the push to get home: "I've overstayed my welcome" [3c].

At first glance, then, this is inconsistent with goal-monism but seems quite consistent with goal-pluralism. An AMS addresses three goals; deviation, distress and disruption make three problems, not one. However, the three problems are simultaneously addressed in such a way that they are not three independent *parts* of a complicated aim; they are three interdependent *aspects* of a complex aim: to *restore order*.

9.1.2 Triad of problems

If deviation, distress and disruption were three *independent* problems, the definition of one need not rely on another; the successful remedy of one need not affect another; a deterioration in one need not disturb

another. However, this is empirically not the case within the AMS. I demonstrate the *interdependence* of the three kinds of problem with a summary of distress futility, deviation futility and disruption futility.

The problem of distress affects the problem of deviation. As Gloria's family discuss her treatment options with consultant Harriet, a turning point in the conversation comes when Bill comments that Gloria's "got no quality of life" [3d]. As a result of her seemingly irreversible distress, Gloria's abnormal physiology is seen as not worth correcting; extending Gloria's quantity of life is not seen as worthwhile in view of her persistently poor quality of life. How problematic Gloria's functional deviation is depends on how problematic her distress is; the two are not independent.

The problem of deviation affects the problem of disruption. Following her interaction with Albert Jenkins, the elderly man who visits his wife's grave without fail, Dr Taylor reflected with me about cardio-pulmonary resuscitation (CPR):

It's a treatment where you say "what am I trying to achieve here? Am I just prolonging death?" [Dr Taylor, 414-415]

If a patient's biological deviation is irreversible, this influences how much they may contribute to the problem of disruption. Admitting and treating patients whose deviation cannot be fixed, such as a frail patient who will not recover mental function following CPR, risks them getting "stuck forever" [Dr Taylor, 530]. How problematic the ensuing disruption is depends on how problematic a patient's deviation is; the two are not independent.

Finally, the problem of disruption affects the problems of distress and deviation. Consultant Tony was exquisitely aware of the hospital's bed crisis as he considered whether or not to admit Stuart, who was a cancer patient with fever:

"To be honest, if there were beds I probably would have kept him in and kept an eye. But as it is, I had to send him home". [6d]

From Tony's point of view, the problem of organisational disruption raised the threshold required to justify Stuart's hospital admission. On further assessment, Stuart's degree of deviation did not meet this heightened threshold:

I knew that he wasn't neutropenic. I also knew he felt well in himself. And that his physiological early warning score... was not ringing any alarm bells. It was near normal. [Tony, 124-127]

How problematic Stuart's fever is depends on how problematic the hospital's disruption is; the two are not independent.

In interview, Tony and I explored a hypothetical variation on this scenario, in which Stuart insisted on hospital admission because being at home was a source of distress for him. The reason for rejecting Stuart's request incorporated the strain of the hospital on this stressful Wednesday:

On Wednesday, the way things were, I think I would have gently challenged him about that.
[Tony, 156-157]

Putting it more explicitly, Tony said:

And we don't really need to be ploughing the very finite and stretched resources of the healthcare system into that personal issue that he has. [Tony, 194-196]

Stuart (in this imaginary scenario) reported a degree of distress at going home. How problematic Stuart's distress is, in Tony's eyes, is influenced by the problem of organisational disruption; the two are not independent.

Deviation, distress and disruption are three distinct kinds of problem. However, they are not three *independent* kinds of problem. Instead, they are *interdependent*. How problematic one of them is influences how problematic the others are. If the three were independent, such dynamic interaction would not occur. In this way, deviation, distress and disruption are not a group of three (pluralism), they are a triad.

The three kinds of problem are analogous to three bulbs which are connected in a series circuit. Each bulb has a distinct place in the circuit. However, the voltage across one bulb depends upon the voltage across the others. Indeed, if one bulb were to blow a fuse and go out, the other bulbs may go out as well⁵⁸. Thus, whilst distinct, they are interdependent as three-in-one: three bulbs in one circuit.

9.1.3 Triad of needs

In similar fashion, *professional* need, *personal* need and *organisational* need are not three in a group of independent needs; they form a triad of interdependent needs that can clash in a way that I previously described as cacophonous (see: Chapter 7 *Cacophony*).

If these kinds of need were independent needs, they could nevertheless compete for resources. This could be a source of stress for staff on the AMU, who are tasked with alleviating *both* one need *and* another; this need and *then* that need. However, my interpretation of empirical data is that this does not accurately capture the stress of staff in situations of competing needs. Rather than simply a *quantitative* difficulty of this-need-on-top-of-that-need, there is also a *qualitative* difficulty of this-need-despite-that-need, as the following review of cacophonous moments illustrates.

⁵⁸ The same cannot be said of bulbs in a parallel circuit (AllAboutCircuits.com, 2020).

Nurse Helen was striving to meet her professional need despite her organisational need. She was in the middle of a busy shift:

Quite heavy⁵⁹ patients that need double attention. Quite a lot of infusions going, so it's just trying to catch up and trying to chase everybody just to see what is needed. [Helen, 5-7]

As a result, she experiences the organisational need to ensure patients are managed efficiently and discharged quickly. A doctor has prescribed a dose of paracetamol that she sees as a breach of professional standards and a threat to her professional registration:

Everybody can be under stress... but, as I had explained, it's my registration. Even though it's prescribed, if I give it, it's my registration that's on the line. So you've got to be able to stand up and say "no"... [Helen, 101-103]

It is not simply that Helen needs to administer painkillers quickly and, in addition, maintain professional standards. It is that these two needs antagonise one another. The organisational need for quick delivery of care threatens her professional need to practise according to recognised standards; her need to practise according to recognised standards entails the delay of collaborating with colleagues to ensure the doctor prescribes an alternative.

The *quantitative* stress of tending to multiple needs is exacerbated by a *qualitative* stress: there is a clashing antagonism, a cacophony, between these needs that exacerbates the stress that Helen experiences. The stress of alleviating organisational need depends on professional need; the two are not independent.

Likewise, the stress of meeting personal needs can be exacerbated by simultaneously meeting professional needs. For example, Dr Taylor reflected on some of the difficulty in Do-Not-Attempt-Resuscitation (DNAR) decisions.

On the one hand, her decision-making approach to Mr Jenkins recognised the diversity of personal need:

[Mr Jenkins] should be at the centre of it, and not just do what doctors tell him is the 'right' thing. [Dr Taylor, 159-161]

On the other hand, her decision-making approach to DNAR plans recognises the standardisation of professional need:

It's the clinician's- it's a consultant's choice. I can't put people on critical care if it's the wrong thing to do... It's a treatment that we're offering and it's not right to offer a treatment if it's not the right

⁵⁹ Helen uses "heavy" figuratively here, to refer to clinical demand rather than patient physique.

thing to do to somebody. And I think as a clinician I think we're legally, that's our position. I think responsibly, ethically, morally, that's the right thing. [Dr Taylor 346-350]

It is not accurate to simply say that Dr Taylor is tending to personal needs and also professional need; rather, tending to personal needs and professional needs are pulling her in different directions simultaneously, exacerbating the stress of this kind of decision-making. Dr Taylor does not simply deal with one in addition to the other; she deals with one *despite* the other. Personal need and professional need are not independent. Finally, the stress of meeting organisational need and the stress of meeting personal need are also influenced by each other. Due to the organisational need to complete his ward round swiftly, Tony recognises he had to cut out some more personal elements of his consultation with Mr Johnson:

I don't know if I really gave him the opportunity to voice what his main priorities are.

[Tony, 296-304]

From Maureen's point of view, the strictness of the AMS visiting hours represented a clash between organisational need and her personal need:

Obviously you've got to limit as to how many people come in at a time 'cause it can be disruptive. And I think when you're in a cubicle on your own, does it matter if you've got a visitor or not?... So, you know, I think you should- a bit of discretion if you don't actually live local. [Maureen, 15-19]

In such situations of cacophony, one kind of need is pursued not simply in *addition* to another but *despite* another. As with problems, the set of needs is like three bulbs in a series circuit; each has its place yet they form one circuit in which each influences the others. Professional need, personal need and organisational need are distinct yet interdependent; they are a *triad*.

9.1.3 Triad of values

Values are standards by which things-that-ought-to-be-corrected within an AMS are appraised. Problems and needs are also ways of portraying things-that-ought-to-be-corrected within an AMS, albeit with different emphases (see: Chapter 8 *From problems and needs to values*). It is unsurprising, then, that the relation between values is, like problems and like needs, triadic. In what way does the interdependence of *welfare*, *choice* and *effectiveness* distinguish them from a pluralist framework?

In a straightforward pluralist framework, appraisal of a situation by one value can conflict with the appraisal of a situation by another value. Indeed, this was an essential feature of my argument for the inadequacy of value-pluralism (see: Chapter 2 *Value pluralism*). However, my interpretive analysis of empirical data from this AMS identifies a feature that distinguishes welfare, choice and effectiveness from a straightforward pluralist framework: *each value presupposes the others*.

9.1.3.1 Welfare

I return briefly to consultant Tony as he considers whether or not a DNAR form should be completed for Mr Johnson (see: Chapter 7 *Personal vs. organisational* and Chapter 8 *Choice vs. welfare*). In this situation, Tony made a decision to complete the form and decline CPR because, in his words, “we’ve just got to be realistic... that we might not be able to cure everything here” [6d]. Speaking in interview, this decision was justified in terms of welfare; the alternative would be:

...subjecting that patient to treatment, to CPR, ventilation, whatever it comes to, that a reasonable body of medical opinion would say is inappropriate, unnecessarily aggressive and futile.

[Tony, 329-331]

However, Tony’s welfare assessment entails an assessment according to the value of effectiveness. Recall the conversation with Mr Johnson:

Tony: If and when things take a turn for the worse, I think we shouldn’t be trying to restart your heart.

Mr Johnson: “Shouldn’t?”

Tony: It wouldn’t work.

Mr Johnson: That’s nice to know. [smiles – unclear if being sarcastic or relieved] [6d]

The concern that CPR “wouldn’t work” is a concern that CPR would not be *effective*; Mr Johnson may not make it off the ventilator or may not make it home. As Tony explained:

In my view it would not be appropriate to put him on a life support machine to try and get him through that. And that’s based on my experience that patients with significant symptom burden from their lung disease, which he had, because he’s breathless walking a couple of yards. That if he became so poorly that he needed organ support on a high dependency or intensive care unit. If it got that point, the chance of him recovering to have what most patients would consider a meaningful existence – quality of life at home – the chance of him recovering would be pretty slim. [Tony, 269-276]

It is noteworthy that Tony’s welfare assessment evidently also entails an assessment according to choice, namely, he anticipates “what most patients [in Mr Johnson’s circumstances] would consider a meaningful existence”.

In short, Tony’s *welfare* assessment is considering whether CPR would restore Mr Johnson to a state of flourishing or whether it would be unnecessarily aggressive and futile. However, in order to complete this evaluation, Tony relies on a preconception of what would be good in terms of *effectiveness* – would resuscitation work? – as well as what would be good in terms of *choice* – would the outcome be desirable

for a patient like Mr Johnson? *Welfare* presupposes *effectiveness* and *choice*; the three evaluative standards are not independent but interdependent; one presupposes the others.

9.1.3.2 Choice

As a second illustration of the interdependence of values, I review a very different moment in this ethnography: Emily, the “regular attender” (Sharon) who is trying to leave the ward and wanting to end her life (see: Chapter 8 *Best interests vs. capacity*). As Emily said:

Now I'm at the point where I don't want them to help me anymore. I hope [my liver] does fail... I hope it – yeah, because I'll die. I think I'll die. If it fails, I think I will die. I don't know too much about it but I'm pretty sure you need your liver... And then if I die, I die. If I don't then I'll just keep taking stuff.

[Emily, 59-67]

Dying, in Emily's eyes, is good thing according to her experience and wishes; it is a good course of action according to the value of *choice*:

I was once asked “are you scared of dying?” I was like “no. I'm actually scared of living!” I'm afraid of trying to survive. It's hard. It's really hard. [Emily, 259-260]

Emily and staff recognise what a state of flourishing for Emily might look like:

So before that [traumatic incident] she was normal. Going to work, going out with her friends, driving her car. This is all from that. Since she came back she just feels the support's not there.

[Sharon, 79-80]

However, where Emily has given up hope that treatments will restore her back to a state of flourishing such that trying to survive is too hard, Sharon is more optimistic:

She is a young girl. I think that if she got the support that she needs, which is – I don't know what it is; I'm not a mental health specialist – maybe she could turn her life back around. She's just young. Far too young for his. 'cause she does seem like a nice girl. [Sharon, 97-100]

Whereas Sharon thinks treatments to restore Emily's welfare could be effective, Emily is convinced they would not be. As a result, what is best according to Emily's *choice* is dying because efforts to promote her *welfare* fail in terms of *effectiveness*. Emily's experience and wishes are shaped by her preconceptions of flourishing and preconceptions of what would work. Her *choice* presupposes *welfare* and *effectiveness*; the three values are not independent but interdependent; one presupposes the others.

9.1.3.3 Effectiveness

As a third and final illustration of the interdependence of values, recall the moment Dr Taylor was speaking with Brandon during her ward round:

They spoke about his reason for admission, and how much better he feels now. Dr Taylor mentioned that, following pneumonia, it takes many weeks to recover strength, emphasising the need for rest. At this moment he became tearful and said he's been having a lot of "trouble with the neighbours". He described it as escalating recently, and now the "police are involved". [6c]

Dr Taylor summarised how she decided what course of action is best:

"Before, I would have just sent him home. But now I wouldn't. He'd only re-present to A&E, which creates a load more work. So I tend to just let them stay another night." [6c]

Dr Taylor's decision to extend Brandon's hospital stay was driven by a concern to do what is best in terms of *effectiveness*: avoid creating a "load more work". However, in order to assess what course of action is most effective, Dr Taylor must incorporate evaluations of the situation in terms of Brandon's state of health and Brandon's wishes. Seeing as Brandon is recovering well, neither home nor hospital poses a threat to his flourishing; both are acceptable courses of action in terms of *welfare*. However, such is Brandon's experience of anxiety at home at the moment that Dr Taylor anticipates he would choose to come back to hospital. Going home is not what is best according to the evaluative standard of *choice*. This would divert hospital resources to his clerking and re-admission. Thus, in order to weigh up what course of action is best in terms of *effectiveness*, Dr Taylor relies on a preconception of what is best for Brandon in terms of *welfare* and *choice*. The three values are not independent but interdependent; one presupposes the others.

9.1.4 Neither monism nor pluralism

Within this AMS, decision-making is a process in which people figure out what course of action is the best way of working together to restore order. According to my interpretive analysis of ethnographic and interview data, the role of values in decision-making within an AMS is neither monist nor pluralist.

Unlike monism, there are three values involved in this decision-making process. The distinction between these values is most evident during times of value conflict.

Unlike pluralism, the appraisal of a course of action according to one evaluative standard involves an appraisal of the same course of action according to the other two evaluative standards; each value presupposes the others. In this way, *welfare*, *choice* and *effectiveness* do not constitute a *group* of three independent values but rather a *triad* of interdependent values.

Not quite one, not quite three, this model of values in decision-making within an AMS is neither monist nor pluralist. Instead, I refer to this three-in-one model in shorthand as a *trivalent* approach.

9.2 A trivalent approach to clinical decision-making models

In the literature review, I surveyed some current models of decision-making within healthcare. One way of categorising such models is along a relational axis, ranging from paternalism to anti-paternalism.

9.2.1 Therapeutic relationship: paternalism and anti-paternalism

As I described in literature review, conflict between paternalist and anti-paternalist decision-making models reflects a conflict in values; the former appeal to *welfare* as their fundamental value and the latter tend to appeal to *choice*. The most prominent model which seeks to transcend this dualism is shared decision-making, which idealises an egalitarian relation between decision-making parties. However, shared decision-making's strength is also its weakness. Its biphasic model consists of a preparatory phase and an executive phase, which appeal to the values *welfare* and *choice* respectively. As to what the *right* or *good* balance is between these two phases, shared decision-making is silent. In this way, it is left open to the charge of arbitrariness. To try to address this conflict by appealing to either welfare or choice would collapse the debate onto one or other side. However, a triad of values could offer a third value by which to negotiate a way through this conflict.

Within an AMS, there is not a pair of values but a triad. As such, there is a third evaluative standard by which to arbitrate between the other two values of welfare and choice. *Effectiveness* is the value which is primarily concerned with the organisational need to do what works in order to minimise the problem of disruption. I now consider how effectiveness, conceived within a trivalent framework, may contribute to the model of shared decision-making.

Within a trivalent framework, the delineation between the paternalist preparatory phase and the anti-paternalist executive phase of shared decision-making could be justified by appeal to a third value: what is most effective. This need not actually change the structure of shared decision-making; rather, a third value may provide its biphasic structure with an evaluative foundation.

Consider the preparatory phase of shared decision-making. It may be highly ineffective, within an AMS, to expect the patient to be extensively involved in what management options should be considered available to them. This requires a depth and breadth of clinical knowledge which the patient, not being medically trained, will understandably lack. It would be highly ineffective for the department as a whole if each patient were expected to be medically educated to such a degree as to work out for themselves what treatments should be available to them. Furthermore, it is extremely unrealistic to expect patients to be willing and able

to engage in such learning and discussion given they are hospitalised with acute illness. Thus, the welfare-based preparatory phase may be justified in terms of effectiveness.

Next, consider the executive phase of shared decision-making. It may be highly ineffective, within an AMS, to expect the clinician to bear sole responsibility for deciding which management option is best for the patient. Within a liberal democracy like the UK, to force treatment upon a capacitous patient without their prior consent constitutes assault (Herring, 2012: 149). Without being able to force treatment upon patients, the benefit of a course of action to a large extent depends upon a patient's compliance. To gain consent and treatment compliance, a patient would typically need to be persuaded as to the benefit of the course of action. For a course of action to be, and be seen to be, of benefit would typically involve consideration of the patient's unique situation and psyche; their world and their *life-world*. On such matters, the expertise of the patient (in conjunction with relatives) grossly outweighs that of the newly-acquainted clinician. As such, there is good reason to suppose that it would be ineffective to extend the paternalist approach of the preparatory phase into the executive phase of shared decision-making, over which patient choice is sovereign. Thus perhaps the choice-based executive phase of shared decision-making can also be justified by appeal to the third value of effectiveness.

This cursory argument is intended to illustrate that a trivalent approach to the model of shared decision-making enables it to be defended against the charge of arbitrariness. I have not, of course, given a fair hearing to counter-arguments to shared decision-making. These include concerns that shared decision-making overlooks the reality of human dependency (Walker, 1998; van Heijst, 2011), relationality and factual inequality (Gilligan, 1982; Kittay, 1999; van Nistelrooij *et al.*, 2017) as well as the hermeneutic and communitarian aspects of knowing (Nelson, 1990; Ricoeur, 1992; Goldenberg, 2015). My point here is simply to show that, in order to make the case for shared decision-making's delineation of paternalist and anti-paternalist phases, appeal must be made to a third value. This is something which the empirically-derived trivalent approach provides.

A trivalent approach promises to avoid the 'tyranny of autonomy' (Foster, 2009) whilst avoiding a tyrannical beneficence at the same time. The integration of a third evaluative standard, *effectiveness*, offers a conceptual means of avoiding the absolutisation of either *choice* or *welfare*, in keeping with Mol's proposed movement of 'patientism' (2008: 36). In short, perhaps it is a ship with trivalent sails that can pass between the Scylla of paternalism and the Charybdis of anti-paternalism.

9.2.2 Cognitive speed

I now turn to consider how the empirically-derived trivalent framework critically interacts with cognitivist dual process theory.

9.2.2.1 Dual process theory

As presented in my literature review, dual process theory developed out of research in cognitive psychology over the last 30 years and has recently been applied to the 'processing' done by clinicians. 'Type 1' processing is fast, intuitive pattern-recognition and is the predominant mode of reasoning by clinicians, particularly experts. 'Type 2' processing, in contrast, is slow, analytic hypothetico-deductivism (Croskerry, 2009).

All three data chapters describe a contrast between two modes of decision-making, concerning problems, needs and values respectively; in *Restoring order*, between what is worthwhile and what is futile; in *Working together*, between what is harmonious and what is cacophonous; in *What's best*, between what is obvious and what is negotiated. Each of these contrasts supports dual process theory.

System 1 processing proceeds when there is no futility, cacophony or negotiation; problems are dealt with, needs are satisfied, and values interact without conflict. The decision-making process can thus proceed in a fast, intuitive manner. In contrast, when the pathway is sensed to be a cul-de-sac, when needs are not satisfied or when values are in conflict, a gear change is prompted: the decision-making process becomes the slow and deliberative approach of system 2.

However, the dual process model does not adequately account for these contrasts. Even once expanded from a binary system to a 'cognitive continuum' (Hammond, 2000), it still remains a *cognitive* continuum. This falls short of accounting for reality within an AMS in the following two respects.

Firstly, a schematization of cognitive processing does not attend to the architectural and genealogical dimension of decision-making in a social field. Much of decision-making, including diagnostic reasoning, is *pre-cognitive*. That is to say, it is shaped by factors such as the institution in which people are located, the tradition according to which they are defined and the concomitant power structures on which people depend (Foucault, 1975, 1989). Figuring out what is the best course of action is not merely a matter of information; it also concerns the habits of power and the power of habit. Hence many decisions are not even seen as decisions. As Victoria said:

...You just do them don't you? That you don't actually register that you're making the decision... The decisions you make can be quite minor... Just how someone would transfer, or them kind of littler decisions... But even that's still like just following a protocol. [Victoria, 49-60]

According to a trivalent framework, dual process theory underplays the need of the organisation to minimise disruption according to the value of *effectiveness*.

With this in mind, type 1 processing is arguably long and slow. The final enactment of following a protocol or announcing a diagnosis may be rapid and require only a brief clinical exchange. However, the

development of the institution and tradition which legitimise such authoritative expressions has taken hold over many years and is itself constitutive of the decision-making process. A protocol could be described as an artefact of 'sedimented valuations' (Sayer, 2011: 25) which have solidified over the 'the long baking process of history' (Foucault in May, 1992: 144). In this sense, fast (type 1) decision-making is slow, and slow (type 2) decision-making is fast. To reduce decision-making to a protocolised momentary encounter is to confuse the race for the finishing line.

Secondly, dual process theory, as appropriated by Croskerry, has informational coherence as a central concept: do the clinical data match the diagnosis? For example, it is informational incoherence that can prompt a 'rational over-ride' into type 2 decision-making (2009: 1024). However, dual process theory's focus on diagnostic accuracy does not adequately characterise decision-making within an AMS. Decision-making within an AMS is not merely concerned with diagnoses; it is concerned with problems and needs. The evaluation of problems and needs requires the significance of *distress* and *personal needs* to be appreciated in the decision-making process. To fail to account for this, by presupposing a purely cognitive paradigm in which patients are mere information sources, is to neglect the meaning of an experience to the particular person; to neglect the meaning of personal experience is to overlook the value of *choice*.

In summary, Croskerry's appropriation of cognitivist decision-making theory fails to appreciate additional dimensions to the decision-making process; in so doing, it particularly overlooks the values of *effectiveness* and *choice*.

In defence of Croskerry, his 'universal model of diagnostic reasoning' (2009: 1022) is not intended to be a framework for all kinds of decision-making in a healthcare environment. Specifically, it relates to diagnosis of an illness presentation. The above criticisms point out the limits (in scope) of such a model rather than its limitations (in quality). Before this discussion moves on from dual process theory, I propose a way in which the theory can be combined with my empirical findings of a trivalent framework to produce an expanded model.

9.2.2.2 Trivalent continuum theory

In *What's best*, I identified two psychological gears in which decisions are made: *obvious* and *negotiated*. As with dual process theory's cousin, cognitive continuum theory, these categories need not be a clear-cut binary system. They could instead be conceived as a spectrum of varying degrees of negotiation. The reason for decision-making needing negotiation is a conflict between the values of *welfare*, *choice* and *effectiveness*. In this way, continuum theory can be reformulated to break free from merely cognitivist preconceptions, to give a continuum theory of values.

Type 1 decision-making remains intuitive and rapid, associated with the use of heuristics and pattern recognition. However, it is not merely diagnostic information that is being processed; it is *values*. If all three evaluative standards endorse the same course of action (*value coincidence*), the best course of action is sensed as obvious and “straightforward” (Tony); decisions in such instances may not even seem like decisions to participants: “you just would” (Sophie).

Type 2 decision-making is towards the other end of the continuums. It is slow and involves deliberation and discussion. People tend to figure out what is the best course of action in this way when different values endorse a different course of action. In such instances, people may feel a sense of futility or cacophony; the best course of action is negotiated through *value conflict*. These are decisions which are experienced as “complex” (Tony), “difficult” (Dr Taylor) and “when you have to think about things a lot more” (Kiran).

This is not to discard the cognitivist concern for information processing. Instead, it is to expand the model to not be *limited* to informational processing, in order to be consistent with ethnographic data and make better contact with reality within an AMS. By not being limited to mere information-processing by the minds of individual clinicians, trivalent continuum theory is a more *holistic* model of decision-making within an AMS than cognitive continuum theory. However, it is more holistic in an atypical sense. A trivalent framework offers a form of holism which is not ontological nor epistemological; it is *normative* holism.

9.2.3 Values-based decision-making

9.2.3.1 Values based practice

In the literature review, I critically presented Fulford’s Values-Based Practice (VBP) as an example of values-conscious decision-making. Whilst initially appearing to be value-pluralist, VBP turns out to be a value-monist framework, founded upon the meta-value of ‘respect for persons’. I identified ontological, epistemological and evaluative problems with VBP. I propose that the epistemological and normative shortcomings of VBP can, in part, be aided by adopting a trivalent ontology of values. This can be summarised in three statements, the first *a priori* and the other two *a posteriori*⁶⁰:

1. Values are the standards by which things are judged good or bad, which are in turn shaped and sustained by such judgments.(see: Chapter 2 *What are values?*)
2. In decision-making within an AMS, three values are involved: *welfare*, *choice* and *effectiveness*.
3. These three values are interdependent as a triad and relate closely to the goals and needs with which decision-making within an AMS is concerned.

⁶⁰ I recognise that these are only relative terms; no theoretical claim is ever empty of prior experience, nor is any empirical claim empty of prior theory.

The epistemological problem with VBP concerned how different value-perspectives are to be balanced in order for a decision to be made. A trivalent approach does not go all the way in answering this; no exhaustive formula has availed itself. Nevertheless, my empirical findings provide a framework to roughly characterise how different value-perspectives are balanced.

Rather than defining value-perspectives as the viewpoints of all relevant stakeholders, a trivalent framework portrays three value-perspectives in terms of evaluative standards. *Welfare*, *choice* and *effectiveness* are three distinct standards by which to appraise a given course of action. They form three value-perspectives.

How then can different value-perspectives be balanced? Empirical findings do confirm the reality of value conflict and thus the need for negotiation. This negotiation need not be arbitrary, however. There is no necessary appeal to authority, for which VBP is criticised (Thornton, 2014). Instead, conflict between two values can be adjudicated according to the third. For example, in decision-maker D's eyes, *welfare* endorses course of action A as what is best and *choice* endorses course of action B as what is best. If A and B are incompatible courses of action, then there is *value conflict*; the decision is not obvious and needs to be negotiated. However, D's evaluative resources are not exhausted; she can weigh up the pros and cons of A and B according to a distinct evaluative standard: *effectiveness*.

There remains ambiguity in this trivalent framework. For instance, decision-maker D is just one person amongst many who are working together to alleviate needs. How do different viewpoints inter-relate? This returns us to the question that challenges VBP: how are different (and conflicting) points of view to be balanced? This concerns the role of different *people* in decision-making within a healthcare setting. Nevertheless, a trivalent framework still aids the VBP model in part. In addition to conflict between people who express views, there is conflict between *values* in decision-making within a healthcare setting. In particular, there can be conflict between the evaluative standards *welfare*, *choice* and *effectiveness*.

Portraying conflict as between evaluative standards is of benefit to VBP with regard to its 'premise', which functions as a fundamental value: respect for persons. This ambiguous and contentious phrase can be characterised a little further with the help of a trivalent framework. What does it mean to respect persons? At least within an AMS, this could be taxonomized in three ways:

1. Doing what is good for persons in terms of *welfare*.
2. Doing what is good for persons in terms of *choice*.
3. Doing what is good for persons in terms of *effectiveness*.

Is preventing Emily from killing herself an instance of showing respect for persons? Sharon and Ryan might say "yes", and appeal to *welfare*. Emily herself might say "no", and appeal to *choice*. Does Tony show respect for persons when he refuses to admit Stuart to a bed overnight even though an insistent Stuart cannot stand

his aunty at home? Stuart might say “no” and appeal to *choice*. Tony might say “yes” and appeal to *effectiveness* with a wider group of persons in view: “that’s not society’s problem” (Tony).

A trivalent approach does not prevent misunderstandings about what it means to show respect for persons. In this sense, it does not help VBP. How it does help, however, is to characterise different interpretations of ‘respect for persons’ in order to help us *understand misunderstandings*.

In sum, VBP is both affirmed and challenged by a trivalent approach. A trivalent approach affirms the necessity of negotiating diverse and potentially conflicting value-perspectives. However, VBP is challenged to not merely characterise such conflict in inter-personal terms but also in terms of evaluative standards (which can be inter-personal or *intra*-personal).

A trivalent approach also affirms the reality of dissensus; not all conflict can be ironed-out, hence the reality of futility, cacophony and value conflict. Decisions often need to be negotiated. However, rather than the arbitrary notion of balancing in VBP, a trivalent approach identifies a third value by which conflict can potentially be negotiated.

A trivalent approach can also affirm the moral significance of respecting persons. However, VBP is challenged to acknowledge the diverse interpretations that this phrase affords. VBP’s value foundation is cracked into three pieces. Specifically, ‘respect for persons’ can be characterised within an AMS by appeal to *welfare*, *choice* and *effectiveness*.

9.2.3.2 Values based medicine

Miles Little’s decision-making model of Values-Based Medicine (VBM) is, like VBP, a form of foundationalism about values. Unlike VBP, VBM is a genuine values-pluralist framework. The foundational, universal values of *survival*, *security* and *flourishing* are seen as necessary for the propagation of human society (2014b).

I discuss VBM in two stages. Firstly, in light of ethnographic findings, I question the claimed universality of VBM’s foundational values. In this way, a trivalent approach *challenges* VBM. Secondly, I explore VBM further to expose its implicit values of welfare, choice and effectiveness. In this way, a trivalent approach *affirms* VBM.

9.2.3.2.1 Universality

According to VBM, survival is a universal foundational value (Little, 2014b, 2014a). That is to say, in theory all people want to live. However, this is difficult to reconcile with the empirical reality: sometimes people want to die. Survival can be negatively valued. Recall the case of Emily the “regular attender” (Sharon), who repeatedly tries to harm and kill herself:

I was once asked “are you scared of dying?” I was like “no. I’m actually scared of living!” I’m afraid of trying to survive. It’s hard. It’s really hard. [Emily, 259-260].

The staff, who know Emily very well, find looking after her upsetting and there is clear disagreement about what is best for her. The disagreement in her case, however, is not merely in Little’s A and P values; there is fundamental disagreement about whether her survival is a *good* thing.

Even if one were to undermine the validity of Emily’s evaluation on the grounds of mental illness or incapacity, damage would still be done to the universality of Little’s foundational values. Rather than being universal, foundational values would be generalisable insofar as the agent is thinking properly. Such a notion of rational propriety would not only be highly contentious (Foucault in May, 1992: 226), it would make implicit appeal to a fourth foundational value: the standard by which a patient’s thinking can be judged *proper*.

It is not self-evident that suicidal inclination is always caused by mental illness or mental incapacity. This was exemplified in the case of Kerrie Woollorton, who presented to Norfolk and Norwich University Hospital in 2007 having tried to kill herself by drinking anti-freeze (BBC News, 2009). Like Emily, Miss Woollorton was a frequent attendee as an acute medical admission to hospital. Unlike Emily, a psychiatrist’s assessment of Miss Woollorton did not support implementing involuntary life-extending treatment on the grounds of the Mental Capacity Act 2005 or Mental Health Act 1983 (Stammers, 2015). As a result, treatment without Miss Woollorton’s consent would have been unlawful (BBC News, 2009). The medical team palliated Miss Woollorton until she died from her ethylene glycol intoxication; a course of action the responsible consultant considered ethically justified because it respected her autonomy (Stammers, 2015). Like Emily, Miss Woollorton did not pursue survival. If ‘death is the end of flourishing’ (Little, 2014b: 180), she did not pursue flourishing either. The same could be said for security.

The rejection of survival is not restricted to cases of suicidality. Mr Whitehead is the man with white wispy hair who was keen to die of his metastatic cancer at home with his grandsons. As he said to Kylie:

“I don’t want to get better; I want to die!” [6b]

The conversation between Gloria’s son (Bill) and consultant Harriet expressed a similar attitude towards survival:

Bill: If it was our dog, I would have no hesitation in putting it down [3d]

Harriet: It might be that the best thing for her is a blood clot [3d]

Or as Dr Taylor put it:

“...after all a PE might not be a bad thing for [Mr Jenkins]. You’ve got to die of something”. [6c]

As these examples demonstrate, Little’s notion of the universal pursuit of survival as a foundational value is out of touch with reality. In wanting to die, people sometimes disvalue survival. In so doing, they implicitly reject security and flourishing too. What’s more, sometimes people disvalue the survival of others. As Upshur comments:

‘...without an argument of a Kantian nature about the dignity of humans or the embrace of a cosmopolitan world view, some further justification regarding the survival criterion is needed, as large numbers of humans have spent massive amounts of time and effort to ensure that other humans do not survive’ (2014: 216).

In Little’s defence, the foundational values take on their particular meaning within a lived societal and cultural context. Perhaps such instances of wanting to die are still cases of pursuing ‘survival’, where ‘survival’ means something along the lines of narrative continuity: that the memory of the person, the impact of the person or the principles by which the person lives, may ‘live’ on. This would relocate the disagreement into the A or P values.

However, for ‘survival’ to mean ‘death’ requires the VBM-user to display an absurd performance of hermeneutic acrobatics. Furthermore, even if this poetic licence were granted, the usefulness of foundational values would be dramatically compromised because a ‘descriptive category’ that can describe anything consequently describes nothing. After all, ‘much of the evolving debate in ethics over the centuries concerns exactly what is meant by such terms’ (Upshur, 2014: 216). To allow such interpretative diversity would undermine the ability of ‘survival’ to be in any way pre-normative, as it would be profoundly unclear what the norm is to which it is preparatory.

As the empirical findings of this study show, survival is not always valued as a good thing. Whilst survival may be a good thing according to the value of *welfare*, it is not always desirable according to the value of *choice*. A trivalent approach thus challenges the foundations of VBM.

If the foundational values of VBM are not in fact universal, then VBM becomes vulnerable to the instability of value-pluralist frameworks that was described in literature review. If F-values are not universal, then there is potential for value conflict. For example, someone’s view of flourishing may entail non-survival. Similarly, a person’s view of flourishing may entail risk-taking that compromises that person’s security. In such instances, commitment to a course of action requires one value to trump another (or to trump the other two values), rendering a pluralist account in theory a monist account in practice.

A trivalent approach challenges VBM in two ways. Firstly, the universality of VBM's foundational values is brought into question. It is empirically demonstrable that people sometimes disvalue foundational values such as survival, according to the value of *choice*. Secondly, the coherence of VBM's foundational values is brought into question. If an F-value is not, in fact, universal, then there is potential conflict between foundational values. Given his presumption that F-values are universal, Little provides no theoretical means by which such conflict is to be reconciled. This leaves his pluralist model in danger of collapsing into value-monism, if one value trumps another in times of value conflict.

9.2.3.2.2 Latent trivalent framework

As well as challenging it, a trivalent approach also affirms the decision-making model of VBM. In fact, in what follows I will try and show that VBM is itself a latent trivalent framework.

At first glance, this ethnography's three values of welfare, choice and effectiveness do not appear to fit with VBM's foundational values of survival, security and flourishing. Instead, all three of VBM's values appear to be closely related to welfare. In *What's best*, the pursuit of survival, safety and best interests were all instantiations of welfare concerns (in contrast to quality of life, preference and capacity). These, in turn, approximate to VBM's survival, security and flourishing. Thus, VBM seems initially to emphasise only one of the values of a trivalent approach: *welfare*. However, further exploration of Little's account of VBM will help expose a latent trivalent framework in the model. To this end, I focus on Little's illustrative case of a haematological patient being prescribed recombinant Factor VII off-licence (2014b).

The way in which Little demonstrates how a VBM framework could be employed in decision-making in this imaginary case shows that, as well as welfare, he emphasises the value of *choice*. Little does not simply evaluate the objective circumstances; he describes an appraisal of the circumstances from different *points of view*. It is 'from a doctor's point of view' that 'the patient's survival is paramount' (2014b: 180). He appreciates the subjectivity of the clinician who will need to be able to say with conviction "I did everything I could" (2014b: 180). That every step should be taken to preserve life is not construed as a free-floating fact but as a priority that is conceived 'from society's point of view' (2014b: 180). In terms of a trivalent approach, then, VBM concords with the evaluative standards of both welfare and choice.

What about the third of a trivalent framework's values, *effectiveness*? Questioning the pre-normative status of Little's foundational values brought to light a key difference between VBP and VBM. Where Fulford appeals to a foundational premise of 'respect for persons', Little does not. Survival, security and flourishing are foundational values not because they are true or good according to a propositional ideal. Instead, they are what works. The three F-values are what make human society sustainable: '*Because that is the way humans are*', or '*Because societies cannot function any other way.*' (2014b: 172). In other words, survival,

security and flourishing are not VBM's foundational values because of their goodness (welfare) or desirability (choice) but because of their *effectiveness*. They work.

The role of effectiveness as an evaluative standard in VBM is implicit in Little's worked clinical example, as the following excerpt demonstrates. Speaking of the priority of survival:

'...every possible step should be taken, because life is precious, and the use of Factor VII is still within the means of most Western societies. That may change, but holds true for the moment' (2014b: 180).

The pursuit of welfare is not unbridled; it must acknowledge practical limitations such as what is within the means of Western societies. Were the same patient and clinician facing this decision within the context of a poorer society, the step towards providing Factor VII is less likely. The affordability factor is an interplay between the value of welfare and the value of effectiveness. What is good for patients is considered in conjunction with what is feasible in the circumstances.

As was the case with VBP, a trivalent approach relates to VBM with ambivalence. VBM fails to make contact with reality⁶¹ to the extent that people within an AMS disvalue its foundational values. As such, VBM's foundational values are not in fact universally held. The non-universality of foundational values creates the potential for conflict between foundational values and a collapse into functional value-monism. In this way, VBM is challenged by a trivalent approach.

The manner in which VBM is applied demonstrates not just welfare considerations but also considerations of choice and effectiveness: a *latent trivalent framework*. In this way, VBM does make contact with reality within an AMS and is affirmed by a trivalent approach.

9.3 A trivalent approach to the philosophy of medicine

So far in this chapter, I have summarised the conclusions of the preceding data chapters in a trivalent framework and applied this to clinical decision-making models. Each model has been met with ambivalence, a trivalent approach both affirming and challenging the models considered. As I have presented it, a trivalent framework offers a non-arbitrary means of progressing through the paternalism - anti-paternalism dualism, a means of expanding cognitive continuum theory to trivalent continuum theory and a means of appraising values-based decision-making models.

Next, I turn to medical concepts that are influential in decision-making within an AMS and that were explored in the literature review: *sickness* and *futility*.

⁶¹ The depiction of good science as making contact with reality is original to Michael Polanyi (Lightcap Meek, 2017; Nye, 2017).

9.3.1 Medical concepts

9.3.1.1 Sickness

In Chapter 2, I surveyed different approaches to the concept of sickness. These different accounts can be grouped into three broad camps, one objectivist (biomedical model) and two subjectivist (biographical disruption and genealogy). I proceeded to identify the fundamental value which is implicit in such conceptions of sickness. Where the biomedical model prized *welfare*, the biographical disruption model prized *choice*. These two positions could be paraphrased in terms of bioethical principles. Welfare-based models tend to prioritise the principle of *beneficence* and choice-based models tend to prioritise the principle of *respect for autonomy*. Arguably, many of the prominent bioethical theories can be categorised into one of these two groups (Fry, 1992). In this way, the question of medicine's fundamental value is of major bioethical importance.

The third concept of sickness, genealogy, proved something of an overlooked younger sibling when compared to the biomedical model and biographical disruption. Specifically, it was unclear what its complementary model of well-being is and what its fundamental value is. Neglect of the architectural and genealogical element in medical concepts may explain the inability of the four principles, and medical ethics generally, to account for the political dynamic involved in healthcare decision-making, hence the critique of it as 'myopic' (Sherwin, 1992: 22).

How does this empirically-derived trivalent framework contribute to the antithesis between welfare and choice, and the historical neglect of the political dynamic in healthcare decision-making?

Decision-making within an AMS is concerned with problems. Not only the problems of functional deviation and psychological distress but also the problem of logistical *disruption*. Likewise, decision-making within an AMS is concerned with needs. Not only professional and personal needs but also *organisational* need: the (departmental) show must go on. Accordingly, decision-making within an AMS involves values: not only the values of welfare and choice but also *effectiveness*.

Whilst it is beyond the scope of an ethnographic study to explore the historical background of clinical institutions and their power structures, nevertheless the value of effectiveness is sensitive to dynamics of power within decision-making. According to effectiveness, a course of action is good if it has the *potential* to alleviate organisational need; it is good if it has the *ability* to achieve the goal of addressing disruption. This is generally conceived in terms of discharge from hospital rather than the patient "getting stuck forever" (Dr Taylor). The evaluative standard of effectiveness appreciates the power of a course of action to get the patient *out*. In view of the never-ending cohort of patients that is rapidly coming "through the doors" (Tony), a course of action is good in terms of effectiveness if it looks after the health of the hospital by maintaining

“flow” (Dr Morrison), giving a “push” towards discharge (Dr Taylor) relieves the “pressure” from management (Fergus) and prevents a “crisis” of beds (Sophie). By its attention to the power dynamics involved in the evaluation of a course of action within an AMS, the value of effectiveness could be described as the fundamental value of a genealogical conception of sickness; what is good is what procures the agenda of those in charge, such as ward staff, management and the hospital as a whole.

A trivalent framework offers a means of locating the different conceptualisations of sickness within a unified model. In Chapter 2, I observed the connection between epistemological approach, ontology and values. Informed by a trivalent approach, this is summarised in table 9.1.

	Epistemological approach	Complementary account of well-being	Fundamental value
1. Biomedical model	Objectivist	Need	Welfare
2. Social constructionism: <ul style="list-style-type: none"> • Biographical disruption 	Subjectivist	Desire	Choice
3. Social constructionism: <ul style="list-style-type: none"> • Genealogy 	Subjectivist	<i>Organisational flow</i>	<i>Effectiveness</i>

Table 9.1: Concepts of sickness

Each of the three models of sickness presupposes a different fundamental value: the biomedical model prizes *welfare*, the biographical disruption model prizes *choice*, and the genealogical model prizes *effectiveness*. According to a trivalent approach, to divorce one value from the other two is not just reductionistic, it is unrealistic. In this way, all three models of sickness require integration within a trivalent framework in order to make contact with reality within an AMS.

A benefit of being able to integrate the three models of sickness is that it transcends the objectivist – subjectivist dichotomy that has divided sickness definitions since Parfit’s theories of well-being (1984). Instead of sickness being either objective (biomedical model) or subjective (social constructionism), sickness is *both*. This synthesis is not achieved by inserting a new and nebulous term such as ‘patient-centredness’ into the debate. It is achieved by reframing the debate: rather than appealing to competing fundamental values, sickness can be conceptualised by the integration of three interdependent values, namely, *welfare*, *choice* and *effectiveness*. Practically, the clinical decision-maker who is mindful of trivalent framework is

more able to acknowledge the multifaceted nature of problems and needs, to articulate a value conflict that is causing moral distress, and to provide a normatively holistic justification for what course of action is *best*.

In summary, a trivalent analysis of the concept of sickness both affirms and challenges the three broad theoretical camps of the biomedical model, biographical disruption and genealogy. Each approach to defining sickness emphasises one of the trivalent framework's values; on that basis it is affirmed. However, each approach is reductionistic and unrealistic by neglecting the simultaneous contribution of the other two values; on that basis it is challenged.

9.3.1.2 Futility

9.3.1.2.1 Complex telos

In Chapter 2, I commented on the potency of the category of futility as well as the shallowness with which it has been characterised. Schneiderman *et al*'s two-part depiction of futility as impact-plus-benefit (1990) is still faced with the daunting problem of defining benefit. The philosophical problem concerning futility was summarised as follows:

‘In the most controversial cases in which futility is invoked the disagreement between doctors and families is not about the probability that an intervention will work but about the goals that it will serve’ (Weijer and Elliott, 1995: 684).

Clarity regarding the criteria of futility depends on clarity regarding the proper *goals* of healthcare. All major frameworks of the goals of healthcare in the philosophy of medicine are of two kinds: goal-pluralism or goal-monism. In controversial cases, goal-pluralism in theory collapses into goal-monism in practice. Contrariwise, in controversial cases, goal-monism in theory disintegrates into goal-pluralism in practice. Thus, in controversial cases, neither kind of framework can be consistently and realistically applied. Neither kind of framework provides sufficient clarity to support further clarification of the criteria of futility. In Chapter 2, this disappointing conclusion led to an investigation of *values* instead of goals.

However, frameworks of the values of healthcare also share the shortcomings of frameworks of the goals of healthcare. All major frameworks are of two kinds: value-pluralism or value-monism. In controversial cases, value-pluralism in theory collapses to value-monism in practice. Contrariwise, in controversial cases, value-monism in theory disintegrates into value-pluralism in practice. As with goals, so with values: *neither kind of values framework provides sufficient clarity to support further clarification of the criteria of futility*. This disappointment is worse if pluralism and monism exhaust the range of possibilities.

However, a trivalent framework is not quite pluralism and not quite monism. It could be considered non-binary. It is a single complex of interdependent values, whose diversity is united and whose unity is diverse.

Does this paradoxical framework fare any better at characterising the goals and values of healthcare and thereby clarifying the criteria of futility?

In *Restoring order*, I described the single aim of decision-making within an AMS: to restore order. This is not simple goal-monism; there are three different kinds of disorder: the problems of deviation, distress and disruption. Nor is this simple goal-pluralism; the three kinds of problem are interdependent and addressed simultaneously, as one. As such, the *telos* of an AMS is not simply one and not simply three; it is *one-in-three*. It is not quite the unity of monism and not quite the diversity of pluralism; it is the transgressional category of a *diverse unity*. It is not quite singular nor multiple; it is *complex*.

9.3.1.2.2 Complex futility

As described above, disagreements about futility in controversial cases are typically not about whether a treatment will work (technically) but whether it will achieve a legitimate goal (ethically) (Weijer and Elliott, 1995: 684). It is in such moments of contestation that it is most apparent that healthcare cannot isolate 'technique from purpose' (Pellegrino and Thomasma, 1981: 34).

If futility is the failure to achieve a legitimate goal, then the concept of futility is in a way the mirror-image of the goals of healthcare. That is to say, if there is only one legitimate goal, then there is only one kind of futility. For example, if making patients happy were the only goal of medicine, then the only possible way in which a technically-impactful treatment could be futile is if it failed to make a patient happy. In other words, goal-monism yields futility-monism. Likewise, goal-pluralism yields futility-pluralism. If there are many separate goals of healthcare, then there are many separate ways in which a course of action could be deemed futile. In short, there are as many ways to go wrong as there are to go right.

What, then, if the goal of healthcare is one-in-three, a diverse unity, a complex? If there is only one goal of an AMS, to restore order, then there is only one way in which a course of action is futile: it fails to *restore order*. However, if there are three manifestations of dis-order (problems), then there are simultaneously three senses in which a course of action is futile: it fails to address deviation, distress or disruption. Thus futility is both singular and plural; it is complex.

A trivalent account of futility could also be put in terms of values. Affirming Schneiderman *et al*'s account, a course of action is futile if it incurs no benefit; it is no *good*. In this way, there is only one kind of futility. However, how good a course of action is can be appraised within an AMS according to three evaluative standards: welfare, choice and effectiveness. Challenging Schneiderman *et al*, there are therefore simultaneously three senses of futility: a course of action is futile if it is bad in terms of welfare, choice or effectiveness.

The empirical findings of this ethnography thus respond with ambivalence to contemporary accounts of futility. Affirming literature on futility, a trivalent framework echoes the criterion of goal-oriented benefit. Challenging literature on futility, a trivalent framework expands the meaning of futility to be one-in-three; a course of action can fail to incur benefit by failing to address three problems according to three evaluative standards. Futility is therefore not singular (monism) nor multiple (pluralism) but a trivalent *complex*.

By proposing that values are operational as a complex, a *diverse unity*, a trivalent conception of healthcare's *telos* enables the concept of futility to be characterised a little further. However, proposing a trivalent framework for decision-making within an AMS only goes so far. It does not answer every question about values in decision-making; it does not eliminate the difficulty of making decisions in practice; it does not eliminate misunderstandings regarding what is worthwhile and what is futile. In part, this may be due to the brief nature of this account, in contrast to the vast and longstanding nature of the issues it addresses. In part, this may be due to my methodological approach; an ethnography is limited by the standpoint and viewpoint of the ethnographer, amongst other things, and is not intended to provide comprehensive knowledge.

However, the proposal of a trivalent framework does make a significant contribution to healthcare decision-making models and concepts within the philosophy of medicine. Firstly, it provides an account of the role of values in decision-making within an AMS that is more realistic than current clinical decision-making models. Secondly, it identifies conceptual connections between epistemological approaches (objectivist, subjectivist), ontological categories (well-being, sickness) and ethics (fundamental values). Thirdly, it provides a means of characterising the manner in which a particular decision is difficult. Fourthly, with regard to what is worthwhile and futile, it provides a realistic means of understanding misunderstandings.

9.3.2 Values and foundationalism within an AMS

So far in this chapter, I have summarised a trivalent framework which is derived from the ethnographic and interview data presented in *Restoring order*, *Working together* and *What's best*. I used this framework as a means of critically appraising clinical decision-making models. These clinical decision-making models included shared decision-making, cognitive dual process theory, values-based practice and values-based medicine. A trivalent approach both affirms and challenges each model.

The interaction between a trivalent framework and the medical concepts *sickness* and *futility* is similarly ambivalent. Each of three major definitions of sickness is both affirmed and challenged: affirmed in its affinity to a value but challenged in its isolation of it. The most prominent conception of medical futility was affirmed in its construal of impact-plus-*benefit* but challenged to characterise such benefit trivalently.

In what follows, I juxtapose a trivalent framework with problematic areas of value theory that were identified in Chapter 2. After considering a trivalent framework's relation to the ontology and epistemology of values, I then draw this chapter to a close by returning to Chapter 7's metaphor of an AMS as a dance.

9.3.2.1 *The ontology of values*

9.3.2.1.1 *Monism and pluralism*

How many values are there? This is a question of ontology; a question of what exists. In the words of philosopher Isaiah Berlin:

'There is not an infinity of [values]: the number of human values, of values which I can pursue while maintaining my human semblance, my human character, is finite – let us say 74, or perhaps 122, or 27, but finite, whatever it may be' (2001: 12).

Setting the numerical ceiling at finitude, however, is only the beginning. Whether the number of values is one (monism) or more than one (pluralism), problems remain.

Philosopher Charles Taylor sees the problematic nature of value monism expressed in political history:

'What should have died along with communism is the belief that modern societies can be run on a single principle' (1991: 110).

Taylor claims that such a value-monist environment can have a tyrannical effect by compromising individuals' authenticity in the collective pursuit of a simplistic evaluative ideal (1991.). In Chapter 2, I presented an additional problem with value-monism. Value-monism is inconsistent and unrealistic when implemented. This is because any single value affords a diverse range of interpretations. As such, value-monism in theory disintegrates into value-pluralism in practice. This was encountered in this chapter's analysis of VBP, whose fundamental premise of 'respect for persons' is hermeneutically fertile ground.

The problems of value-monism within healthcare are certainly not limited to VBP, however. As surveyed in literature review, there are a range of competing claims for *the* fundamental value in contemporary healthcare. These include patient-centredness (Atkins and Ersser, 2008; Barry and Edgman-Levitan, 2012; Francis, 2013a; Coggon, 2016; Royal College of Psychiatrists, 2018), choice (Jensen and Mooney, 1990; Veatch and Spicer, 1994; Department of Health, 2010), trust (Archard *et al.*, 2013; General Medical Council, 2013), welfare (Pellegrino and Thomasma, 1981, 1988; Shinebourne and Bush, 1994) and care (Noddings, 1984; Fry, 1992; Ross Boyer and Lindemann Nelson, 1992; Kittay, 1999; Mueller *et al.*, 2008; Sloane, 2016). Whilst each of these depictions of value monism in healthcare has its original contribution to an evolving dialogue, none breaks free of the inherent shortcomings of monism as a species. To borrow an image from GK Chesterton, they free the tiger from its cage but not from its stripes (1908: 28).

Value-pluralism also has its problems. In a multiplicity of values, it becomes ambiguous how to actually evaluate a situation. As summarised in literature review:

‘If one state of affairs is better than another just in case it contains more value than the other, and there are two or more basic intrinsic values, then it is not clear how two states of affairs can be compared, if one contains more of the first value, but the other contains more of the second’ (Schroeder, 2016).

Diversity of evaluative standards causes a stalemate. Where, in monism, one poor chef is doing all the work, in pluralism, too many cooks are spoiling the broth. In situations of unavoidable value conflict, the justification of a course of action requires the recommendation of one evaluative standard to out-compete another. One value trumps the other(s). Value-pluralism in theory collapses into value-monism in practice.

The shortcomings of value-pluralism are evident in VBM (see above) and were observed in cases such as Emily, who saw her *survival* as incompatible with her *flourishing*. Similar shortcomings can be expected in other pluralist accounts, such as the NHS values (Department of Health, 2015; Groothuizen *et al*, 2018), the Care Quality Commission (2016) and professional guidance such as the six Cs of nursing⁶² (Cummings, 2013).

9.3.2.1.2 Trivalent framework

A trivalent framework is not quite monism and not quite pluralism. Like pluralism, it features a range of values by which to appraise a situation. Unlike pluralism, these values are simultaneously operative ‘as one’. Values come into conflict and can result in a compromise but no value is eliminated. When two values are in conflict, arbitration can be made by reference to the third value rather than by the arbitrary defeat of one conflicting value. As such, the three remain a single triad. This triad is reflected in the triad of problems and the triad of needs which are persistently at stake. This may be reflective of the persistently triadic nature of an AMS, which remains a single entity despite its three aspects as a medical specialty, an organisational unit and a place for healing.

Like monism, a trivalent approach features a single framework by which to appraise a situation: *is this course of action best?* Unlike monism, this framework features diversity, operating as a ‘three’. Values are all simultaneously operative in the same situation and sometimes in the same individual, but values do not merge into one another; the framework remains a triad, hence the possibility of value conflict. This value conflict is reflected in problems, where value conflict is sensed as futility; value conflict is also reflected in needs, where value conflict can be sensed as cacophony. This is reflective of an AMS as a whole, which, like other medical wards, is a multifaceted, complex intervention (Pannick *et al.*, 2014, 2015). By transgressing

⁶² Care, compassion, competence, communication, courage and commitment. These six values have been endorsed by NHS England as applicable to all health and social care staff (2015a).

the categories of value-monism and value-pluralism, a trivalent framework opens up an area for further study: the place of complexity and paradox⁶³ in the philosophy of medicine in general and bioethics in particular.

A trivalent framework seems to be reconcilable with Ronald Dworkin's well-known taxonomy of goods (1993). Each kind of good in Dworkin's account loosely approximates to an evaluative standard in this narrative of decision-making within an AMS. Dworkin describes three main kinds of good: *intrinsic* goods are good for their own sake, objectively (welfare); *subjective* goods are good according to their desirability for someone (choice); *instrumental* goods are good for achieving some other good (effectiveness). On the other hand, a trivalent framework simultaneously challenges Dworkin's account; where Dworkin's goods are independent and hierarchical, a trivalent framework's values are interdependent and non-hierarchical. However, strictly speaking, Dworkin is accounting for things which are *valued* rather than things which are *values*.

9.3.2.2 *The epistemology of values*

Whilst foundationalism has enjoyed some prominence at least since the time of René Descartes, it is not the only epistemological system. As mentioned in the literature review, other approaches include *coherentism* and *pragmatism*. Coherentism rejects the construction metaphor of foundationalism, instead considering knowledge to be justified by its consistency with a network of other held beliefs (Bonjour, 2005). Pragmatism, on the other hand, considers knowledge to be justified on the grounds of its effect: knowledge is what works. One of pragmatism's main proponents, Richard Rorty, considered foundationalism and coherentism to have both succumbed to a flawed metaphor in which the mind mirrors reality (1979). Instead:

[The pragmatist] drops the notion of truth as correspondence with reality altogether, and says that modern science does not enable us to cope because it corresponds, it just plain enables us to cope' (1982: xvi–xvii).

With empirical findings in mind, I now return to these epistemological approaches to see how a trivalent approach to decision-making interacts with them.

⁶³ There is some commonality here with the concept of a personal trinity in Christian theology. Values involved in decision-making within an AMS are three-in-one and one-in-three. To avoid plain contradiction, the three-ness and the one-ness of values must have different senses. In theological terms, a case has been made for the number three being conceptually unique in that only a set of three is capable of functioning as a diverse unity (Bosserman, 2014; V.S. Poythress, 2018).

9.3.2.2.1 Foundationalism

Knowledge is more than belief that happens to be true. In philosophical circles, one popular definition of knowledge is *justified* true belief⁶⁴ (Pollock, 1986). According to a foundationalist scheme, a belief is justified on the basis of its support from a second, more established, belief. That second belief is justified on the basis of its support from a third, yet more established, belief and so on; it is turtles all the way down. 'A potential regress of epistemic justification looms, with scepticism as the threatened outcome' (Bonjour, 2005: 518). In order to avoid an infinite regress, a set of foundational beliefs is posited. These have also been termed 'basic beliefs', which provide epistemic warrant to more superficial beliefs (Plantinga, 1993). Foundationalism, in turn, is sub-divided into *hard* and *soft* foundationalism, according to whether foundational beliefs are considered defeasible (Klein, 2005).

In view of its similarity with the foundationalist frameworks of monism and pluralism, a trivalent approach loosely fits a form of foundationalist justification. After all, the evaluative standards of welfare, choice and effectiveness enable appraisals which provide *grounds* for a commitment to a course of action. In my discussion of futility (above), I claimed that these three values are standards by which to characterise benefit. Arguably, then, a trivalent approach is a three-fold set of foundational values: 'welfare is good', 'choice is good' and 'effectiveness is good'⁶⁵.

However, it could be argued that a trivalent approach does not quite fit into a foundationalist model. It is questionable that the three values are capable of functioning as basic beliefs which justify other beliefs (such as the belief 'course of action x is best'). In what way do they actually provide epistemic *support* for a more superficial belief? Foundationalism alone is insufficient to explain how values (within a trivalent framework or otherwise) can support other beliefs (Bonjour, 2005).

9.3.2.2.2 Anti-foundationalism

9.3.2.2.2.1 Coherentism

A trivalent approach also loosely fits a coherentist conception of justification. The evaluative standards of welfare, choice and effectiveness interact with one another and can come into conflict. Just as in *Restoring order* participants sought to avoid futility and in *Working together* participants sought to avoid cacophony, so in figuring out what course of action is best (in *What's best*) participants sought to avoid *value conflict*. Putting it in propositional terms, the claim that 'course of action x is what is best' must cohere with the fundamental values 'welfare is good', 'choice is good' and 'effectiveness is good'. To fail to do this, within an

⁶⁴ This definition has been challenged since 1963 by some instances of knowing that fail to meet these criteria, and some instances of meeting these criteria that fail to count as knowing (Gettier, 1966).

⁶⁵ Conceiving values as evaluative standards, it might be more precise to say 'welfare is goodness', 'choice is goodness' and 'effectiveness is goodness'.

AMS, results in a sense of futility and stressful cacophony. A trivalent approach is thus a *coherentist* foundationalism.

There are, however, outstanding problems with this amalgamation. Firstly, there are times when such a coherentist foundationalism is simply not feasible. Sometimes, conflict between the values of a trivalent framework is inevitable. This occurs when one value lends support to a belief that a course of action is best whilst another value lends support to its negation. For example, consultant Tony assessed Stuart's need for an extended stay in hospital during a bed crisis:

"[Stuart] was febrile, but not neutropenic. To be honest, if there were beds I probably would have kept him in and kept an eye. But as it is, I had to send him home." [6d]

According to welfare, admission to hospital is best; according to effectiveness, discharge from hospital is best. It is incoherent to suggest that extending hospital stay and not-extending hospital stay are both better than the alternative.

Secondly, it is not clear that 'coherence' is itself coherent when predicating foundational values. Empirically, 'conflict' is what I understood to be going on; an evaluation of the situation according to the value of *welfare* can conflict with an evaluation of the situation according to the value of *choice*, for example. Coherence is an attribute of *information* according to a principle of logical consistency (Bonjour, 2005: 520); to propose that coherence is a property of foundational values is to perform a cognitivist reduction, which my ethnographic interpretation expressly challenges (see: *Cognitive speed*).

Thus even when foundationalism is combined with coherentism, which some authors have termed 'foundherentism' (Upshur, 2014), such an epistemological approach is insufficient to account for how people figure out what course of action is best within an AMS.

9.3.2.2.2 Pragmatism

These three problems are alleviated, in part, by also conceiving of a trivalent approach within a pragmatist epistemology.

Firstly, a trivalent approach features the evaluative standard of *effectiveness*. In order to be justified in claiming that a certain course of action is best, decision-makers must appraise whether the course of action is what works. In this way, a trivalent approach has an element of pragmatist epistemology built-in.

Secondly, the problematic notion of 'coherence' with its reductionistic cognitive connotations is expanded by conceiving a trivalent approach within a pragmatist epistemology. The conflict in values described in *What's best* includes informational content but cannot be reduced to that content. Conflict in values tends to result in futility and an experience of stressful cacophony for participants within an AMS. A sense of futility

and an experience of cacophony are not merely informational phenomena; they are experiences of people in certain circumstances. Conflict is not simply an incoherence-driven 'rational over-ride' (Croskerry, 2009); it is a compromise which is negotiated by people in practice.

Thirdly, a pragmatist approach does not seek (or permit) a decontextualized approach to knowledge. As Wittgenstein famously described, the meaning of a term is determined by its usage within a form of life (1967: 238–242) or, as a contemporary author puts it:

'Meaning emerges from and is influenced by the contextual discourse. During interactions, words assume a gestural significance' (Kontos, 2004, in Hughes, 2011: 50).

According to pragmatism, knowledge is what *works* within a form of life and truth is 'what our peers will... let us get away with saying' (Rorty, 1979: 176). Putting linguistic and pragmatist insights together, then, the meaning of what is known depends on its usage within a form of life.

With regard to a trivalent approach, the meanings of *welfare*, *choice* and *effectiveness* can be found in how I have used them as an ethnographer within this AMS. To the extent that these three terms become abstracted and universalised, they become slogans which are as meaningless as *liberté, égalité and fraternité* would be if they were divorced from their context of the 1789 French Revolution. However, to the extent that these terms are understood within the narrative of this ethnography and then used interpretively by others in similar but different circumstances according to their 'horizon of significance' (Taylor, 1991), they retain their usefulness; they require re-contextualisation, not de-contextualisation. With its emphasis on usage within a form of life of concrete particulars (Rorty, 1982), a pragmatist epistemology loosely fits a trivalent approach to figuring out what course of action is best within an AMS.

In summary, a trivalent approach approximates to foundationalism but foundationalism does not adequately characterise the way in which values justify judgments of the best course of action. The shortcomings of foundationalism are supplemented by conceiving of a trivalent approach also within a coherentist epistemology. Likewise, the shortcomings of coherentism are supplemented by conceiving of a trivalent approach within a pragmatist epistemology. As such, a trivalent approach to figuring out what course of action is best could be described as a *pragmatist coherentist foundationalism*. Rather than aggregate syllables, however, it may be more useful to simply acknowledge once again the paradoxical ambivalence of a trivalent approach. Namely, the role of values in decision-making both affirms and challenges epistemological foundationalism.

9.4 Realism and reductionism

The role of values in decision-making within an AMS is complex. According to my interpretation of empirical data, three values are involved: *welfare*, *choice* and *effectiveness*. People within an AMS use these evaluative standards in order to know what course of action is the *best* way of working together to restore order. In this way, the three values are closely related to the *problems* that people work to address and the *needs* that people work to alleviate. Both problems and needs are things-that-ought-to-be-corrected within an AMS, and the three values are standards by which a course of action that corrects such things is appraised.

However, the three values operate simultaneously and interdependently as a *triad*; none can be divorced from the others because each presupposes the others. In this sense, the three values are also one; they are a single means of assessing how good a course of action is, and whether it is what's best. Despite an abundance of healthcare literature portraying value-monist and value-pluralist frameworks, my theoretical analysis of them suggested that such frameworks may be unrealistic (see: Chapter 2 *How many values are there?*). My interpretive analysis of empirical data supports this suggestion. Neither value-monism nor value-pluralism is a realistic account of the role of values in decision-making within an AMS. Instead, values operate as a diverse unity, a triad, a complex.

9.4.1 Back to the dancefloor

A diverse unity of values can be simplistically misunderstood in two broad ways. Firstly, by emphasising diversity without unity: a pluralist reduction. Secondly, by emphasising unity without diversity: a monist reduction. Whilst simpler, such frameworks are less realistic. Simple-but-unrealistic is a luxury that patients, relatives and clinicians within an AMS cannot afford.

I return briefly to the allegory of Chapter 7: an AMS is a dance. In this peculiar scene, there are a series of threes. Firstly, the multi-coloured autographs represent *personal need*; the grey-suited classical pianist represents *professional need*; the cemented metronome with a blue-and-white logo represents *organisational need*. Secondly, the anxious dancers with paint on their hands represent patients in *distress*; the proper-dancing dancers in grey pyjamas represent professionals dealing with *deviation*; the blue-and-white dancefloor, which is fitted with an alarm, represents the organisation preventing *disruption*. Thirdly, the multi-coloured headset button represents the diverse nature of *choice*; the grey button represents *welfare*; the blue-and-white button represents *effectiveness*; these are ways of selecting what's best.

A monist reduction fails to distinguish between a grand piano, a pianist and a metronome. A pluralist reduction places each of these in a separate room. Neither monism nor pluralism accounts for needs that are different-but-together within an AMS.

A monist reduction fails to notice the different styles of dancers. A pluralist reduction would place white-and-green dancers, grey dancers and the dancefloor in separate rooms. Neither monism nor pluralism accounts for problems that are different-but-together within an AMS.

A monist reduction fails to notice the three different music channels. A pluralist reduction insists that different music channels are danced to in separate rooms. Neither monism nor pluralism is able to account for values that are different-but-together within an AMS.

9.4.2 Conclusion

In conclusion, this thesis has provided two arguments for a trivalent framework of values in decision-making within an AMS. The first is a negative argument, identifying what the role of values in decision-making within an AMS (and healthcare generally) is *not*:

- 1a. All monist and pluralist frameworks of values in decision-making within healthcare are unrealistic.
- 1b. All frameworks of values in decision-making within healthcare are either monist or pluralist.
- 1c. Therefore all frameworks of values in decision-making within healthcare are unrealistic.

The second is a positive argument, presented through an interpretive analysis of ethnographic and interview data, of what the role actually *is* of values in decision-making within an AMS:

- 2a. Decision-making within an AMS involves three distinct values of welfare, choice and effectiveness.
- 2b. The three distinct values of welfare, choice and effectiveness operate interdependently as a single triad (a trivalent framework).
- 2c. Therefore decision-making within an AMS involves three distinct values that operate interdependently as a single triad (a trivalent framework).

This positive argument shows premise 1b to be false. A third clarificatory argument can now be put as follows:

- 3a. The framework of values in decision-making within an AMS is either monist, pluralist or trivalent.
- 3b. The framework of values in decision-making within an AMS is neither monist nor pluralist⁶⁶.
- 3c. Therefore the framework of values in decision-making within an AMS is trivalent.

Indeed, the trivalent approach described in this thesis is more than merely a framework of values but an account of the *role* of values. An account of the role of values includes the way values operate in decision-

⁶⁶ This was theoretically suggested in Chapter 2 and empirically supported in Chapter 8.

making within an AMS, such as during times of value coincidence and value conflict. An account of the role of values also includes a broad depiction of values, couched within a narrative of the work of an AMS, which is oriented around problems and needs. The implications of this account of the role of values in decision-making within an AMS are the subject of the final chapter.

Chapter 10. Conclusions

In the previous chapter, I discussed the interaction between empirical findings and theoretical issues identified in Chapters 2-4 with regard to the philosophy of medicine and clinical decision-making models. In this chapter, I summarise the conclusions of this interaction. Each major theoretical issue from the literature review is followed by an empirically-informed response.

10.1 Philosophy of medicine

The difficulty in finding a consensus on the concept of *sickness* reflects the difficulty in finding a consensus on the fundamental value of healthcare. Prominent models of sickness include the biomedical model, biographical disruption and genealogy. These models tend to prize a value of *welfare*, *choice* and something else.

- A trivalent framework provides a means of accommodating these three models into a single conceptual scheme. The 'something else' of genealogy could be the evaluative standard of *effectiveness*. Rather than any one value being dominant, each of three values presupposes the other two; they are interdependent. In this way, each prominent model of sickness can function as an aspect of a trivalent conception of sickness.

The difficulty in characterising the concept of *futility* reflects the difficulty in establishing the *telos* of healthcare. Monist and pluralist frameworks of the goals of healthcare prove inconsistent and unrealistic; unity diversifies and diversity unifies.

- A trivalent framework provides an alternative to monist and pluralist conceptions of healthcare's *telos*. The complex notion of a diverse unity makes contact with reality within an AMS. The single aim of an AMS, to *restore order*, entails addressing three problems: *deviation*, *distress* and *disruption*. These problems are interdependent; they are a triad; the *telos* of an AMS takes the form of one-in-three.

As a result of a complex *telos*, the concept of *futility* within an AMS is complex; it is both singular and plural. A course of action can be futile in only one way: it fails to restore order. At the same time, a course of action can be futile in three ways: it fails to address deviation, distress or disruption. Like the aim of decision-making, *futility* is triadic; it takes the form of one-in-three.

There is ongoing dispute as to the value-base of medicine. There are abundant proposals for both value-monism and value-pluralism. Such disputes involve disagreement over the number of fundamental values as well as the content of the value-base.

- A trivalent approach offers a new alternative to monism and pluralism. Rather than a simple unity or a simple diversity, a trivalent approach describes a complex, a diverse unity. This framework is supported in two ways.

Firstly, monism and pluralism result in a *reductio ad absurdum* when translated from theory to practice in controversial cases: monism disintegrates into pluralism and pluralism collapses into monism. As a result, neither is consistent and realistic. Secondly, a trivalent approach is supported by an interpretive analysis of how people within an AMS deal with problems and needs: courses of action are appraised by three distinct values of welfare, choice and effectiveness. However, these three values operate simultaneously and interdependently and result in a single appraisal of whether a course of action is what's best; they function as a triad. A trivalent approach offers an empirically-supported conceptual scheme that transcends the current antithesis between monism and pluralism.

One area of agreement between value-monist and value-pluralist frameworks is a presupposition of a foundationalist theory of values. This is evident in grey literature as well as academic bioethics literature. The majority of bioethical theories can also be characterised by their value-foundation. Thus, a foundationalist epistemology is widespread in literature concerning good clinical care and bioethics.

- A trivalent approach to decision-making both affirms and challenges foundationalism about values. Affirmatively, welfare, choice and effectiveness could be said to provide grounds for a belief that a course of action is what's best. In this way, they constitute a three-fold value foundation. However, my interpretation of empirical data emphasises the importance also of the interaction between values; this resembles a *coherentist* system of justification. In addition, judgments of what course of action is best entail an assessment of what is likely to work in the particular circumstances; what has the power to bring about an effect. This is emphasised by the third value, *effectiveness*. Therefore, a trivalent approach to knowing what course of action is best also features elements of a *pragmatist* epistemology.

10.2 Clinical decision-making models

The historical tension between paternalist and anti-paternalist decision-making is a manifestation of a difference in fundamental values. Paternalist models such as substituted decision-making tend to prize *welfare*; anti-paternalist models such as supported decision-making tend to prize *choice*. The most prominent attempt to transcend this dualism is the model of shared decision-making. However, just as paternalism and anti-paternalism are arbitrary in their selection of value-base, so shared decision-making is arbitrary in its delineation between its paternalist preparatory phase and anti-paternalist executive phase.

- According to an interpretive analysis of how decisions are made within an AMS, neither welfare nor choice predominates. Rather, welfare and choice are two out of three equally fundamental values. What is more, this triadic structure enables a non-arbitrary adjudication between competing evaluations. For instance, where one course of action is deemed best according to the evaluative standard of *welfare*, and another course of action is deemed best according to the evaluative standard of *choice*, which course of action is indeed best can be justified according to the third value of *effectiveness*.

Recent developments in cognitive psychology have given rise to new models of decision-making, including clinical decision-making. An adaptation of dual process theory and cognitive continuum theory describes two kinds of thinking: fast, intuitive reasoning and slow, deliberative reasoning. Transition from one to the other is influenced by the degree of coherence between a diagnostic category that is proposed and the clinical data that are apparent.

- Empirical findings within an AMS affirm dual process theory to some extent. Decision-making, especially from clinicians' perspectives, involves a psychological change of gear. Some decisions are obvious and fast; other decisions are slow, difficult and involve negotiation. However, the difference between *obvious* and *negotiated* decisions is not adequately characterised by the notion of coherence nor any other cognitivist category. Decisions are obvious when a proposed course of action exhibits *value coincidence*; the same course of action is appraised as what's best according to welfare, choice and effectiveness in unison. Decisions are negotiated when a proposed course of action exhibits *value conflict*; the same course of action is appraised as what's best and *not-what's-best* according to welfare, choice and effectiveness in synchrony. A more realistic account of decision-making within an AMS would thus be *trivalent continuum theory*.

Out of growing awareness of the role of values in healthcare decision-making, decision-making models have been proposed that complement the well-established movement of evidence-based practice. One such model is KWM Fulford's Values-Based Practice (VBP). Although purportedly value-pluralist, VBP is effectively monist about values, with 'respect for persons' as its fundamental (meta-)value. VBP faces an epistemological problem: how are diverse value-perspectives to be balanced? VBP also faces a normative problem: what does 'respect for persons' mean?

- A trivalent framework of values in decision-making does not resolve these problems but does help to characterise them further. With regard to VBP's epistemological problem, a trivalent approach identifies a second dimension of conflict which VBP overlooks. As well as diverse value-perspectives of different stakeholders, there can also be diverse value-perspectives within the *same* stakeholder.

Namely, an individual person can appraise a course of action according to three values simultaneously; hence the unpleasant sense of futility, the stress of cacophony and the difficulty of value conflict; value conflict can be *intra*-personal, not just inter-personal.

With regard to VBP's normative problem, a trivalent approach enables an initial characterisation of 'respect for persons.' Namely, the range of meanings of 'respect for persons' can be taxonomized according to each of trivalent framework's values: welfare, choice and effectiveness. This does not help the decision-maker know what to do, nor does it provide more than a trace of anthropology. Instead, it may help an individual decision-maker to understand the evaluative aspect of their moral distress, and it may help a group of decision-makers to understand their misunderstandings.

An alternative model of values-conscious decision-making in healthcare is Miles Little's Values-Based Medicine (VBM). This account claims that *survival*, *security* and *flourishing* are universal, pre-normative descriptive categories. However, the meaning of these terms is unclear, and their universality is questionable.

- The very base of VBM is challenged by my interpretive analysis of ethnographic and interview data. Specifically, it is evident that survival is not universally valued. As well as contradicting one of VBM's basic tenets, this phenomenon creates the possibility of conflict between values, for which Little's VBM is unprepared. However, as well as this challenge, VBM is affirmed by this study's empirical findings. Putting aside the de-contextualised terms survival, security and flourishing, Little's application of VBM is consonant with the trivalent approach to decision-making described within an AMS. Namely, deciding what course of action is best involves an interplay of concerns in terms of welfare, choice and effectiveness.

10.3 Further research

The account of decision-making within an AMS that is described in this study contributes a new framework of values by which to approach theoretical issues in clinical decision-making and the philosophy of medicine. Further research is required, however, in order to address questions such as the following:

- To what extent is the triadic framework of values reflective of the three aspects of an AMS, which is simultaneously a medical specialty, a place for healing and an organisational unit?
- I defined values in Chapter 2 as 'the standards by which things are judged good or bad, which are in turn shaped and sustained by such judgments'. In what ways are welfare, choice and effectiveness *shaped and sustained* by decision-making within an AMS?
- In what ways does a trivalent approach to decision-making manifest in other healthcare settings?

- Are there *only* three kinds of problem, *only* three kinds of need, and *only* three values? Would the three-ness and triadic relation of values be evident to a different researcher? Are they equally evident within a different AMS?
- By appeal to the concepts of complexity and paradox, I claim that a trivalent approach transcends the dichotomy between value-monism and value-pluralism. Are there other dichotomies that could be transcended in a similar way in the philosophy of medicine, bioethics and clinical decision-making?
- What is the relation between a trivalent framework and key notions in bioethics that are mentioned in this thesis, such as *patient-centredness*, *trust*, *care* and *respect for persons*?
- What *should be* the role of values in decision-making within an AMS?

The final question I have positioned last for a reason. There is no shortage of prescriptive literature on clinical decision-making. However, unless prescriptive models first take account of descriptive models, they may fail to make much contact with reality, a reality which is loaded with value-conflict and value-complexity. Before claiming generalisability and reaching for authoritative endorsement, models of how decisions *should* be made and what the role of values *should* be must first take care to understand how decisions currently *are* made and what the role of values currently *is* in particular situations. I hope that this interpretive account of the role of values in decision-making within an AMS contributes another step in this direction.

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Appendix A. Information for Ward Staff

A.1 Email to ward manager and clinical lead

The following email was sent on 13/06/2017 for dissemination to non-medical staff by the AMS ward manager and to medical staff by the AMS clinical lead:

Dear ward staff

From June onwards, we will have a researcher, Dr Luke Martin, starting with us on the ward. Some of you will know Luke from working with him at [Southside hospital]. He is a doctor who is currently doing a PhD in acute medicine, looking particularly at decision-making. He is hoping to observe ward activities and do short interviews with staff, patients, and relatives. If you're interested in finding out more, please see the attached 'information sheet for staff'.

Attachment: Information sheet for staff (version 2.3)

INFORMATION SHEET FOR STAFF

Values and decision-making in acute medicine

Introduction

This ward is supporting a research project which is sponsored by [our NHS Trust]. If you are willing, we would like you to be involved. This is an information sheet to let you know what the research is about. If you would like to know more about it, please feel free to ask the researcher (Dr Luke Martin) more about it when he is on the ward. Alternatively, there are contact details at the bottom of this information sheet.

What is the purpose of the study?

Luke is a medical doctor who is currently doing PhD research in Acute Medicine. He is looking at how we make decisions in Acute Medicine, and the role of values in those decisions. Values are judgments of what is good and what is bad, what is appropriate and what is inappropriate⁶⁷. Our decision-making in Acute Medicine uses a mixture of facts and values. Sometimes decisions are simple and easy; other times decisions are complex and difficult. This study will look more closely at how staff, patients and relatives use values in our decision-making.

What will the researcher be doing?

Even though Luke is medically trained, and some of us know him as a clinician, he is here solely as a researcher. He will not be contributing to decision-making or acting as a clinician while he is here. **The only situation where he would make suggestions is where there is a risk of harm to a patient.**

- OBSERVATION

Luke will be with us on the ward, observing a wide range of clinical interactions. He is not here to criticise what we are doing, but to observe and understand it. The information he gathers will all be **anonymised**; he will not record any one's name or personal information.

Luke will join in with ward rounds, drug rounds, meetings, and general ward activities. On these, he will be observing how decisions are made. He is interested in our perspectives, as members of staff, and may

⁶⁷ This information sheet was drafted and disseminated at an early stage in this research. The definition of 'values' used in this study was subsequently adapted to refer to the standards by which judgments are made rather than the judgments themselves (see: Chapter 2 *What are values?*).

sometimes ask questions. But he does not intend to 'get in the way' or slow us down on busy shifts. Luke will also spend time observing from patients' bedsides.

- INTERVIEWS

In order to hear our thoughts and experiences, Luke would like to interview some staff, as well as patients and relatives. Whatever your role, he may invite you for a short interview. The aim of the interview is not to test or criticise, but rather to understand in more detail how decisions are made, and our perspective on them. These interviews will be recorded on Dictaphone. Quotations may be used from interviews when writing up the research but all information will be **anonymised**. The kinds of topics covered in interview might be: imaginary cases, recent cases, difficult decisions, our thoughts on how values are used in decisions. Interviews may be between 10 mins and 45 mins, as time allows, and might be on the ward or elsewhere in the hospital.

Luke will also be interviewing some patients, on the ward, as well as some relatives, on the ward or elsewhere in the hospital. Again, this is not to rate the care that they have received, but to better understand their perspective on how decisions are made and what values are in play. **The only situation where he would break confidentiality is where there is risk of harm to a patient.**

What will happen to the information?

Audio recordings of interviews will be stored securely in a locked cabinet at [this NHS trust] and Newcastle University. Once they are typed into computerised form by the researcher, audio recordings will be deleted. Signed consent forms and declaration forms will be stored in a locked cabinet at [this NHS trust] and Newcastle University for no more than ten years. Only the researcher and authorised staff from [this NHS trust] and Newcastle University can access these.

All other information, including what is quoted when the research is written up, will be anonymised. No participant's name will be mentioned when the research is written up.

Do I have to take part?

No. Nobody has to take part who does not want to. All participation in interviews is voluntary. If you would like to not be involved even in the researcher's general observation of the ward, then please let Luke know either in person or by the contact details below. If you are unsure whether to take part, or if you are keen in principle but it depends what is required of you, there is no rush to decide. You can take time to think about it, or to withdraw participation from this study at any time.

Who can I discuss the project with?

Luke will be around on the ward and is very happy to speak about this study with anybody who is interested or who has questions.

What if there is a problem?

If you have any concerns about this study or how it is being conducted, there are various people who you could contact. You can contact the researcher at any point. His contact details are listed below. In addition, the contact details for the consultant and research supervisor for this study, Dr Katie Frew, are also listed below. Alternatively, you could highlight any concerns to a senior member of ward staff.

CONTACT DETAILS

Main Researcher

Dr Luke Martin

[Work email address]

[Postal address of workplace]

Research Supervisor

Dr Katie Frew

[Work email address]

[Postal address of workplace]

Complaints

If you wish to make a complaint about this study or something related to this research study, please contact the Patient Advice and Liaison Service (PALS) using the information below. This route is independent of the clinical and research teams.

Patient Advice and Liaison Service (PALS)

[Email address]

Tel: 0800 032 0202

[Postal address]

Appendix B. Research Study Notification

‘VALUES AND DECISION-MAKING IN ACUTE MEDICINE’

In order to improve the standard of healthcare in our hospitals, we are supporting a research study on this ward.



Luke Martin is a researcher who will be observing different clinical situations and inviting participants for short interviews relating to decision-making in acute medicine. This will take place from June 2017.

If you would like to opt out of this study, please inform a member of ward staff. If you would like more information, please contact the researcher either in person or via his contact details below.

Dr Luke Martin

Teaching and Research Fellow

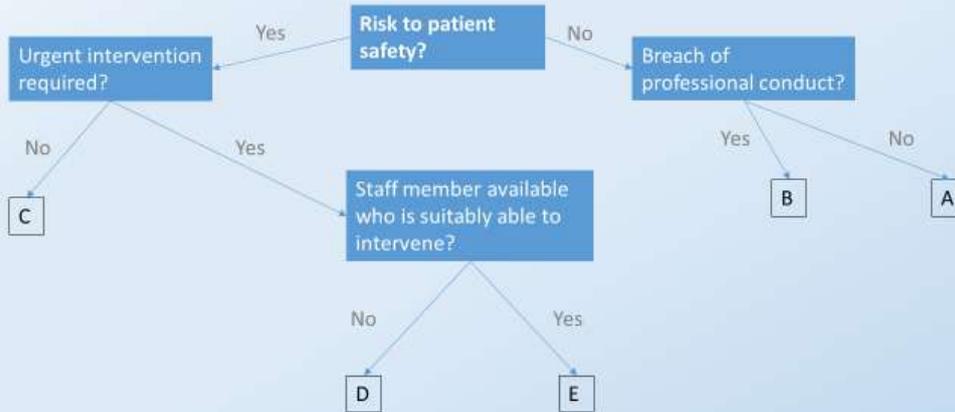
[Postal address of workplace]

[Work email address]

Appendix C. Clinical Safety Protocol

C.1 Overview

Protocol regarding the procedure if evidence of poor clinical practice is witnessed during the study observations



Version: 1
12/05/2017

Protocol regarding the procedure if evidence of poor clinical practice is witnessed during the study observations

- A** • No action.
- B** • LM will inform a member of senior clinical staff who has responsibility for the member of staff whose poor clinical practice has been observed.
- C** • LM will identify another member of staff who is suitable able to intervene. LM will communicate to this other member of staff his concerns and recommended response. LM will seek to maintain members of the public's trust in the clinical team as much as possible. LM will communicate his intervention to a responsible member of the clinical team. Where appropriate, LM will also communicate a statement of fact to his clinical supervisor and/or academic supervisors.
- D** • LM will intervene in a manner adequate to ensure the urgent establishment of patient safety. LM will endeavour at the earliest opportunity to hand over responsibility of the situation to another member of staff who is able to maintain patient safety. LM's intervention will not be excessive with respect to the need to establish patient safety. LM will seek to maintain members of the public's trust in the clinical team as much as possible. LM will communicate his intervention to a responsible member of the clinical team. Where appropriate, LM will also communicate a statement of fact to his clinical supervisor and/or academic supervisors.
- E** • LM will urgently inform this other member of staff. LM will communicate his concern and recommended urgent response.

C.2 Guiding principles

i. Maintaining patient safety

Throughout this study LM will adhere to the GMC guidance to ‘take prompt action if you think that patient safety... is being compromised’ (2013a: 2). This prompt action may take the form of direct intervention or timely liaison with other members of healthcare staff. Which course of action is most appropriate is a matter of situational judgment by the researcher, informed by clinical experience. Patient safety is compromised when a situation or course of action is likely to, or has the potential to, cause significant harm to a patient’s well-being. The action taken must be sufficient to maintain patient safety. The action taken must not be excessive in a way which would undermine the public’s trust in the clinical team, or undermine the integrity of the study unnecessarily.

ii. Maintaining integrity of the research study

GMC guidance on research practice advises that ‘the safety, dignity and wellbeing of participants take precedence over the development of treatments and the furthering of knowledge’ (2013b: 3). Respecting this priority, LM will endeavour to maintain the integrity of this study. This requires a clear understanding from participants regarding his non-clinical role. Misinterpretations and ambiguities of the role of the researcher may distort the research process and research data. As such, LM will limit his interventions to situations where patient safety is at risk, or professional misconduct is clearly exhibited.

iii. Maintaining trust

Throughout this study, LM will ‘work with colleagues in the ways that best serve patients’ interests’, and will not ‘abuse... patients’ trust... or the public’s trust in the profession’ (GMC, 2013a: 2). When poor clinical practice is witnessed during study observations, this requires LM’s action to work with the clinical team in a manner that best serves patients’ interests. When providing intervention or information in an instance of witnessed poor practice, LM will do so with honesty and integrity, to maintain the public’s trust in the medical profession and the broader clinical team.

C.3 References

General Medical Council, 2013a. *Good Medical Practice*. London: GMC

General Medical Council, 2013b. *Good practice in research and Consent to research Good practice in research*. London: GMC

Appendix D. Sample Consent Form

Participant Identification No: _____

Version: 2 09/05/2017

CONSENT FORM FOR PATIENT: INTERVIEW

Name of Researcher:

Name of the Patient:

Please initial box

I wish to take part in this study.

I have had the opportunity to consider the information on the information sheet (version 2.1) and ask questions, which have been answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw my participation at any time, without giving any reason. This would not affect my legal rights or medical care.

I understand that the information collected during the study will be stored on secure computers in [this NHS trust] and Newcastle University.

I understand that information collected during the study may be looked at by individuals with responsibility for this research, from [this NHS trust], Newcastle University or regulatory authorities.

I understand that my interview with the researcher will be recorded.

If I were to become unwell and be unable to give this consent, I wish for information previously gained to be used in data analysis.

If I were to become unwell and unable to give this consent, I wish to carry on participating in this study.

Yes / No

Name of Participant

Date

Signature

D.O.B.

Researcher

Date

Signature

I would like to receive a summary of the results of this research:

(Please initial box)

Yes

No

If yes, please provide your email address and/or postal address below:

.....

.....

.....

.....

Appendix E. A Selective History of Philosophical Hermeneutics

The purpose of this brief survey of philosophical hermeneutics is two-fold.

1. To characterise a general outlook of this movement, which highlights *interpreting* as an essential feature of all human being-in-the-world.
2. To describe the two dimensions of the so-called *hermeneutic circle*: there is interdependence between the whole and its parts, and between the object and the subject.

It is these insights in particular that have significance for the analytic methodology of this study.

Schleiermacher and the hermeneutic circle

In his review of the historical development of theological hermeneutics, Werner Jeanrond comments that ‘only since the Enlightenment has hermeneutical reflection been able to free itself from the predominance of theological concerns’ (1991: xii). It took a philosophically-minded theologian to furnish this opportunity, who has come to be heralded by many as the father of modern hermeneutics (Mueller-Vollmer, 1986: 72; Jeanrond, 1991; Frame, 2015): Daniel Friedrich Schleiermacher.

Writing in Germany at a time when the Romantic movement was opposing the dry rationalism bequeathed to European thought by philosophers such as Descartes, Schleiermacher appealed to the Romantic notion of world-Spirit (*Weltgeist*) in his writing. This meant ‘a kind of creative, intelligent life force that sustained the cosmos, animating both human beings and nature’ (Zimmerman, 2015: 25). This world-Spirit served as the unifying ingredient which enabled a meaningful integration between the mind and the world, and the whole and its parts (Zimmerman, 2015: 25). A part is understood by its relation to the whole; a whole is understood by its composite parts. This interdependence of part and whole came to be known as the *hermeneutic circle*⁶⁸, which Jens Zimmerman proposes as a defining feature of hermeneutics:

⁶⁸ The concept of a circular relation between part and whole predated Schleiermacher but he is accredited for characterising it in more detail (Zimmerman, 2015).

‘hermeneutics... refers to the sort of understanding by which we integrate facts into a meaningful whole’ (2015: 2).

Schleiermacher’s popularity was in part a product of his time. Cartesian epistemology had assumed knowledge-formation to be an individualist, cognitivist spectator sport performed by self-sufficient minds, an anthropology later termed the ‘disengaged self’ (Taylor, 1996). Subsequent Enlightenment epistemologies, whether rationalist or empiricist, had struggled to bridge the gap between the mind and the world (Zimmerman, 2015). By positing a world-Spirit, Schleiermacher’s ontology translates epistemology into hermeneutics; thinking is part of a whole (being); being is part of a whole (world). The circular interdependence of part and whole is evident for Schleiermacher ontologically and relationally: ‘both in the macrocosm of the world and the microcosm of human communication’ (Zimmerman, 2015: 26).

Schleiermacher to Gadamer

Wilhelm Dilthey followed Schleiermacher in overcoming the division between mind and world but sought to do so without the need for supernatural realities such as world-Spirit. Instead, for Dilthey, the ground for the unity of human knowledge was to be found in common experience, namely, the already-meaningful experience of life itself (Mueller-Vollmer, 1986: 25–26).

Dilthey’s focus on the inherent meaningfulness of human experience was developed by Edmund Husserl, who noted that ‘objects always appear to human consciousness as endowed with meaning’ (Zimmerman, 2015: 33); all seeing is therefore seeing *as*; perception is ‘apperception’ (Husserl, 1986: 185–186). For phenomenologists such as Husserl, human consciousness is the starting point for understanding meaning (Zimmerman, 2015: 34).

Husserl’s student, Martin Heidegger, extended the insights of phenomenology by describing the meaningfulness of objects as not revealed to us conceptually so much as *practically*. Heidegger’s famous example is that of a hammer. Rather than perceiving a hammer as an object to be examined, we typically perceive it as a tool to be used; it is not simply physically present (*vorhanden*) but usefully ready-to-hand (*zuhanden*) (1927a). In stark contrast to Descartes’ disengaged self (Taylor, 1996), a Heideggerian knower arrives at understanding through purposive *engagement* with the world. Rather than *emptying* oneself of assumptions and traditions, Heidegger emphasised the importance of *acknowledging* preconceptions and

historical situatedness, as these are what make understanding possible (Zimmerman, 2015: 38).

Hans-Georg Gadamer was another German philosopher, and one who synthesised many of the insights of Schleiermacher, Dilthey, Husserl and Heidegger (Zimmerman, 2015: 39). It is with the publication of his major work *Truth and Method* in 1960 that philosophical hermeneutics became established as a discipline in its own right, one concerned with 'understanding understanding' (Gadamer in Zimmerman, 2015: 7). Gadamer contended that, whilst interpreting may involve principles of method, it cannot be reduced to these principles (Jeanrond, 1991: 9; Grondin, 1994: 106–108). Furthermore, knowledge is not something we obtain and possess but something in which we *participate*; the subject is part of the object; we are a part of the history we study. For this reason, Gadamer suggested not speaking of our 'consciousness of history' so much as our 'historically effected consciousness' (2013).

Following on from Heidegger's portrayal of human beings as interpreting animals (Zimmerman, 2015: 35), Gadamer likened human participation in language to a fish moving through water (2013). Our immersion in language is the common ground that makes understanding possible:

'Language is the middle ground in which understanding and agreement concerning the object take place between two people' (Gadamer in Jeanrond, 1991: 71).

To characterise the nature of understanding between two people, Gadamer used the metaphor of the 'fusing of horizons' (*Horizontverschmelzung*) (2013). When two people communicate with one another, they do so from different positions. Such distance is not merely physical, however, it is also temporal and cultural; they have different locations of *tradition*. This can be described metaphorically as having different 'horizons of significance' (Taylor, 1991). However, there is nevertheless 'similarity in difference' (Zimmerman, 2015: 48) and this makes connections between the two horizons possible. Tradition, then, is not a hindrance to understanding but a precondition of it:

'To acquire a horizon means that one learns to look beyond what is close at hand – not in order to look away from it, but to see it better within a larger whole and in truer proportion' (Gadamer, 1960: 271).

Gadamer's philosophical hermeneutics is a major break from much of modernist epistemology, according to which appeals to tradition are antithetical to proper knowing, 'inherently bad because they shackle our freedom of expression and independent thought' (Zimmerman, 2015: 44). In contrast, Gadamer reinstates the role of tradition in knowing. As Zimmerman paraphrases, 'tradition furnishes the web of conceptions within which we live, move and have our historical being' (2015: 44). In a deliberate blurring of the Cartesian subject-object dichotomy, Gadamer describes human understanding of the world and of ourselves as a single project; it is 'the conversation that we are' (2013: 386).

Gadamer and the hermeneutic circle

Thus, by the time of Gadamer's *Truth and Method*, there has developed a second dimension to the hermeneutic circle. As well as the dialectical relation between part and whole, there is also a dialectical relation between subject and object. By participating in the stream of history (our effective-historical consciousness) and embodying an epistemic tradition (pre-judgments), the second dimension of the hermeneutic circle is made concrete (Jeanrond, 1991: 67). The interpreting subject is inseparable from the interpreted object; sight requires *fore-sight* (Heidegger, 1927b: 223) and understanding requires *pre-understanding* (Jeanrond, 1991: 5); philosophical hermeneutics transforms the one-way microscope to a two-way conversation.

Does the hermeneutic circle apply only to the interpretation of texts? A hermeneutic philosopher is likely to answer both "no" and "yes". No, in that all aspects of our symbol-laden life require interpretation, from actions to events to gestures. Yes, in that all such aspects could be construed as textual. As Jeanrond states, 'a text is more than the sum of its words or sentences. A text is a meaningful whole, a structured whole' (1991: 84).

The postmodern writer Jacques Derrida disputed the notion that only written text requires hermeneutic effort. Even speech and direct interaction is essentially interpretive behaviour. If textuality is a precondition for interpretation, then there is nothing which is beyond-text⁶⁹. Interpreting is a way of life from which we cannot excuse ourselves; we are 'condemned' to

⁶⁹ 'Il n'y a pas de hors-texte' is Derrida's original phrase which famously captures this sentiment (1976: 158) although it has been subject to diverse treatments (Smith, 2006).

it (Merleau-Ponty in Cooper, 2003: 39). This feature of human existence came to be known as the universality of hermeneutics (Gadamer, 2013; Malpas, 2018).

Hermeneutic philosophers such as these, and more besides, provide a deeper characterisation of what is involved in the process of *understanding*. I am indebted to them in my portrayal of what methodology and methods enable me, as researcher, to come to an understanding of the role of values in decision-making within an AMS. For an application of these insights to the context of ethnography and semi-structured interviewing, see Chapter 5 *Analytic methodology*.

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Index of Ethnography Participants

The table below indicates the chapter section in which each ethnography participant is first presented in chapters 6-8.

Name	Section	Role
Alan	6.1.3	Patient
Albert Jenkins	6.3.2	Patient
Alison	7.2.2	Psychiatry liaison team
Amanda	7.3.3	Nurse
Amber	7.2.2	Psychiatry liaison team
Arthur	6.1.1.2	Patient
Audrey	6.2.1	Patient
Beatrice Jones	6.1.3	Patient
Bill	6.3.2	Relative
Brandon	6.3.3.3	Patient
Brenda	7.2.4.2	Phlebotomist
Brigitte	6.2.1	Patient
Charles	6.1.3	Consultant
Charlotte	6.1.3	Patient
Chris Jones	6.1.3	Relative
Deanne	6.2.2	Relative
Dr Morrison	6.1.2	Consultant
Dr Taylor	6.1.1.2	Consultant
Dr Williams	6.1.1.1	Consultant
Emily	6.3.3.1	Patient
Emma	7.1.1	Nurse
Faisal	6.3.1	Trainee doctor
Fergus	6.1.1.2	Pharmacist
Gary	6.1.1.2	Patient
Gloria	6.3.2	Patient
Harold	6.2.1	Patient

Harriet	6.1.2	Consultant
Heidi	6.2.2	Patient
Helen	7.3.1	Nurse
Jackie	6.3.1	Trainee doctor
Jane	7.2.3	Ward clerk
Jenny	6.3.2	Relative
Ken	6.1.3	Trainee doctor
Kerry	8.2.4	Healthcare assistant
Kiran	8.4.1	Consultant
Kylie	6.2.2	Palliative care liaison team
Laura	6.1.2	Trainee doctor
Ling	7.3.3	Trainee doctor
Mark	7.3.3	Nurse
Maureen	6.2.1	Patient
Meghan	7.2.2	Psychiatry liaison team
Mike	6.2.1	Patient
Mr Johnson	7.3.3	Patient
Mr Whitehead	6.2.2	Patient
Nick	6.1.3	Consultant
Rachel	7.2.3	Nurse
Rahul	6.1.3	Physiotherapist
Rosemary	7.2.3	Nurse
Ryan	6.1.2	Nurse
Sandra	6.1.1.2	Nurse
Sarah	6.1.1.2	Nurse
Sharon	6.3.3.1	Healthcare assistant
Sheila	8.2.5	Patient
Sophie	6.2.3	Trainee doctor
Stuart	6.2.3	Patient
Suzie	6.1.3	Patient
Tina	6.3.1	Patient

Tony	6.1.1.1	Consultant
Victoria	7.1.2	Nurse
Zoe	8.2.5	Trainee doctor