Palliative and end of life care provision for people with Parkinson's disease, Progressive Supranuclear Palsy & Multiple System Atrophy

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Abstract

Background

Parkinson's Disease (PD), Progressive Supranuclear Palsy (PSP) and Multiple System Atrophy (MSA) are incurable neurodegenerative conditions. A lack of palliative care provision has been demonstrated for people with PD. Few studies have investigated the palliative care needs of people with PSP or MSA. Place of death for those with PD differs from age matched controls, but the effect of place of death on the quality of end of life care has not been explored.

The aims for this project were to explore:

a) the palliative and end of life care needs for people with PD/PSP/MSA
b) whether the quality of the end of life care experience varies by location

Methods

This is a mixed methods study involving closed internet forums, semi-structured interviews and survey data from national bereavement surveys.

Results

The rarity of PSP/MSA shaped experiences. There was a need for continuity of care which was often lacking in the NHS/social care.

The factors that were important at time of death were that individual worth was recognised, time was given and good communication was attempted. Hospices delivered the highest rated care, due to their holistic nature. The chaotic nature of hospitals made personalised care provision difficult. Care homes provided good emotional support. Although home was the most preferred place of death, if additional support was not present it was difficult for informal carers to manage.

Discussion

There are ongoing studies investigating palliative care provision for people with neurological diseases, focussing on short term interventions. Although this may work for those with PD it is likely to work less well for those with PSP/MSA.

The difficulties people with PD/PSP/MSA encounter with communication affects the way they are treated within the NHS and means that earlier discussions about the future are required if wishes are to be understood.

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Chapter 1 Introduction

This chapter briefly outlines the background to the project, its main aims and the methods used to explore those aims. At the end of the chapter is an outline of the thesis.

1.1 Background and Aims

PD, PSP and MSA are all incurable, progressive, neurodegenerative conditions. As they progress they can affect mobility, speech, swallowing and cognition; with pain, falls and infections common. PD is the second most common neurodegenerative disorder whereas PSP and MSA are rare. Prognosis varies widely within the disease groups. On average PSP and MSA survival times from the start of symptoms are thought to be 6-10 years; there is debate about whether PD shortens life expectancy at all. Each condition causes a wide range of physical symptoms, including pain and fatigue, psychological symptoms of depression and anxiety, difficulties with social care due to decreasing mobility and potentially impact on spirituality as loss of independence (and for PD/PSP cognition) is so marked.

Palliative care is the 'active holistic care of patients with advanced progressive illness' (1, p20) and aims to address physical, psychological, social and spiritual concerns. Its aim is to achieve the best quality of life possible for a person who has a life limiting disease and their family. The provision of palliative care has no timescale attached and is applicable from the diagnosis of a life threatening condition (2). End of life care varies in definition but in most UK policy it encompasses the care provided for people who are likely to die in the next twelve months, including those in the last few days of life (3).

A surprisingly small number of articles exploring palliative care for people with PD exist, although they are increasing in frequency (4-11); only two explicitly explore the end of life (5, 12). Aside from Saleem et al's (11) study which looked at the experiences of people with PD, PSP and MSA there are only a couple of original articles that explore palliative care concerns in PSP and MSA alone and they are related to retrospective note reviews regarding

single issues such as advance care planning in MSA (13) or triggers for hospice admissions in PSP (14) rather than experiences as a whole.

For some time one of the factors felt necessary for achieving 'a good death' has been whether a person dies in their preferred place of care. Although PD palliative care needs have been explored, achievement of a PPOD and whether the location of end of life care impacts on the quality of that care has not previously been explored for people with PD.

This thesis therefore aims to investigate two relatively unexplored areas of palliative and end of life care research:

1. The palliative and end of life care needs of people with PD, PSP and MSA
2. Whether the quality of the end of life care experience varies by location for people with PD, PSP or MSA.

1.2 The palliative and end of life care needs for people with PSP and MSA

Previous studies have shown that people with PD have a palliative care need equivalent to those with cancer (7, 15) or motor neurone disease (MND) (12). Although people with cancer and MND have had access to specialist palliative care (SPC) and hospice support since its inception in the 1960s, the same is not true of people with PD. Despite PSP and MSA progressing more rapidly than PD and people with these conditions having lower quality of life scores than those with PD (6, 16, 17), there are very few studies exploring the palliative care needs and experiences of care for people with PSP or MSA (6, 18) and none of a qualitative nature.

As palliative and end of life care, regarding people with PSP and MSA had been rarely explored, the decision was made to undertake this part of the study using qualitative methods, so that issues could be explored in greater depth. It was likely that many of the issues that have previously been described in palliative care, such as a lack of information and co-ordinated support, would be present for those with PSP and MSA and would be similar to people with PD. However, because the conditions are rarer and progress more

quickly it was felt there may be additional palliative and end of life care concerns that were unique to people with these conditions and their carers.

Chapter 5 of this thesis relates to this aim and shows the ways in which the experiences of people dying with PD differ from the experiences of people dying with PSP and MSA.

1.3 Location of end of life care

When this project began ensuring that people who were dying achieved their PPOD was still high on the political and sociological agenda. Only one study had previously ascertained where the PPOD might be for people with PD, that of Goy and Carter in the USA (12); UK preferences were unknown. There had for some time been a goal of achieving a home death for most people and yet in 2009 Snell et al (19) had shown that only 9% of people with PD died at home, compared to 17% of those dying with other conditions in an age matched population. In 2013 Sleeman et al (20) showed similar findings when comparing PD (9.7% died at home) to MND (27.1%). They also demonstrated that far fewer deaths occurred in hospices for people with PD (0.6% vs 11.2% MND). In 2018 Public Health England produced a data analysis report regarding deaths associated with neurological diseases, which showed that people with PD die most frequently in institutional settings, (care homes and hospitals) rather than in their own private homes (21). However, as many people with PD have moved into care homes during the course of their disease, people with PD die in their usual place of residence more often than people with other neurological diseases (57% vs 45% MND) (21) whether or not this impacts on their experience is unknown.

Gradually there has been a decrease in emphasis on achieving the goal of PPOD, predominantly because when the views of people who are actually dying are explored, rather than that of the general population, place of death appears to be of less importance than policy had previously suggested (22).

Currently the focus has moved to improving care regardless of the location and aiming to address the attributes that can improve the end of life care, wherever that care occurs (23).

Although most people with PD die in hospitals or care homes there has not been any exploration into whether this impacted on their end of life care experience. The National bereavement surveys indicated that care homes provided a higher level of symptom support than hospitals and home environments, with hospices seeming to score best (24); but it is not known whether this stands true for people with PD, PSP or MSA. In addition, place of death has not been explored to ascertain the attributes that matter regarding staff and environment for people with PD, PSP or MSA. This thesis aims to address these concerns and the results are presented in Chapter 6.

In order to investigate whether location has an impact on the quality of end of life care for people with PD, PSP and MSA a mixed methods approach was taken. This involved accessing data from the national bereavement surveys (VOICES 2012-15) and analysing the data that related to people who had died from PD (n=1007), PSP (n=44) and MSA (n=23). In addition, qualitative interviews with bereaved carers of people who had died from PD, PSP or MSA provided additional depth and allowed a better understanding of experiences across the differing care locations.

1.4 Methodology

As a practising UK geriatrics trainee with an interest in PD, PSP, MSA and palliative care the underlying methodology of this mixed methods project was pragmatism. The aim was to explore the experiences of bereaved carers in order to make recommendations for practice that might improve the palliative and end of life care experiences of people with these conditions and their relatives. To achieve this aim, aspects of the interviews that were more closely related to encounters with healthcare professionals (HCPs) were the focus of the analysis and as such the aspects that related more closely to relationships with family, friends and communities are not explored in depth within this thesis.

1.5 Carers

The term carer is not a term that the relatives I interviewed would necessarily identify with, and Roger and Medved (25) found that as a term it is actively disliked by people with PD

themselves as it presents their relationships with their main family support in too clinical a manner. I did not use the term 'carer' when conducting the interviews and referred to people by name or relationship i.e. wife, mum etc however, the term 'carer' or 'informal carer' is used within this thesis for ease of group comparisons and because it is the term used within the VOICES survey analysis and throughout the literature.

1.6 Outline of thesis

Chapter 2: Literature review

This chapter sets out the background to the project. The first part explains the pathology, clinical findings and epidemiology of PD, PSP and MSA, and explains that they have a high degree of symptom burden and that there is a potential need for specialist palliative care input from the start. The second part discusses end of life care provision and the current policies in place to guide end of life care provision in the UK. The third part discusses place of death and why it may affect the quality of the end of a person's life; it also considers the historical background of dying and illustrates why place of death is thought to be so important.

Chapter 3: Methodology and methods

This chapter explains why pragmatism was the methodology of choice for this mixed methods project and then outlines the project design. It discusses the methods used for recruitment, sampling and analysis.

Chapter 4: Demographic results

This chapter outlines the demographic details of the quantitative and qualitative samples.

Chapter 5: Palliative care needs of people with PD, PSP and MSA

This chapter considers the palliative care needs of people with PD, PSP and MSA, comparing PD to the two rarer diseases. As this chapter explores needs from diagnosis onwards most of the factors relate to people living in their own homes. It first outlines issues regarding information gathering and shows how these might impact on ACP. It then highlights

problems with navigating the system and getting adequate home support. The third part discusses how a lack of knowledge about the diseases impacted on the care that was provided and the final part shows how crucial support from family, friends and the disease charities was to enable a person to stay at home for as long as possible.

Chapter 6: Quality of service provision in the last three months of life, place of death and bereavement

This chapter compares the quality of service provision in the last three months across four different places of death; hospitals, care homes, home and hospices. It discusses staff attitudes towards the dying, the control of symptoms, awareness of dying and choices about PPOD and explains how these impact on the end of life experience. The last section covers staff attitudes towards carers themselves and includes bereavement support. As the end stages of the diseases occur in a similar way, and the qualitative data did not indicate a difference between the diseases with regard to specific locations (and the numbers for PSP/MSA were too small to provide meaningful statistical comparisons in regard to place of death) the diseases are combined in this chapter, so it is the comparison of the location of the services that is the focus, rather than a comparison of the diseases. The quantitative and qualitative data are integrated to illustrate where there are differences across the locations of care and what those differences might mean.

Chapter 7: Discussion of themes

This chapter pulls together the two previous results chapters and explains how they fit into the overall themes of the project: the emotional and practical elements of preparation, support and identity, before then comparing them with existing literature.

Chapter 8: Discussion regarding changes to service provision

This chapter starts with a summary of the PD, PSP and MSA specific literature and how it compares to the findings of this project. The main section suggests improvements for service provision in line with the pragmatic methodology that underpins this project. The final part of this discussion chapter outlines the strengths and limitation of the project and

suggests avenues for future research. It then concludes with the main findings of the project.

Chapter 2 Literature Review

2.1 Methods/search terms of the literature review

Prior to commencing this research project, a literature search was performed in regard to the main research question: the palliative and end of life care needs for people with PD, PSP and MSA. This was undertaken using Medline and Scopus.

Within Medline the keywords of 'Parkinson's disease or PD', 'Multiple system atrophy or MSA' and 'Progressive supranuclear palsy or PSP' were combined with a search with the keywords 'palliative care OR terminal care OR end of life'. Within Scopus 'Parkinson's disease', 'Progressive Supranuclear Palsy, and 'Multiple system atrophy' were searched for as article titles, abstracts or keywords and the terms 'palliative care or end of life' were searched for within the results. The initial searches were performed in September 2015 with the results illustrated in Figure 1.

Journal articles, review articles, conference abstracts and letters regarding original research were included in the searches. Review articles were predominantly used to hand search for additional relevant literature. Articles that were opinions/advisory, related solely to medication or the development of survey tools and outlines for future projects were excluded. Articles that focussed predominantly on carer burden or the impact on HCPs, rather than on the experiences of those with the diseases were also excluded. Within the initial search were several conference abstracts that included data that was then published as a journal article at a later date and it is the later journal articles that are included in this literature review.

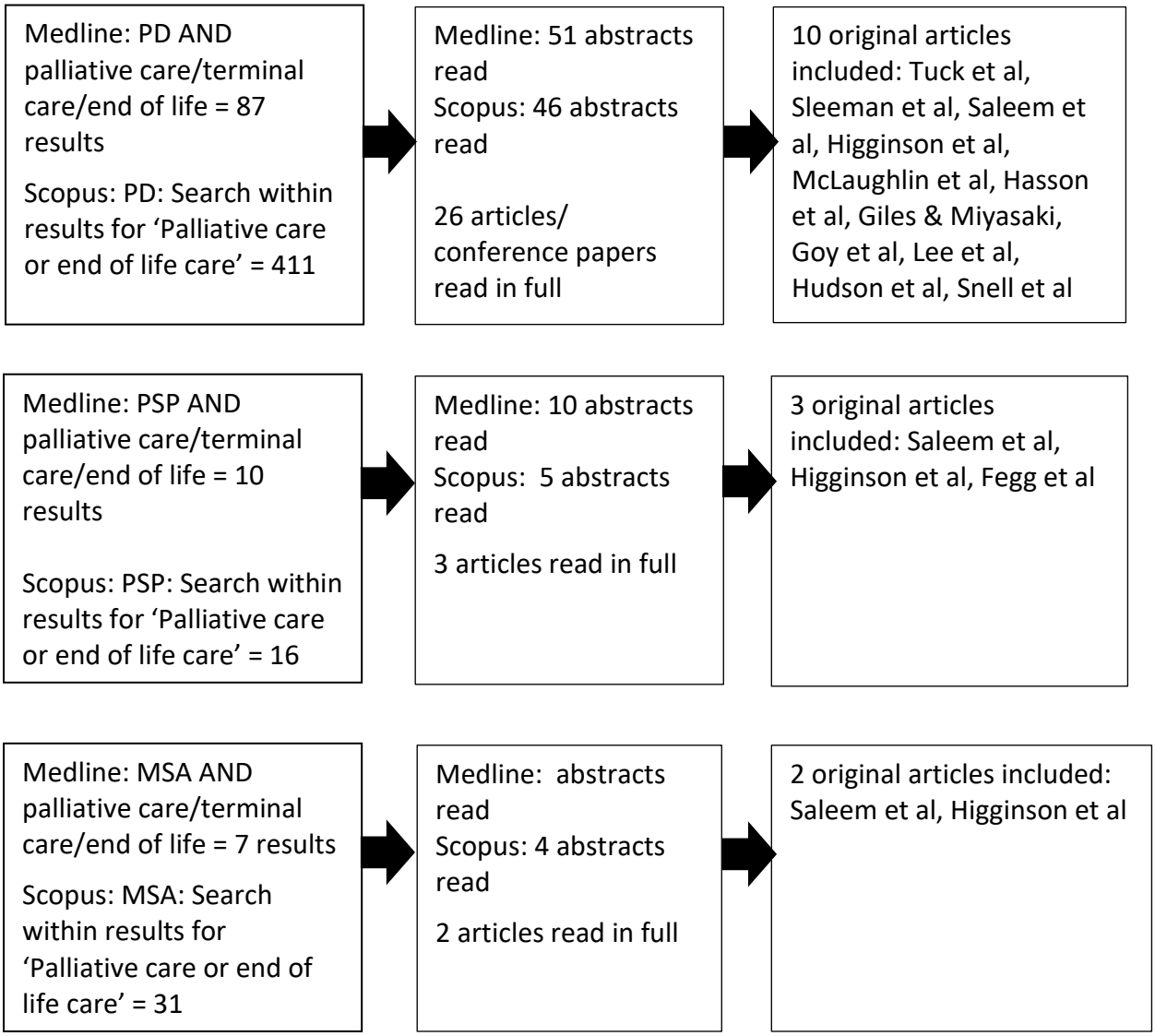

Figure 1 Initial literature search

Throughout the project regular literature searches were performed using the same terms on both Medline and Scopus, with the final searches occurring in Summer 2019. Grey literature in the form of theses, audits and websites relating to the diseases was also searched to ensure developing areas of research were not missed. As the methodology of the project was pragmatism, meaning there was a need to relate the findings to current policy, a large amount of grey literature was also searched through and read in regard to UK policy. This was searched for through NHS England's website, the gov.uk website and using search engines to search for 'end of life care policy UK' and 'palliative care policy UK'. Further reports/grey literature were also reviewed after checking the reference lists of policy reports and the ambitions for palliative care framework.

Once data had been collected, analysed, and the developing themes were clearer, further literature searches were performed in regard to issues such as identity, loss of self, the wish to die/ hasten death, advanced care planning, preparation and bereavement. If the data were scarce in regard to these topics within the movement disorder literature, then a search for these factors and motor neurone disease (mnd/als[1]) was also used. Mnd has long been considered a palliative disease and as such a greater amount of palliative/end of life care literature exists concerning the experiences of people with mnd.

During all searches any relevant literature was added to an excel workbook that was used as a framework to ascertain the main results and themes of each piece of literature. This workbook was used to update the original literature review in order to provide a chronological and conceptual background to this research project.

A narrative literature review was used so that biomedical studies regarding PD/PSP/MSA could be readily combined with social theory about dying and current policy. The fact that a large proportion of the project was qualitative meant it was important to explore sociological concepts within the literature review/discussion chapters and the pragmatic methodology of the project meant that suggested improvements in care had to be relevant to current UK policy.

2.2 Background

PD, PSP and MSA are all progressive neurodegenerative conditions for which there is no known cure. They overlap in terms of symptoms, with all showing variable signs of Parkinsonism – comprising slowing down (aka bradykinesia), rigidity, postural instability and tremor (26), but they have differing pathophysiology, additional features and prognoses. They are also known as 'movement disorders' and people with the conditions are reviewed

[1] ALS – amyotrophic lateral sclerosis in the term use for mnd in the USA. It is a rapidly progressing, rare, neurodegenerative disease with no cure and an average prognosis of 2-4 years from symptom onset.

regularly in ‘movement disorder clinics’ which may be run by neurologists, geriatricians, or both, with input from specialist nurses.

2.3 Epidemiology

PD is the most common of the three disorders, with a prevalence of around 130/100000 in the UK (27), whereas MSA and PSP have prevalences of around 2-5/100000 and 4-5/100000 respectively (28-30). The incidence of all three increases with advancing age (31, 32) and normally occurs above the age of 50.

2.4 Pathophysiology and clinical features

All three diseases are caused by a loss of neurones. Although the exact aetiology of the neuronal loss is unknown it is felt to be due to various different mechanisms, including oxidative stress and the accumulation of additional proteins in the brain (tau for PSP and α-synuclein for PD and MSA)(33-35). It is this protein accumulation that is used to make a definitive diagnosis at post mortem (26, 36, 37). As the neurones die, dopamine levels are reduced. Dopamine is the main neurotransmitter in the basal ganglia area of the brain. The basal ganglia are responsible for fine motor control and planning movement, which explains the motor features of Parkinsonism detailed above. A DaTscan, which shows the level of dopamine transporters (DaT) present in the brain, can be a useful tool to aid clinical diagnosis, as in all three diseases the scan will be positive (i.e. show reduced dopamine transporters, reflecting the loss of the neurones the transporters are on). In PSP, the area superior to the nuclei is also affected, leading to a vertical gaze palsy; the disease is also associated with an increased incidence of early falls (36). In MSA, as the name implies, multiple areas of the brain are affected, including the cerebellar pathways (responsible for co-ordination) and the autonomic pathways, deficiencies in which can lead to urinary incontinence and an orthostatic decrease in blood pressure (37).

2.5 Staging of PD, PSP and MSA

All three diseases are progressive and over time lead to increasing disability. One of the common tools used to denote the severity of PD is the Hoehn and Yahr rating scale (as shown in Table 1). The scale is often used in research to denote the equivalent stage of MSA and PSP as well.

Stage	Features
1	Unilateral involvement only usually with minimal or no functional disability
2	Bilateral or midline involvement without impairment of balance
3	Bilateral disease: mild to moderate disability with impaired postural reflexes; physically independent
4	Severely disabling disease; still able to walk or stand unassisted
5	Confinement to a bed or wheelchair unless aided

Table 1 The Hoehn and Yahr Rating scale, reproduced from Goetz et al (38 p1021)

The Hoehn and Yahr scale is used in research, as well as in clinical practise, alongside the Unified Parkinson's Disease Rating Scale (UPDRS). This scale was developed in the 1980s and originally consisted of four parts covering mood, motor disability, motor impairment and the motor/non-motor complications of treatment (39). A criticism of these scales was that they concentrated predominantly on the motor features of the disease. There are many non-motor symptoms that commonly affect people diagnosed with PD including sleep disturbances, fatigue, gastrointestinal problems, psychiatric problems (anxiety and depression), pain and cognitive impairment (40). As these symptoms are so common, and often lead to more morbidity than the motor symptoms, especially at an earlier stage, the UPDRS was modified in 2008 by the movement disorder society to include more of the non-motor symptoms (41). Similar rating scales have been developed for PSP and MSA, the PSPRS (42) and the UMSARS (43) respectively. However, as with the original UPDRS they predominantly focus on diagnostic motor features rather than non-motor issues. The same non-motor problems are known to occur in MSA and PSP, perhaps to an even greater extent

and severity than in PD, as these conditions progress more quickly than PD (37), with less effective treatment available.

In 1998 MacMahon and Thomas (44) described four clinical stages of PD starting with diagnosis, where information is shared; a maintenance phase where drugs control symptoms; a more complex phase where drugs work less effectively and increasingly complicated drug regimens or surgical options are considered; and lastly a palliative phase of the disease.

2.6 Treatment

In the 1960s levodopa (a synthetic dopamine precursor) was developed. It is absorbed from the gut in combination with an aromatic amino acid decarboxylase inhibitor[2], which prevents peripheral breakdown of the drug. Once it crosses the blood brain barrier it is converted into dopamine by the brain and it has proven to be a very effective treatment for PD in terms of reducing motor symptoms. There have been other treatments developed, which act by stimulating post-synaptic dopamine receptors (dopamine agonists) or by preventing the breakdown of dopamine, either centrally (MAO-B inhibitors) or peripherally (COMT inhibitors), and all help motor symptoms to some degree. None of these drugs has had any significant effect on disease progression however and they do not aid non-motor symptoms. The same drugs are often tried to help motor symptoms in MSA (37) and PSP (35) but they do not work as well, or for as long, as in PD and for some people they offer no benefit at all.

2.7 Prognosis

Survival times for PSP are thought to be between 6-12 years (45) from start of symptoms and MSA has been shown to have a median survival of 9.8 years (46). There is ongoing debate about whether PD shortens survival at all; patient information sites and leading

[2] carbidopa in the case of 'sinemet' or benserazide in the case of 'madopar'

charities deny a shortened life expectancy, though two meta-analyses suggest a mortality ratio of between 1.5-2.2 (47, 48). More recently, a 2017 study regarding synucleinopathies (PD, MSA) in the USA showed that people with PD were 1.75 times more likely to die than age matched controls, and this increased to 3.86 if dementia was present (for MSA the hazard ratio was 10.5) (49). PD, PSP and MSA show a lot of variability amongst diagnosed individuals with regard to symptoms and prognosis and this is perhaps why some public patient sites claim that the disorders are not life-threatening (50, 51). In part, for PD at least, this seems to come down to semantics. NHS Choices (50), Parkinson's UK (52) and the Michael J Fox research foundation (53) all claim that PD does not directly cause death but as symptoms worsen the body is more susceptible to life-threatening incidents or infections; so without the weakened state of advanced PD a person would likely live longer.

2.7.1 *Cause of death (COD)*

Several studies have analysed death certificate data to determine what people with PD died from and all have shown that pneumonia is a far more common COD amongst PD patients than the general population, with the prevalence of ischaemic heart disease, cerebrovascular disease and malignancy the same, or often less, than an age-matched population (54-57). As pneumonia is more common with reduced mobility and impaired swallowing, both common problems with advanced PD, the PD is very likely to have contributed to these deaths. Nath et al (58) showed the same was true for PSP, with pneumonia by far the commonest terminal event prior to death. Much discussion regarding COD centres around how the death certificate is written and where the neurological disorder is placed on the death certificate, if at all (Chapter 3.8.3 and Appendix C explain this in greater detail). Nath et al (58) discuss that PSP is often not recorded properly and so it is hard to obtain death certificates for this population and Pennington et al in North East England and Hobson et al in Wales both showed that only 63% of their known PD patients had PD mentioned anywhere on the death certificate (55, 57).

There are four studies looking specifically at COD in MSA (59-62) and three showed sudden death is relatively common (59, 61, 62) ranging from 14.5% (62) to 38.1% (61). Other than

sudden death, the patients with MSA tended to have died from pneumonia, urine infection or aspiration, so normally with direct complications from the disease. One study compared MSA to PD and though the numbers were small (n=21 for each) all those with MSA died from potential complications, whereas people with PD also died from cancer, stroke or myocardial infarction (61). It would seem that MSA and PSP contribute to death more directly than PD, where a large number of patients die from other problems common with ageing, possibly before they have reached an advanced stage of PD. A recent study by Moscovich et al would support this claim as those dying in an earlier stage of PD had similar causes of death to an age matched population, whereas those with advanced stage PD died of similar causes to those with PSP/MSA, mostly from sepsis or pneumonia (63).

2.8 Palliative Care need

As all three conditions are incurable they could be considered palliative, in line with the original 1990 definition of palliative care from the World Health Organisation, where palliative care was seen to be "The active total care of patients whose disease is no longer responsive to curative treatment"(64 p11).

However since their definition of palliative care changed in 2010 to "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (65) deciding whether or not the diseases are life-threatening has potentially become a more important issue.

Hudson et al (7) discussed that the uncertainty about whether PD should be considered a life-threatening disease places PD at odds with other palliative care populations. They undertook a qualitative descriptive study in Australia, where they interviewed 8 patients, 21 relatives and 6 health professionals to explore issues surrounding support and practicalities to answer the question 'Would people with PD benefit from palliative care?' Their robust thematic analysis identified 5 themes: the emotional impact of diagnosis, staying connected,

enduring financial hardship, managing physical challenges and finding help for advanced stages. They explained that many of their findings, such as the grief response to a diagnosis of PD, feelings of isolation due to communication problems and challenges meeting the numerous physical changes PD brings, such as immobility, were very similar to those in a cancer population, the usual beneficiaries of specialist palliative care (SPC). They also discussed the need patients and relatives felt for more information about PD from specialist teams and that PD should be managed with multidisciplinary expertise from staff adequately trained in PD, with large levels of support being required as patients advanced. Giles and Miyasaki (4) reported similar findings with regard to the need for more information, coupled with a need for guidance about where to get it. Their small scale exploratory phenomenological work probed the lived experiences of the Canadian healthcare system for three people in the palliative stage of PD and their family members (n=4). They also discuss the theme of 'wanting and not wanting', where relatives said they wanted more information but were ambivalent as to how much, especially regarding deterioration. Given that this ambivalence existed even with advanced patients (Hoehn and Yahr 2.5-5) (4) this seems to support the point made by Hudson et al (7) that it is difficult to know when to offer a palliative approach to patients with PD as their long and variable disease trajectory may mean they do not consider themselves to have a life-threatening disease, even though they have similar needs to other patients using SPC services.

Much of Giles and Miyasaki's paper (4) was concerned with problems regarding home-care services in Canada; the participants were recruited from a tertiary hospital lacking a multidisciplinary team (MDT). This makes their findings less generalizable to the UK where an MDT approach is more commonplace. Hudson et al's (7) participants were self-selecting and so it is unfortunately not clear how certain their PD diagnosis was. In addition, the authors did not use a staging system specific to PD but separated participants into early stage (where they were essentially independent in everything) to middle/late stage (including any degree of help) (7); this makes it hard to understand how advanced the patients might be. The small number of participants in both studies could also affect generalisability but nevertheless they explored the issues that matter to patients and their

carers and showed why instigating palliative care might be a problem. Hudson et al's concluding point is that using prognosis for a SPC referral in neurodegenerative conditions is fraught with difficulties (7). Indeed, since their paper was published further studies (6, 11, 15) have discussed that due to their symptom burden people with PD should have SPC input from an early stage; not just at the point they appear to be deteriorating or approaching the end of life.

A review article by Wiblin et al, summarising the evidence for palliative care in neurodegenerative disease, suggests the same is true for those with PSP and MSA (18). Only two published articles regarding palliative care need have included people with PSP and MSA (6, 11); these articles concentrated predominantly on the symptom load of a single London cohort followed up in a longitudinal study.

2.8.1 *Symptom load*

Lee et al (15) undertook a descriptive cross sectional survey of 123 patients known to have PD, with Hoehn and Yahr scores ranging from 1-5 (median 3), living in Northern England. They carried out face to face interviews to complete a Palliative Care Assessment Tool (PACA) for each participant. The PACA allows patients to identify their symptoms and subjectively attest to their severity (in terms of how greatly they impact on their day) and it had previously been validated for cancer diagnoses and non-malignant conditions. Lee et al found that participants had an average of 14.3 symptoms. The most frequent were slowness of movement and pain, which were present in more than 85% of participants and dominated the day for 17% and 20% respectively. Immobility was present in 50% and dominated the day in 29% and drowsiness, anxiety and insomnia were also common. Of the 161 patients initially identified, those who did not take part were older, had more advanced disease, more cognitive impairment and were more likely to be living in nursing homes. Given that the authors found an increase in the frequency and severity of symptoms as the disease progresses, the study may have underestimated the degree of symptom load for PD patients. Despite this, symptoms such as pain, immobility and constipation were present in comparable frequency and severity to cancer patients and so the authors argued that when

symptom load is high, regardless of Hoehn and Yahr stage, a palliative care referral may be warranted.

Higginson et al (6) also showed that the cohort of patients they followed over a year had a symptom load similar to, or more severe, than that of cancer patients. They conducted a longitudinal community study involving 82 patients in the south east of England (48 with PD, 18 with MSA and 18 with PSP); all participants were equivalent to Hoehn and Yahr stage 3-5, had mental capacity with minimal cognitive impairment, if any, and lived at home when recruited. The authors conducted face to face interviews using a multitude of well validated questionnaires, many used previously or adapted to PD, to determine disability, symptom load, quality of life and depression levels. Two thirds of the participants had at least severe disability, though this was more common for the PSP and MSA groups. All three conditions had poor average quality of life scores and showed evidence of considerable psychological distress at baseline assessment. By the end of the year almost 50% of those with MSA and PSP had died, compared to 6% with PD. Problems with swallowing and communication were more prevalent for PSP (60%;80%) and MSA (76.5%;76.5%) than PD (40%;58%) and those with MSA had far more difficulty controlling urine. Over the year the subjects stayed the same or deteriorated; the Hoehn and Yahr stage did not predict which participants would develop more symptoms over the year, but the higher the initial symptom burden at baseline, the more likely additional symptoms were to develop. The authors postulated that given the long-term nature of symptoms a solution may be to initiate a referral to SPC for potential short-term intervention, which might assess and help manage pertinent symptoms, but could also allow those with multiple problems and deteriorating courses to remain under review. This short-term symptom review option may sit better with patients not wanting to consider themselves terminal.

The same cohort's palliative care needs and initial baseline symptoms, including their severity, were also presented by Saleem et al (11) as a cross-sectional study. Like Lee et al (15) the most burdensome symptoms found were lack of mobility (present in 50%) and pain (39%) (11) with other severe symptoms being difficulty using arms, difficulty

communicating, fatigue, drooling, constipation, insomnia and falls. The most frequent symptoms were immobility, pain, fatigue and daytime sleepiness which were all present in more than 80% of Saleem et al's participants (11). Patient and family anxiety was common and 65% of participants had been depressed to some extent in the previous 2 weeks. Saleem et al also discussed provision of information and practical support; 62% felt they had been given full information about their disease, though 38% would have liked more and 59% had their practical problems addressed (11). Like Lee et al (15), Saleem et al showed that the higher the Hoehn and Yahr stage, the higher the symptom burden and they also showed that the prevalence of symptoms was equal to an advanced cancer population (11). They explained that the guidance for long term neurological conditions talked about triggers for palliative care support but even though their patients met many of these triggers the majority had not been referred to SPC.

These three papers have several strengths. There are reasonable numbers of patients included, enough to make statistical conclusions sound, and the tools used to investigate symptoms and quality of life have been well validated previously. As symptoms are likely to be linked to the disease, for which the same criteria are used worldwide, the findings regarding symptom load are likely transferable to other countries as well. The main weakness of these studies is that they do not include anyone with a significant degree of cognitive impairment, despite the fact that in advanced PD around 40% have developed dementia (40). This is likely due to the logistics of the studies, as those with cognitive impairment may well not recall symptoms, but it means there is a potentially large group of patients whose symptom burden we are less sure about and cognition, especially with regard to family relationships and whether participants are independent or not, is likely to play a large role in quality of life. They also concentrated on people living in their own homes, whereas those with more advanced disease and closer to the end of life, indeed the people who may be at most need from palliative care support, are more likely to be in residential or nursing care.

Initiating palliative care as a response to symptoms rather than prognosis fits with the 'early identification and impeccable assessment of needs' statement in the WHO definition of palliative care (65) and NICE guidance for PD (3) currently reflects this, with the suggestion that referral to SPC should be according to need, regardless of disease stage.

A more recent study exploring the implications for SPC in Germany by Strupp et al (66) aimed to explore factors which led to people with Parkinsonism feeling subjectively more severely affected by their disease. A survey was developed including open questions about why a person felt severely affected by their disease and the 814 complete responses were analysed against the more objective closed questions regarding disease severity and demographics. In this study, although pain was a factor for 8.1%, unmet social needs such as help with everyday tasks, finances, information access and social integration were mentioned more often (in 28.1%, 11.6%, 9.9% and 9.9% respectively) as severely affecting a person; immobility was mentioned most (34.9%). This indicates other factors, aside from symptom load that might be improved through a more palliative approach. As a caution this study included all forms of Parkinsonism, including those without a known cause, and this likely affects the generalisability of the findings to a definite PD population.

There is less guidance for PSP and MSA, but timely referral to SPC services is suggested in the guidance to professionals on the charity websites (67, 68). In addition, in 2016 the European Association of Palliative Care and the European Academy of Neurology issued a consensus review suggesting that palliative care is included in guidelines regarding the care of all people with progressive neurological disease, in the same way it already exists for those with MND/ALS (69).

2.8.2 *Would people with PD, PSP and MSA be receptive to specialist palliative care input?*

Studies, such as those related above, indicate that people with PD might benefit from SPC input. Yet Fox et al, in a 2016 Irish study, found that HCPs were sometimes reticent to refer to SPC due to a perception that it could be emotionally harmful to patients (70).

Fox et al later undertook a qualitative study with people who had PD (and to a lesser extent their carers) to establish what they perceived their care needs to be (9). They also ascertained their views about SPC input. Boersma et al carried out a similar study in Canada (10). Both studies indicated a high degree of emotional burden from having PD and the effects it had on self-concept and social interaction (9, 10). Decreasing mobility, independence and cognition contributed to changing roles within families and a reduced sense of identity (9, 10). Both studies reported the difficulties with being uncertain about how the condition would progress and a mixed view on how much knowledge and discussion about the future was wanted (9, 10). Significant gaps in care were identified in both studies, especially regarding emotional and spiritual support for coping with the impact of PD (9, 10). This was thought to occur because medication management and physical symptoms were the focus of physician reviews. A general lack of co-ordinated care from the multidisciplinary team was related and people with PD (and their carers) often felt unsupported. Fox et al highlighted a lack of support was particularly true for people with PD who did not have informal carers (9). In regard to SPC/hospice both studies showed the perception was that this was for people with cancer and many of those interviewed were not aware it was available for people with PD (9, 10). Despite some initial misgivings about the term 'palliative' once the role of SPC was explained most people with PD, and their carers, were receptive to its input, even early in the disease process (9, 10).

A strength of Boersma et al's study (10) was that they purposefully sampled for cognitive impairment, thus gaining the views of a previously unexplored group. This may well be why identity loss was a more prominent theme in their study than in others. In addition, the authors undertook several steps to ensure the validity of their work including triangulation by using interviews and focus groups, and member checking. A strength of Fox et al's study (9) was that a third of the participants with PD had no informal carer; allowing the views of people living alone with PD to be explored. In addition, the lead author kept a reflexivity diary to minimise bias towards the interpretation of the results. Unfortunately, the description of analysis techniques was limited in both studies, which may reflect negatively on their quality (71).

Boersma et al (10) and Fox et al's (9) findings add weight to Hudson et al's (7) argument that people with PD would benefit from SPC from an emotional and social point of view, as well as from a symptom load point of view. They also indicate that most people with PD and their carers would be open to SPC input if the ways it could help were clearly explained from an early stage. In these studies (9, 10), those with more advanced disease were keener to have SPC input, but desire for help was variable at all stages of disease and very individual. There remains a question about the best way to deliver SPC services to people with PD, with more traditional style services/day hospices, joint working between neurological and SPC services, and short-term intervention all having been/being trialled.

There are no published papers exploring the views of people with PSP/MSA, or their carers, regarding SPC provision. Wiblin, in her thesis regarding palliative care need in MSA and PSP found that almost half of the people she interviewed had received SPC input and though a third of them could not define what palliative care was, they recognised its value in their care (72). She also found that nearly half of her participants felt SPC equated to the end of life (72), which may dissuade some people from accepting its input, thus identifying the same potential barrier that Boersma et al (10) had found for people with PD. Wiblin's (72) conclusion was that people with PSP/MSA and their carers would benefit from an individually tailored palliative care approach throughout the course of their disease and would be receptive to SPC input .

2.8.3 *Models of palliative care provision*

Given that individuality is key, is there a preferred model of palliative care provision for people with PD, PSP and MSA? Boersma et al (10)and Fox et al (9) both argue that a holistic palliative care approach is needed but that this does not necessarily equate to SPC for all, i.e. emotionally and spiritually supportive coordinated care could potentially be delivered within existing services. Wiblin et al (18) in their review regarding palliative care in neurological diseases showed where the roles of neurological services and SPC might overlap and the situations in which SPC may be needed (see Figure 2)

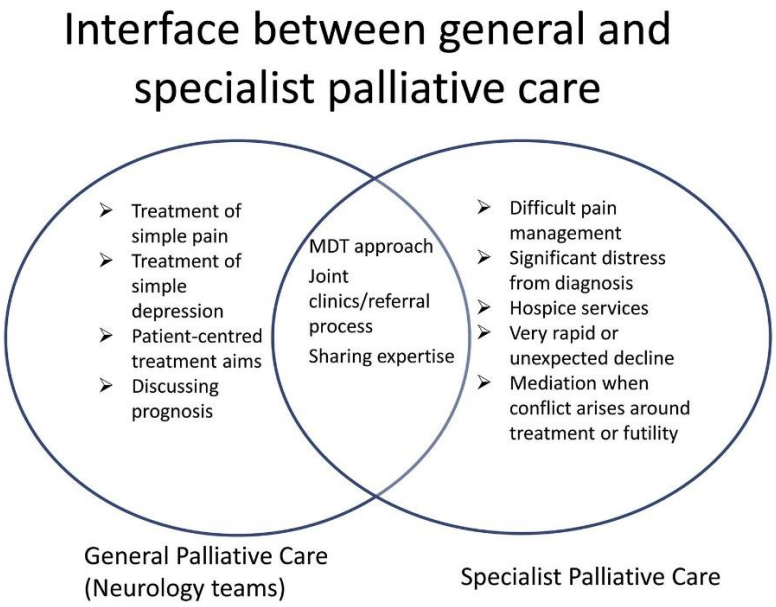

Figure 2 The overlapping roles of clinicians providing general palliative care and those providing specialist palliative care. From Wiblin et al (18 p8)

In terms of SPC there are few studies that exist in terms of evaluating the benefit to people with PD, PSP or MSA.

Those that exist or are in progress look at:

- traditional hospice services: where people attend hospice day centres regularly
- integrated services: where movement disorder services and SPC work side by side throughout the disease course
- short term palliative care input: shorts bursts of input at specific trigger points

Badger et al (73) in the UK undertook a qualitative study (using semi structured interviews and an IPA[3] approach) with 3 patients with advanced PD and 5 carers to explore the effect of SPC on coping with PD. All were recruited from an integrated SPC movement disorder service. The participants reported the same main stressors that Boersma et al (10) and Fox et al (9) had found, specifically those of uncertainty and impact on the self. Badger et al (73) found that SPC helped manage uncertainty for people with PD and allowed carers to reduce

[3] Interpretative phenomenological analysis – a qualitative approach that focuses on each individual participant's interpretation of their lived experience

their levels of worry and vigilance. SPC also addressed discussing the end of life and practical adaptations in a way non-SPC had not. In terms of self-impact SPC helped people to engage in coping efforts to manage the change in their self-concept and made them feel worthy of care. SPC also helped carers reduce their caring role briefly. A major limitation of the study was that it only included people who were involved with, and continuing to have, SPC and so it would be less likely to report any negative effects. There was also no information gathered about non-participants.

Veronese et al (74), in Turin, undertook a phase 2 pilot RCT comparing fast track referral to SPC to a standard track SPC referral (a wait of 16 weeks) for people with advanced neurological diseases (PD = 16). The main outcomes were to compare quality of life (QOL) indicators and carer burden. Those in the fast track group showed significant improvements in QOL, pain, sleep, breathlessness, bowel symptoms and social isolation. There were no significant reductions in carer isolation or burden, which the authors postulated might be because of the long-term nature of caring for people with neurodegenerative diseases. There was also a trend towards coping less well with the disease which was felt to be due to the advanced nature of the diseases and the conversations about dying that were taking place. After the intervention ended participants could continue receiving SPC for as long as they wished to do so, but unfortunately the numbers of people that chose to do this were not reported.

'OPTCARE neuro' is an ongoing RCT taking place at seven sites in the UK and is evaluating short-term integrated SPC provision for people with long term neurological conditions, including those with PD, PSP and MSA (75, 76). The results of the trial are not yet published but the collaborators undertook a scoping exercise to ascertain the views of neurologists and SPC physicians in regard to existing services and barriers to the proposed intervention (75). There were mixed views about the quality of interaction between existing services and the barriers identified related to perception about palliative care from patients and resources if SPC was available to all. Interestingly a key barrier identified was that people with neurological conditions may require longer term SPC input and the palliative care

physicians alluded to the difficulty that might be encountered in discharging people who had gained benefit.

2.8.4 *Summary of palliative care need*

Several studies have indicated that SPC would be appropriate for people with PD, PSP and MSA to help with a high level of symptom burden (6, 11, 15). Exploration of palliative care need for people with PD also identified a range of emotional and social issues, including the loss of self and a lack of co-ordinated care (7, 9, 10, 73). SPC has been shown to be welcomed and beneficial to people with PD (73, 74) though timing of referrals and the most appropriate way to deliver the service has not yet been ascertained.

2.9 End of life

'End of life' has widely different definitions across studies, within the healthcare profession and amongst people with life threatening diseases. To try and provide clarity the 'Ambitions for palliative care and end of life care' document defines a person as being at the end of life when they are likely to die within the next twelve months (77) (section 2.12 explains this document in greater detail). There are only two studies that specifically sought to explore PD and the end of life, Goy et al's (12) USA study, where end of life was defined as the last month and Hasson et al's (5) Northern Ireland study, where end of life was not defined by time.

In 2008 Goy et al (12) explored the degree of suffering and needs at the end of life for people with PD related diseases (PDRD) compared to a sample of people with Amyotrophic Lateral Sclerosis[4] (ALS). ALS is recognised to be a cause of significant suffering at the end of life, with a high level of supportive need, and the authors hypothesized that PDRD needs and suffering might be similar and in need of just as much health care provision. The authors conducted surveys with 54 bereaved carers of patients with PDRD (50 PD, 3 PSP and

[4] also known as MND in the UK

1 MSA) and 50 bereaved carers of patients with ALS. Fifty-two of the PDRD patients were felt to have died from Parkinsonism or its related complications. The authors' questions were based on previous survey instruments and expert opinion/experience and were concerned with the last month of life. In terms of symptoms, difficulties with eating and communicating were frequent and severe for both conditions. Forty-two percent of the parkinsonian patients had been in severe pain most of the time, with 27% receiving no pain medication for this. Confusion and depressed mood were also found to be frequent and severe in PD and more common than in ALS. Ninety percent of PDRD patients had a living will, 88% had a healthcare proxy and 81% of PDRD caregivers could state their loved one's treatment goal. Despite this however, only 73% felt their loved ones' wishes were closely followed (compared to 85% of those with ALS). Comfort was the goal for most yet 27% had feeding tubes and 27% had breathing support. 56% of PDRD patients had received some hospice care, 70% knew death was imminent and 75% were accepting of death, with 85% at peace when they died. The authors also looked at place of death and reported that 13% of PDRD patients died in hospital, 25% in their own home, 12% in another home and 40% died in long term care. Only 42% died where they had desired. ALS patients were more likely to die at home (56%) and 76% died where they desired. The authors discussed that severity of suffering was identical between those people with PDRD and ALS but the PDRD patients had less hospice involvement (55% vs 66%). They acknowledged that the number of PDRD patients with hospice involvement in their study was far greater than the national average of 13% but they did not provide an explanation for this finding. They also pointed out that even though PDRD are less often considered to be life threatening, the carers and patients must have recognised the terminal trajectory of the diseases as they had made plans, were aiming for comfort and had hospice care involved.

The only other research looking specifically at the end of life period regarding PD was reported by Hasson et al in 2010 (5). This was a qualitative study, using semi-structured interviews to explore 15 former carers' lived experience of palliative stage PD in Northern Ireland. Two themes, 'carer's role' and 'burden and bereavement', highlighted the difficulties of being a carer before and after the death of a relative. They explained the

feeling of social isolation and strain caring puts upon carers and the loss of role experienced once the relative with PD has died, made harder by poor bereavement support. The strain, coupled with a lack of SPC service provision, or knowledge that a person with PD would be eligible for this, meant that it was not always possible to keep people with PD at home in the end, despite the wishes of their carers. Carers also felt that specialists were difficult to access and concentrated too much on medication and not enough on the holistic aspects of the disease or practical social support. Many carers were unprepared for their relative's deaths, finding the eventual decline to be sudden, and all felt they should have been better informed about the advancement of the disease/imminent death.

Hasson et al's study (5) seems to contrast with Goy et al's (12) findings in terms of patients and relatives being ready for death. All carers in Hasson et al's study claimed the need to be better informed about disease advancement and many were unaware death was imminent, whereas in Goy et al's study 70% knew death was approaching and many had planned for the end, suggesting they knew the disease had advanced. This may be to do with the way the participants were recruited. Goy et al partly recruited through a movement disorder clinic, whereas Hasson et al recruited through posters in GP surgeries, libraries and PD support groups. It is likely that those in Goy et al's study therefore had better access to a PD team and support than people recruited from the community might have done. The differences probably also reflect the countries where the research was carried out, with levels of intervention and ACP known to be higher in the USA (78).

Both studies (5, 12) used the views of bereaved carers to explore the end of life experience. There has been discussion about how valid a bereaved carer's view might be, and whether views change over time as bereavement progresses (79), which would be particularly relevant in Goy et al's case as some carers were bereaved 53months prior to interview. A comprehensive review by McPherson et al (80) found that views of patients and carers correlated well for service evaluation, factual information given and overt features such as the ability to carry out tasks; but less well for pain and feelings, with carers over-estimating the level of pain and depression, which again has relevance for some of Goy et al's findings.

The review also makes the point, however, that often proxies, in the shape of bereaved carers, are the only way to get even close to reliable information about the end of life experience for people with uncertain disease trajectories; as identifying patients in this group who are terminal, is very difficult. The cognitive impairment that is experienced in advanced PD and PSP, along with communication difficulties in the advanced stages of all three diseases also means gaining views from patients about their experience at the end of life would be very difficult. More recently Sebring et al (81) conducted a cross sectional study of people with PD and their carers to compare their ratings of symptoms, emotional burden and social support. They showed moderate to good agreement for many factors but found that agreement was poor for body pain, stigma, social support and anticipatory grief. Sebring's study did not assess opinions regarding service evaluation. When disagreement occurred, carers tended to report pain, depression and stigma as being more severe than the people they cared for with PD did. The authors pointed out that often people with PD underplay mood symptoms compared to formal psychiatric assessment, but nevertheless cautioned against the use of proxy reporting for more subjective symptoms, especially in advanced disease.

However, palliative care from its inception aimed to care not just for the person with a terminal disease but also their family, as a unit, and as such family views regarding service provision are not necessarily less valid than the views of the dying themselves. In addition, one of the roles of palliative and end of life care is to ensure adequate bereavement support exists for family members.

Certainly, carers are an important voice in shaping end of life care provision for patients and many of the reviews that have recently occurred within end of life care in the UK were born out of bereaved carers' experiences.

2.10 Recent history of UK End of Life care guidance

The end of life care strategy (82), a joint effort between the government and the national council for palliative care, was published in 2008 with the aim of improving access to high

quality end of life care for all, regardless of diagnosis or disability. Its aim was to increase the profile of end of life care and to improve the experience, as it stated many people do not die as they would wish. It highlighted changes in attitudes towards death and dying, explaining that people are less comfortable with death and dying than they were in the past. It also set out guidance for good quality care, such as improved communication about the fact a person was dying, good co-ordination of services, high quality care regardless of place of death and effective management of symptoms whilst treating the dying person with dignity and respect. It also highlighted the need for monitoring services through surveys of bereaved relatives, national audit and complaints processes.

At the time this strategy was published the Liverpool Care Pathway was widely regarded as the gold standard tool in end of life care (83). It was essentially a checklist, to be used by HCPs, to ensure that they had informed the patient and/or their relatives that they were dying, that staff were regularly checking a patient for symptoms such as pain, breathlessness and nausea and that they had considered the patient's spiritual needs. However, in 2013, a media furore occurred where examples of poor care associated with the Liverpool Care Pathway made headlines and this led to a review chaired by Baroness Neuberger (83) entitled 'More Care, Less Pathway'; thus showing the power of bereaved relatives' voices. This review highlighted the fact that around 50% of people died in hospital and though many received good care through the pathway, there were cases where patients were not treated with the respect they deserved. Where care was poor, the pathway was used as a tick box exercise accompanied by poor communication with patients and relatives, and this led to the recommendation that the pathway should be phased out. The review recommended the development of guidelines reflecting the principles of palliative care and technical guidance specific to certain disease groups. It also recommended a system wide approach to improving care, suggesting the government make end of life care a larger priority, that end of life care is incorporated into hospital inspections and that more research is conducted into the experience of dying from the view point of patients, relatives and carers.

2.11 Place of Death (POD)

The government's commitment to gathering views from bereaved carers, through the use of the VOICES questionnaire, was outlined year on year in the NHS Outcomes frameworks. VOICES (Views of Informal Carers Evaluation of Services postal questionnaire) was developed in 1995 by Professor Addington-Hall (84) and redesigned in 2011 to enable it to be used as a National survey (85). It asked bereaved carers to comment on the experience of care/services in the last three months of life and looked at POD, i.e. home, hospital, care home or hospice.

The survey was initially commissioned to be delivered annually by the Department of Health in 2011 and between 2013 and 2015 it was commissioned by NHS England. The questionnaire was administered by the Office of National statistics (ONS) to a sample of nearly 50000 people annually (86, 87) whose relatives had died in the previous 4-11 months, with response rates of roughly 45% each year (86, 87). Since the National survey began the results have shown little change year on year; telling us more people die in hospital than choose to, overall quality of care is felt to be poorest in hospital and best in a hospice, and pain is controlled least well at home. The surveys have shown differences in quality of care according to COD, with the overall quality of experience felt to be better for people dying from cancer compared to other diseases (86, 87). Deaths from cancer, cardiovascular causes and dementia have been looked at individually from the national data, but this has not occurred for other disease groups.

There are studies regarding place of death for PD, but there are no studies regarding place of death for MSA or PSP. Snell et al (19) compared patients who had died from PD to a control population over an eight year period and found that more people with PD died in a care home (36% vs 21%), less died at home (9% vs 17%) and the results for hospital deaths were similar (55% vs 59%). Sleeman et al (20) compared patients with PD to those dying from MND and multiple sclerosis, and found that people with PD were more likely to die in a care home and less likely to die at home or in a hospice. Cardiovascular disease or cancer increased the chances of a death at home, whereas pneumonia increased the chance of

hospital death (20). Hobson et al in their community based cohort study found that people with PD were less likely to die in hospital than age matched controls (57).

Although these studies show us where people with PD die, there is currently no data to tell us whether place impacts on the quality of end of life care they receive. In addition, there are no studies that explore where people with PD, PSP or MSA might choose as their preferred place of death (PPOD), nor data to tell us whether this would be a priority for them at the end of life.

2.11.1 *Preferred place of death (PPOD)*

There has for some time been a suggestion that dying at home is preferable, driven in part by an ideological stance regarding dying in traditional societies (88-90). Aries, a French historian, compared the 'tame death' of the past, where people died at home surrounded by friends, religious customs and managed their death the way they saw fit to the 'wild death' that occurred within institutions, where responsibility and choice in dying was removed from the command of the dying person (88, 91). Elias similarly alluded to the loneliness of the dying, especially within institutions, though he felt that Aries somewhat romanticised traditional deaths, which were likely to occur in pain without the symptom relief of modern medicine (92). During the 1960s concern was growing in the USA at the increasing medicalisation of dying (93), with more people dying in hospital with reduced autonomy (94, 95) and similar concerns led Cicely Saunders to found the hospice movement in the UK, beginning the launch of palliative care as a speciality (91). A part of the aim to de-medicalise dying was to try and bring death out of hospitals and back into communities and homes. This was championed as being an issue of importance by sociologists and policy makers and dying at home became somewhat synonymous with good end of life care and achieving a good death (96). In policy, the end of life care strategy suggested that a good death was one that took place in familiar surroundings (82) and the National End of Life Care Intelligence Network in their 'what we know now' 2014 report stated that "Meeting people's preferences for place of care and place of death is an important measure of the quality of end of life care" (97).

The VOICES data suggests that most people, if they have a preference, want to die at home (24, 98, 99) and other surveys have shown hospital to be the least PPOD (100). However, the majority of people within in the VOICES surveys had not expressed any preference and much of the work on PPOD, certainly the larger scale surveys, have taken place with healthy younger individuals rather than people with life limiting diseases. Indeed in one of the largest UK surveys, by Gomes et al, only 13% of participants had been diagnosed with a serious illness in the preceding 5 years and as people aged their preference for dying at home decreased (100). Gomes et al later undertook a systemic review of worldwide studies exploring preferences for place of death (101). This found moderate strength evidence that people preferred dying at home. However, the evidence for older people was less strong with qualitative data suggesting that even if a home death was ideally desired, circumstances precluded this being a realistic choice. People dying from cancer were more likely to prefer a home death than those with non-malignant conditions and views were subject to change over time in around 20% of patients, with a declining preference for home as diseases progressed. The review concluded that because most people choose home, more should be done to allow people to achieve their aim, but as a substantial minority change their mind, or think differently, flexibility should exist within the system (101).

Conversely, other authors have pointed out that policy decries a home death as synonymous with a good death and that this puts a huge amount of pressure on those who are dying, and their families, to ensure a home death is achieved, with a tremendous amount of guilt felt by those left behind if it is not (22, 90). In addition, pushing a home agenda fails to recognise that family members becoming carers can impact on the identity of relationships and formal care workers and equipment entering homes can change the meaning of 'home' (22, 90).

Sue Ryder, a UK charity providing palliative, neurological and bereavement support also produced a report in 2013 which was critical of the political focus on dying at home. Their report 'a time and a place' (102) criticised the use of dying at home as a proxy for quality end of life care and explained that few studies explored the reasons behind a preference for

home. They understood the desire for home death to be at the forefront of policy because of the alignment between assumed public preference and the financial savings that dying at home, rather than in institutions, provides to the treasury. However, they suggested that just accepting home is best prevented gathering knowledge of the factors that matter to people at the end of their lives and hindered the improvement of care across all locations of death. They championed more personalisation in end of life care rather than a focus on place.

No-one has explored the wishes of people with PD, PSP or MSA previously. As people with these conditions are older, dying at home may not be the priority. In addition, the high degree of symptom burden, including impaired cognition, may well make dying at home a less realistically achievable choice.

2.12 Advanced care planning (ACP)

One way for people with degenerative diseases to make their views about preferred place of care known to HCPs is through ACP (103). ACP allows a person to write down their wishes for the future and in the case of an advanced decision to refuse treatment (ADRT) they allow a person to refuse certain life prolonging treatment in a way that should be legally upheld. ACP is strongly advised for people with progressive neurological conditions (104) as a way of maintaining autonomy if cognition or communication declines. Despite their uses, and the fact that 60-90% of the general public is supportive of ACP, only 8% of the population in England and Wales is thought to have completed written plans (103).

In 2015 Pollock and Wilson undertook a qualitative study in the UK investigating communication between HCPs and patients with life limiting diseases (105). This revealed that less than half of the patients thought to be in the last month of life had made any plans. HCPs found it difficult to discuss ACP in terms of when to raise the issue and many patients did not welcome the idea of discussion either. This meant that discussions were often reactive, in response to significant deterioration, and that ACP was primarily concerned with PPOD and resuscitation. The authors commented very few plans were instigated to

maintain autonomy for people who might later have diminished cognition and so opportunities were lost; they also felt more research into the experience of the frail elderly should be undertaken regarding communication and decision making.

Also in 2015 Tuck et al (8) surveyed 267 PD patients in Oregon, across all disease stages, to ascertain their preferences for the timing of discussion about prognosis, ACP and end of life options. They found 50% of the patients wanted early discussion about ACP and around 12.5% wanted to discuss end of life options at diagnosis, though most preferred to wait until the disease worsened. 50% felt they could raise the issue of prognosis and 50% felt this should be the neurologist's duty. Age and time since diagnosis did not affect when participants felt discussion was warranted or who they felt should raise the issue. A small proportion never wanted to discuss ACP (5.7%) or end of life plans (2%) and some only wanted discussion if they raised the issue themselves (12.6% for ACP and 20% for end of life planning). Of the PD patients taking part 51.3% already had advanced care plans, 42.7% had ADRTs and 39% had a power of attorney (ie they had assigned someone to represent their views should they lose their own mental capacity). Overall views were mixed and were not predictable by disease burden and so the authors suggested the only way to know if a person wanted to discuss the issue further was to sensitively ask. We do not know how many patients in the UK with PD, PSP or MSA have made advanced plans but it is likely to be smaller than the percentages suggested by Tuck as ACP is more common in the USA (78, 105).

We do not actually know whether undertaking ACP improves the end of life experience for people with PD, PSP or MSA. Some research has been done to explore whether plans improve the end of life experience for people with MND (106, 107) and this showed that they led to peace of mind for the patient and caregiver, and prompted more discussion so that awareness of the person's wishes could build. Participants also felt they helped to increase HCP's awareness of a patient's wishes. However, they also felt a lack of HCP's knowledge about the legality sometimes hampered their use and when plans were not followed this led to a lot of frustration and heartache (106).

2.13 Current UK palliative and end of life guidance:

Following the aforementioned Neuberger report 'More care, less pathway' (83) a large amount of work has been undertaken by the National Council for Palliative Care, along with multiple charities supporting people with life limiting disease and those caring for them, and new guidance has been published.

Initially, as a direct response to the Neuberger report, the National Council of Palliative Care and their collaborators published, as the Leadership Alliance for the Care of Dying People, 'One chance to get it right' (108) which essentially replaced the principles of the LCP and laid out the five priorities of care that should be fulfilled for a person who was imminently dying (see Figure 3)

The Priorities for Care are that, when it is thought that a person may die within the next few days or hours..

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Figure 3 The five priorities of care for a person who is imminently dying, taken from 'One chance to get it right' (108, p7)

These priorities focus on clear communication, including informing people that they are imminently likely to die. This is in line with the awareness that many people would consider a necessary component of good end of life care. Much like 'place of death' awareness of dying has long been felt necessary to allow a 'good death' (91, 94, 95, 109). The fervour for making sure everyone is made aware has perhaps decreased somewhat (110) in line with a better understanding that people alternate between denial and acceptance to cope with their prognosis (111).

The emphasis on comparing locations has lessened in the most recent palliative and end of life care guidance in favour of identifying aspects of good care that should be in place across locations. 'One Chance to Get it Right' states that these priorities should be followed wherever a person might be dying, be it at home, in a hospital, care home or hospice (108). Similarly the NHS framework for end of life care in 2018 stated that transforming the experience of end of life care in the community and hospitals was one of its overarching workstreams (23).

Following the release of 'One Chance to Get it Right' the 'Ambitions for Palliative and End of Life Care' document was published (77). This sets out six ambitions (see Figure *4*) responsible for delivering care to people with incurable conditions and has been incorporated into national UK guidance. These ambitions cover the time from diagnosis of an incurable disease through to after death bereavement support for carers. This document will be explored in more depth in Chapter 8, as recommendations for practice borne out of this study are reported in line with these ambitions.

Figure 4 The six ambitions for palliative and end of life care, taken from 'Ambitions for Palliative and End of Life Care' (77 p11)

2.14 Summary

The available literature shows that people with PD have a high symptom load which is comparable with other populations frequently receiving SPC. The literature also shows that the emotional and spiritual needs of people with PD are high but not always adequately addressed by existing PD services, where medication and physical symptoms are often the predominant focus. There has been shown to be a lack of information and co-ordinated health service provision for people with PD and an uncertainty about when to discuss future plans, despite recommendations this should be done early. All these points indicate a potential role for SPC and people with PD are largely receptive to palliative care input.

There has been very little qualitative work exploring the lived experience of people with PSP/MSA or their carers, especially in regard to their palliative and end of life care needs, despite the literature showing their symptom load is higher and quality of life scores lower than people with PD.

We do not know where people with PSP and MSA die and although we know more people with PD die in care homes than at home, we do not know whether this affects their end of life experience. Although ACP is advocated strongly for these conditions, we have no idea whether future plans improve the experience for people who make them. Even though dying where one would choose is recognised as a marker of good end of life care we do not know whether people with these conditions express a preference and where that preferred place would be if they do. Current guidance suggests more work should be done to explore the experiences of patients and their relatives at the end of life, including bereavement support, especially for those with complex conditions leading to increased frailty. Despite this only Hasson et al touched-on bereavement for carers of people with PD and their lack of preparation for the end; bereavement for carers of those with PD, PSP or MSA has not been explored elsewhere.

This study aims to address some of these gaps; Table 2 outlines the gaps in the literature and explains where they are addressed within this thesis

GAP	Where addressed
Where are people dying from PSP/MSA most likely to die?	Chapter 4 outlines this finding
What are the palliative and end of life needs of people with PSP, MSA and their carers?	Chapter 5 addresses this and compares the findings to those dying from PD
What are the bereavement needs of carers of people with PD, PSP and MSA and are they adequately supported?	Chapters 5 and 6 address bereavement
Do people with PD, PSP and MSA have a PPOD?	Chapters 5 and 6 both address this gap
Does place of death affect experience and if so, how?	Chapter 6 addresses this gap

Table 2 Gaps in the literature and the locations within this thesis that addresses these gaps

Chapter 3 Methods

This chapter outlines the methods that were used to answer the aims and objectives of the study. It begins with the methodology behind the project, discussing prior debates regarding the mixing of methods and the perspective of pragmatism. The latter part presents a rationale for the project design and a flowchart to illustrate the components of the project. It then addresses the methods used for sampling and recruitment, data collection, analysis and integration.

3.1 Methodology

3.1.1 *The worldviews of positivism and interpretivism*

Positivism and interpretivism are opposing worldviews. They are based on differing ontologies (views about reality) and epistemologies (views about knowledge).

Traditional positivism is based on ontological realism (there is one true reality waiting to be discovered) and epistemological views that knowledge is only gained by discovering the truth about that single reality (112, 113). Crotty (114 p8) stated this is an objectivist epistemology where a thing has meaning in itself as an object, irrespective of whether a human has interacted with it or is conscious of its existence. This reflects research into the natural sciences where we are looking to explain something according to the laws of nature, but for centuries it had also been the preferred method of social science inquiry into human behaviour (115). Over time, the difficulties with verifying one absolute truth led to some scholars discrediting such a fixed view (114) and most social scientists on this side of the reality/knowledge spectrum now practice a post-positivist view which accepts there is always possible doubt about the truth of a belief (116). In practice this translates so that findings are presented with a probability of them being true (112). From a positivist viewpoint, a research study should not be subject to bias, which might distort true meaning, and so steps are taken to reduce a researcher's interference (116, 117). Clear parameters are defined and set before the research takes place. Positivism is traditionally associated

with quantitative types of data (118); a hypothesis can be proposed and tested in an analytical manner, through the use of statistics, to provide a probability that something holds true. The hypothesis behind the VOICES survey was that the place a person spent the end of their life would affect its quality.

Conversely, rather than believing there is one true reality to be discovered, ontologically interpretivists believe there are multiple realities (or perspectives) which vary between individuals or societies (112). Interpretivists follow a constructionist epistemology (114), something only has meaning because we interact with it and give it a meaning with the mind. Interpretive research will be interested in finding out what things mean from an individual or societal perspective (118) and is more often associated with qualitative types of data because researchers are trying to understand the views of participants in their own words and in-depth (118). Due to this, parameters cannot be pre-assigned. Figure 5 details the ways in which subjects relating to this project might be seen according to the two epistemologies.

Research subject	Objectivist	Constructionist
End of life	The end of life is the twelve months preceding a person's death.	Some might believe the end of life starts as soon as an incurable disease is diagnosed. For some the end of life is the last few hours. For some the end of life is a chance to apologise/make right wrongs. For some the end of life can be a relief from suffering.
Death	Biological: the heart stops, breathing stops, the brain ceases to function	Possibly biological but could be social. A person may believe they lost their relative long before they biologically died due to a change in personality or cognition. Conversely, they may not feel they have died because their memory of them persists.

Figure 5 The ways in which the differing epistemologies might consider elements of this research project

3.1.2 *Paradigms*

Positivism and interpretivism have been referred to as opposing paradigms. Researchers interested in qualitative methods sought to bring about change as social science research,

aside from anthropology, had largely been dominated by a scientific method of inquiry, relying largely on quantitative methods and data (119). They championed the idea that quantitative research was tied to a realist (objectivist) epistemological paradigm and qualitative to a constructionist one (119). From this point, for many, interpretivism (also known as naturalistic inquiry or constructivism) became synonymous with qualitative research/methods/data and positivism with quantitative (120, 121). This further led to 'the paradigm wars' with arguments over which form of research presented more correct conclusions. It led to purists from either side being left unable to acknowledge the research outputs from the other, even though they may be looking at the same field of study, and led to degree programmes which taught only one form of research (112). However, some researchers were finding that it was practically useful to mix quantitative and qualitative data within a single research study to provide a more comprehensive view. In 1988 Howe (120) argued in his seminal paper that methods for undertaking research were not tied to one worldview or the other, that the differing approaches in 'qualitative research and quantitative research' were not all that different at any level (i.e. data, analysis etc) and that interpretivism and positivism do not exhaust all possibilities for world views. Howe argued the case for taking a pragmatic approach to research and suggested that it was feasible and probably advisable to mix qualitative and quantitative components to answer a research question (120). Since then there has been a growing drive for combining qualitative and quantitative methods and agreement has largely been reached that such research is to be termed 'mixed methods' (122). The paradigm wars and arguments about compatibility have largely died down, but there remains discussion about the extent to which philosophical concerns should guide research inquiry, especially within the mixed methods community (122).

3.1.3 *My theoretical stance/perspective*

When starting this project, as a practising UK doctor, I was unaware that there could be any negative reaction to the idea of mixing qualitative and quantitative data. My overarching aim was to complete a piece of research that would explore end of life care delivery for

people with PD, MSA and PSP and allow suggestions for improvements to be made if any deficiencies were found. As Gorard (113) suggests, research objectives being the driving force for a project is likely to be the case for most novice researchers, especially if they have not come from a social science background. He suggests that research questions are more practically important than philosophical concerns, something which other methodologist based researchers agree with(122), and certainly my project design was driven more by research questions that may lead to useful improvements in care than philosophy. However, I understand the view that research can never be entirely devoid of philosophy because the researcher inevitably brings their experience with them when designing their project. This being the case, in order to be transparent I would suggest that my views are similar to Johnson and Onwuegbuzie (117): I agree that there are objective, subjective and intersubjective perspectives and so my stance equates to ontological plurism. If I extrapolate this into the relevance of my initial views about this research project I believe that for people with PD, PSP and MSA the underlying pathophysiology is occurring, leading to a reduction in dopamine levels which then causes signs/symptoms, and this will happen whether the person has a diagnosis or not (objectively they have the disease). However, how important it is for a person to get a diagnosis and how they live their life with the disease label varies from person to person (subjective) and will in part be influenced by societal views (intersubjective), for example, views on disability. The same will likely be true of their views on wanting to know about their prognosis, which may have relevance in terms of planning for the end of life and impact on place of death.

3.1.4 *Pragmatism*

My views best align with a pragmatic approach in which, Morgan states, 'there is no problem with asserting both that there is a single "real world" and that all individuals have their own unique interpretations of that world' (119, p72). Pragmatists would argue that the outcome of the study is more important than philosophical concerns (117, 121) and some would assert that discussions about the nature of reality are only important if they would make a difference to the problem at hand (119). One could argue that being more concerned with

research questions and outputs than philosophy aligns to an a-paradigmatic stance towards research (123) rather than a pragmatic one, but my desire for the research outputs to make a positive difference to the care of people with PD, PSP and MSA approaching the end of their lives fits with the value-orientated approach of pragmatism (117, 120). I am also cognisant that what is relevant at the time that I undertake this study may change in the future, for example, a cure may be discovered and pragmatism embraces the idea that a theory is only true whilst it works; there may be a time in the future where something we think we know is proven false (121).

3.2 Project design

3.2.1 *Mixed methods*

Through taking a pragmatic approach, the initial research questions as described below were most appropriately addressed using a mixed method approach

- What are the palliative and end of life needs for people with PSP and MSA? (QUAL)
- Where do people with PD, PSP and MSA die? (QUAN and QUAL)
- Where did they want to die and why? (QUAN and QUAL)
- Is place of death important? (QUAL)
- Does place of death affect quality of death? (QUAN and QUAL)
- What impacted most on the end of life experience? (QUAL)

It was felt that using both qualitative and quantitative data would allow a more comprehensive and generalizable overview of factors affecting end of life care because they could answer questions which were both different and overlapping, with the purpose for mixing therefore being one of complementarity (124). The VOICES (Views of Informal Carers Evaluation of Services) survey is well validated (85), considers the needs of carers as well as those of the dying person and has been used multiple times to compare places of death for various causes of death. It was therefore chosen as the survey tool for this project to provide the quantitative data. Semi structured interviews were chosen to provide

qualitative data, as we postulated that other factors might overshadow place of death in terms of importance at the end of life and a survey alone would not allow exploration of issues in depth. Even if place of death was the factor of principle concern the survey might have told us that people were perceived to be treated with more respect and dignity in a hospice than a hospital, as with other causes of death (24), but not why there was a difference, nor what respondents viewed as the meaning of respect and dignity. It was the depth of exploration into what made one place seemingly 'better' than another that was of interest, because without knowing this it would be difficult to suggest effective change to improve/individualise the quality of care.

3.2.2 *Study participants*

Bereaved carers were recruited to be the participants in this study as the uncertain trajectories of PD, PSP and MSA means it is hard to know when the end of life is approaching. In addition, decreases in communication and cognition are common as the diseases progress and fatigue becomes an increasing problem, especially at the very end of life, meaning that interviews near the end of life would be challenging and potentially inappropriate. The validity of using caregivers' viewpoints to explore the end of life has been discussed by McPherson et al (79) who showed that proxy views were well matched with regard to service evaluation. Therefore, using caregivers viewpoints was felt to be appropriate as the main aim of the project was about whether interaction with the health and social care system affected the end of life experience, and if so, in what way.

3.3 The original project plan

The initial plan was to undertake an identical[5], sequential[6], QUAN→QUAL[7] mixed methods study. The plan was to send questionnaires to bereaved carers of those with PD, PSP and MSA, who were known to the Northumbria Healthcare NHS foundation trust's PD service; alongside the questionnaire would be an opt-in option for those carers who were willing to be interviewed. Purposeful sampling would then be used to determine the interview sample, so that of the carers who had opted in, ideally each 'place of death' (hospital, home, care home and hospice) was represented.

After designing the project and populating an IRAS form I realised I needed to apply to our local Caldicott guardian (the healthcare trust's Information Governance officer) in order to gain access to our former patients' records and thus their next of kin details. Unfortunately, the trust's Caldicott guardian forbade the use of the next of kin details in deceased patients' notes to contact potential participants. The issue for the Caldicott guardian was one of data protection as he felt that using the next-of-kin details in the deceased patients' notes to contact their relatives, for research purposes, would contravene the Data Protection Act (DPA). Principle 2 'processing personal data for specified purposes' was the area of concern; the carer's personal details in patient's notes were there for the purpose of contacting them regarding issues to do with patients, at no point had the carers been asked whether their next of kin details could be used to contact them about research projects. However, other researchers seemed to have carried out similar projects without encountering this issue and NHS England has a toolkit for using VOICES locally which advises researchers to use the next-of-kin details in patient' notes to contact potential participants (125). I spoke to one of the authors, from a similar study, to ask how they had managed to circumnavigate this issue and was told that their Caldicott Guardian had allowed them to proceed because they felt that

[5] The same participants take part in the Quan and Qual strands

[6] Information gathered from one strand is used to inform the other strand, which follows afterwards

[7] Both strands are of equal importance and the qualitative would follow the quantitative

end of life research was important. Explanation for these differing opinions was found in the guidance from the Information Commissioner's Office (ICO) on the DPA. Within the ICO's guidance was a paragraph that stated 'data can be used for previously unspecified purposes if the use is thought to be fair' (126, p35). The guidance further explained that it would be unfair to use the data if 'it would be outside what the individual concerned would reasonably expect, or would have an unjustified adverse effect on them' (126, p35); therefore it was up to the individual guardians to decide whether contacting relatives was fair or not. Our Caldicott guardian was unmoved on the matter and so I was not able to retrospectively recruit bereaved carers. Therefore, a revised design that allowed for local recruitment within the confines of the DPA was devised and combined with a strategy for national recruitment.

3.4 The revised project plan and ethics approval

After adjusting the recruitment strategy the design of the project changed to be a parallel[8], concurrent[9], QUAL+QUAN[10] mixed methods study, illustrated in Figure 6.

The project was registered with the Newcastle and Northumbria 1 research ethics committee (ref: 15/NE/0066). It was granted an initial approval for the qualitative side of the project in March 2015 and a significant amendment was granted in September 2016 to allow access to the VOICES datasets and for national recruitment.

[8] Participants are all bereaved carers but different carers are recruited for each strand

[9] Data collection and analysis of the two strands takes place at the same time

[10] Both strands are of equal importance with regard to answering the goals of the study

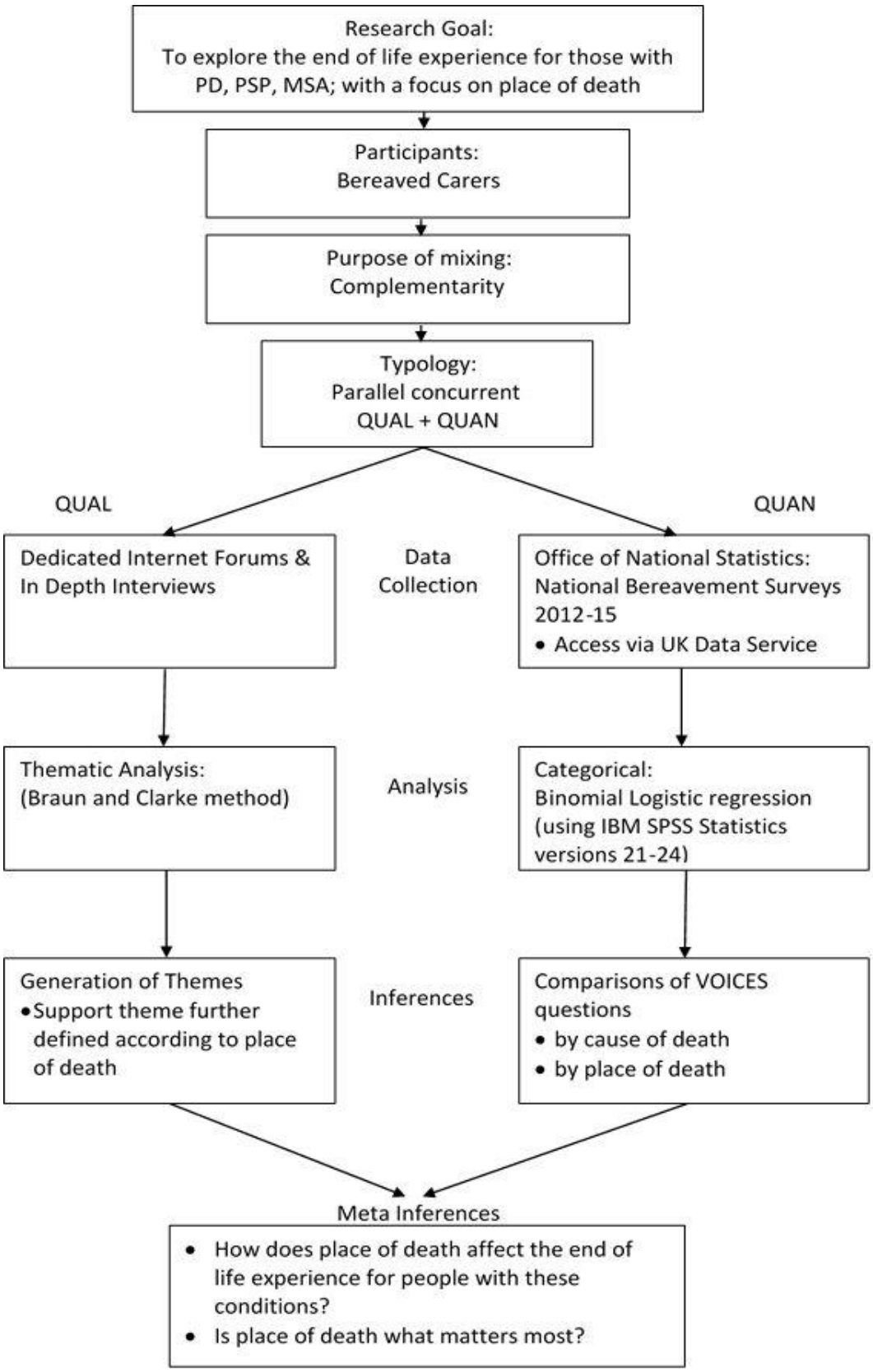

Figure 6 A flowchart illustrating the project design

3.5 Ethical considerations

3.5.1 *Increased grief in bereaved carers*

The principal ethical consideration was that carers had to revisit the end of their loved one's life, which could have caused an increase in their grief. It was made clear throughout the invitation letter, patient invitation leaflets and telephone introduction that there was no obligation to take part and that a participant could withdraw at any time. This was reiterated during the interviews if carers seemed distressed by the issues they were relating. I undertook bereavement training with Cruse bereavement care prior to any interviews taking place and had arranged that the local chaplaincy service was happy to be contacted for local participants to provide support; as Cruse did not have a service in the north east at the time of the study taking place. Prior to commencing the project I worked full time as an elderly care registrar and I was accustomed to discussing sensitive issues, such as death and dying, with patients and their relatives. The potential for increased grief was more difficult to manage on the forums but clear signposting for the charity helplines and Cruse was provided and carers had an e-mail address to contact me on as well.

3.5.2 *Internet forums*

Rather than taking comments from existing charity forums, closed forums were set up through the university and advertised on the charity websites. Closed forums/message boards are only accessible to those who have registered with the site (127). This meant that participants were made aware that their comments might be published and had to consent to take part, knowing their comments were for research purposes. Although some of the comments on the existing charity forums could be accessed via an online search, without requiring a log in, using such comments seemed ethically wrong as the people posting probably felt they were doing so on a private message board (127). To protect anonymity carer's pseudonyms have been changed within this thesis and will remain changed in any

further publications. The forums were also closed and deleted after 6 months, which participants were informed about at the start (See Appendix A iv).

3.5.3 *Informed consent*

Informed consent was gained from all participants. For interview participants this was recorded on paper and for forum participants carers clicked to evidence understanding of terms and conditions (see Appendix A iii and v).

3.6 Qualitative Data Collection

3.6.1 *Local recruitment*

The Parkinson's team were planning to send current patients a newsletter, summarising their completed research projects, and so I added a separate letter asking carers to send back their contact details if they were willing to be approached by the team about future research projects. Positive responses to the letter generated a database of carers who had given their personal details to us for the specified purpose of being contacted about research (n=240). Over time, as patients died, I checked the list to see whether their bereaved carers had given permission to be contacted about research. If they had, after a bereavement period of at least three months, an invitation letter and information pack with details about the project was sent out (see Appendix A i and ii). Included with the information was a reply slip that carers could return to indicate that they were interested in taking part. If interested the reply slip prompted them to return the consent form in a pre-paid envelope and provide an up to date phone number so that they could be contacted. I then called the carers who had expressed an interest to verbally explain the project, check understanding of the process and arrange an interview date and location. Because hospital records for the people who had died could be checked, a degree of purposeful sampling was undertaken; the carers of people who had been more advanced in their disease were preferentially sampled, as were those who appeared to have died from their PD rather than

something else. An attempt was made to purposefully sample for place of death but this was difficult to ascertain from hospital records.

3.6.2 *National recruitment: Forums*

Given the delay faced with local recruitment, other recruitment strategies were contemplated including the use of forums/blogs. I looked on the existing forums on PD, PSP and MSA specific websites by searching for streams concerning 'death', 'dying' and 'end of life', and I searched the internet using the same terms combined with the names of the three conditions.

Whilst there were a couple of forum threads where bereaved carers had shared their experiences forums were 'closed', due to the fact that they needed an e-mail address and password to participate in the forum. The charities that represented all three diseases in the UK did not feel informed consent for research could be arranged through their existing forums but they agreed that if I set up my own forums they would provide a link and advertise through their websites.

Newcastle University's IT department set up three separate forums on the university servers, one for each disease. A truncated participant information sheet was provided as an introductory section on the forum site (Appendix A iv); this explained about the project and that the plan was for the forums to stay open for about six months and then be closed down. Below this came the points of consent, and a statement explaining that by joining the forum participants agreed with these terms (Appendix A v). Once the forums were made live, I joined them as the administrator which ensured I could adjust the settings of the forum and be the main contact point for participants. All three had a thread started entitled 'welcome' and a disease specific opening statement was posted as shown in Figure 7.

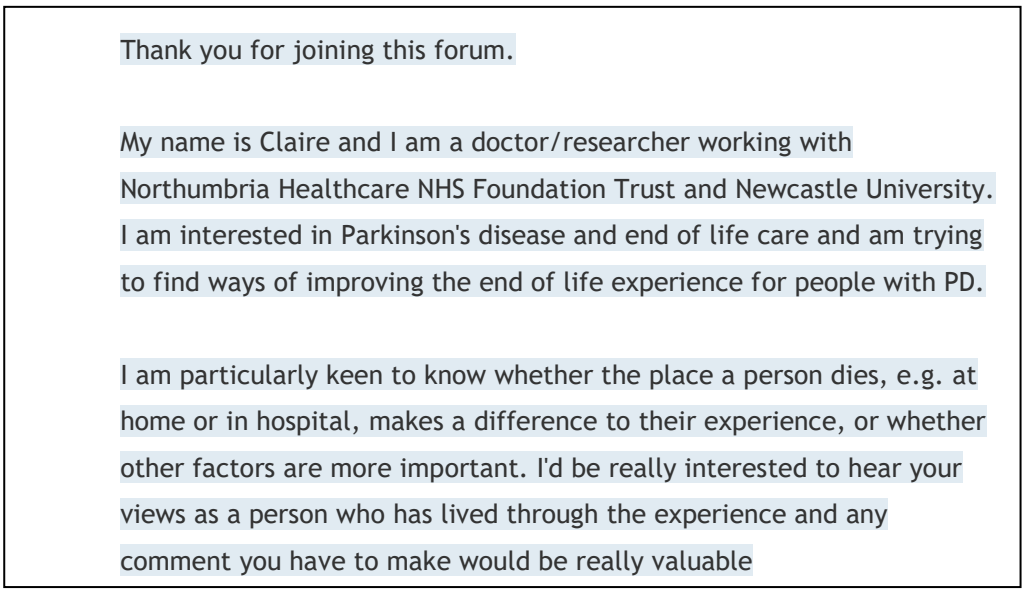

Figure 7 The initial post on the PD forum thread

Once participants joined they could start their own threads if they chose. As soon as the forums were working I contacted the charities again to ask them to advertise the sites – the approach taken by each organisation varied and the response was limited (see Figure 8).

Overall the forums acted more like online interviews than an actual forum as the participants were directing comments to me, rather than interacting with each other. Some people contacted me and said they would rather talk about their experiences one-to-one than on the forum and so I gave them the option of e-mails or a telephone interview. Because the carers had opted-in to the project we felt that ethically it was reasonable to offer telephone interviews if that was more in line with their wishes. Some people started on the forums and then privately messaged me and so I continued to send them questions over e-mail. One carer sent a document they had written about their previous experience. I wanted to remain flexible and to do whatever worked best for the carers.

	Parkinson's UK	The PSP Association	The MSA Trust
How the charities advertised the forum	Initially advertised on the research section of their existing forums. Later they agreed to send the information out through their research interest group	Posted a link to the forum on their own forum but without any guidance or introduction	Posted a link to the project onto their Facebook site
Effect on recruitment	5 People joined at differing times over a couple of months and stayed to answer multiple questions	15 people joined but only a couple commented. Both answered several questions	14 People joined, 7 commented immediately but most then left. As the advert dropped down the Facebook feed recruitment dropped
Excluded from analysis	0	1 (lady whose husband was still alive with CBD)	3 (1 healthcare professional, 1 person currently living with MSA and 1 daughter of someone with MSA)
Number of forum recruitments	5	2	4
Number recruited to interview	1	0	1 (+ 1 sent a written narrative)

Figure 8 A table illustrating the advertising methods of the charities and the resulting recruitment

3.6.3 *National recruitment: Interviews*

The MSA Trust agreed to send out information about the project to bereaved carers on an existing database, initially in the North East, then nationally. The PSP association also agreed to contact bereaved carers about the study and sent out the information packs asking carers who wished to take part to contact me; one carer who had agreed to take part ran a support

group and she contacted other bereaved carers about the project as well, so a small amount of snowballing took place. Parkinson's UK had contacted me about my project because they had appointed a lead for end of life care. She wanted to know about this project and any potential difficulties in recruiting through Parkinson's UK and after our discussion she agreed to talk to her colleagues about recruiting more carers; two additional carers were then recruited to interview. Once carers had expressed an interest I contacted them by phone to explain the project verbally, check their understanding and to arrange an interview date, and sent them the consent form to sign (by hand or electronically).

Figure 9 and Figure 10 show the timeline through the project and indicate the points at which carers were recruited.

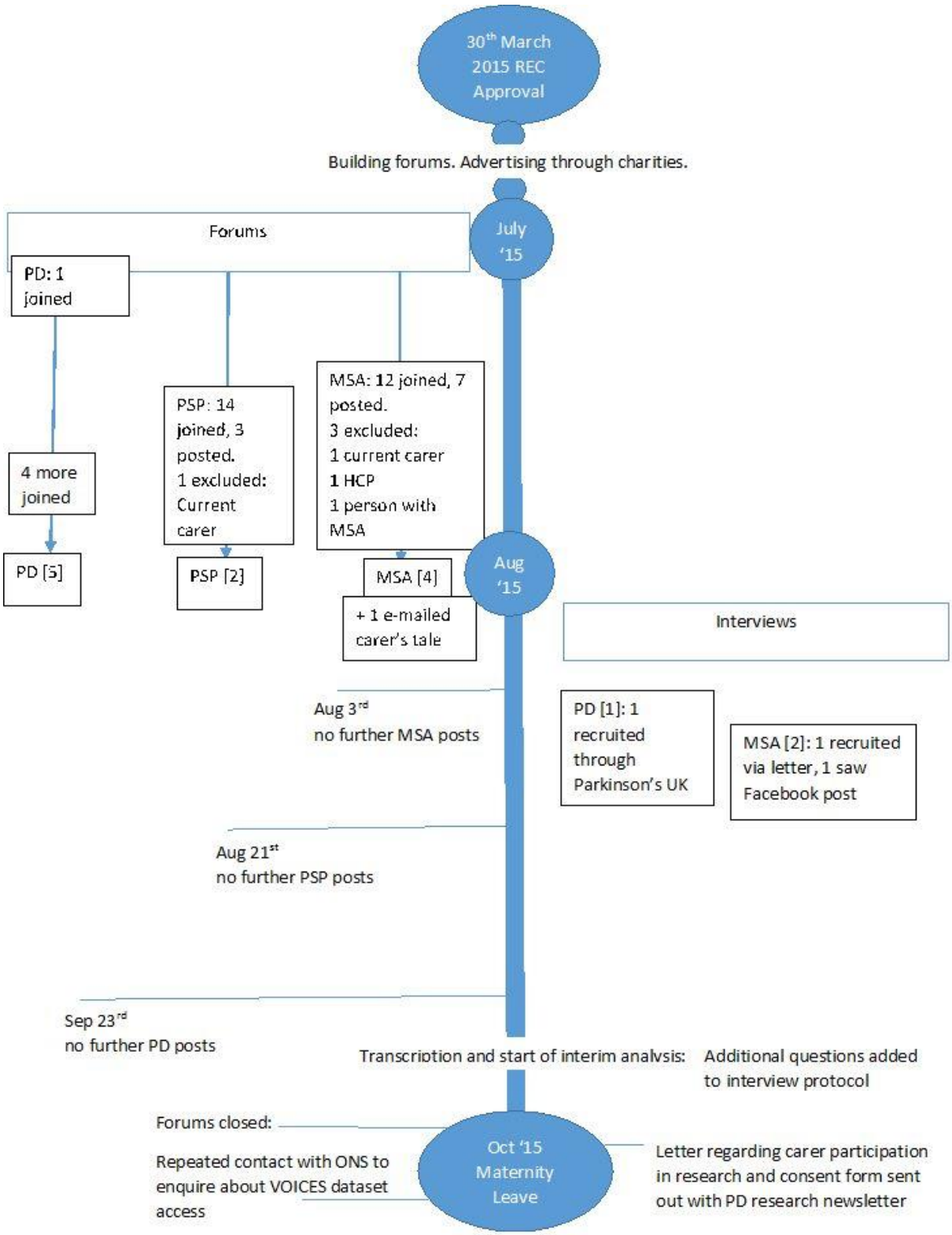

Figure 9 Timeline through the first part of the project

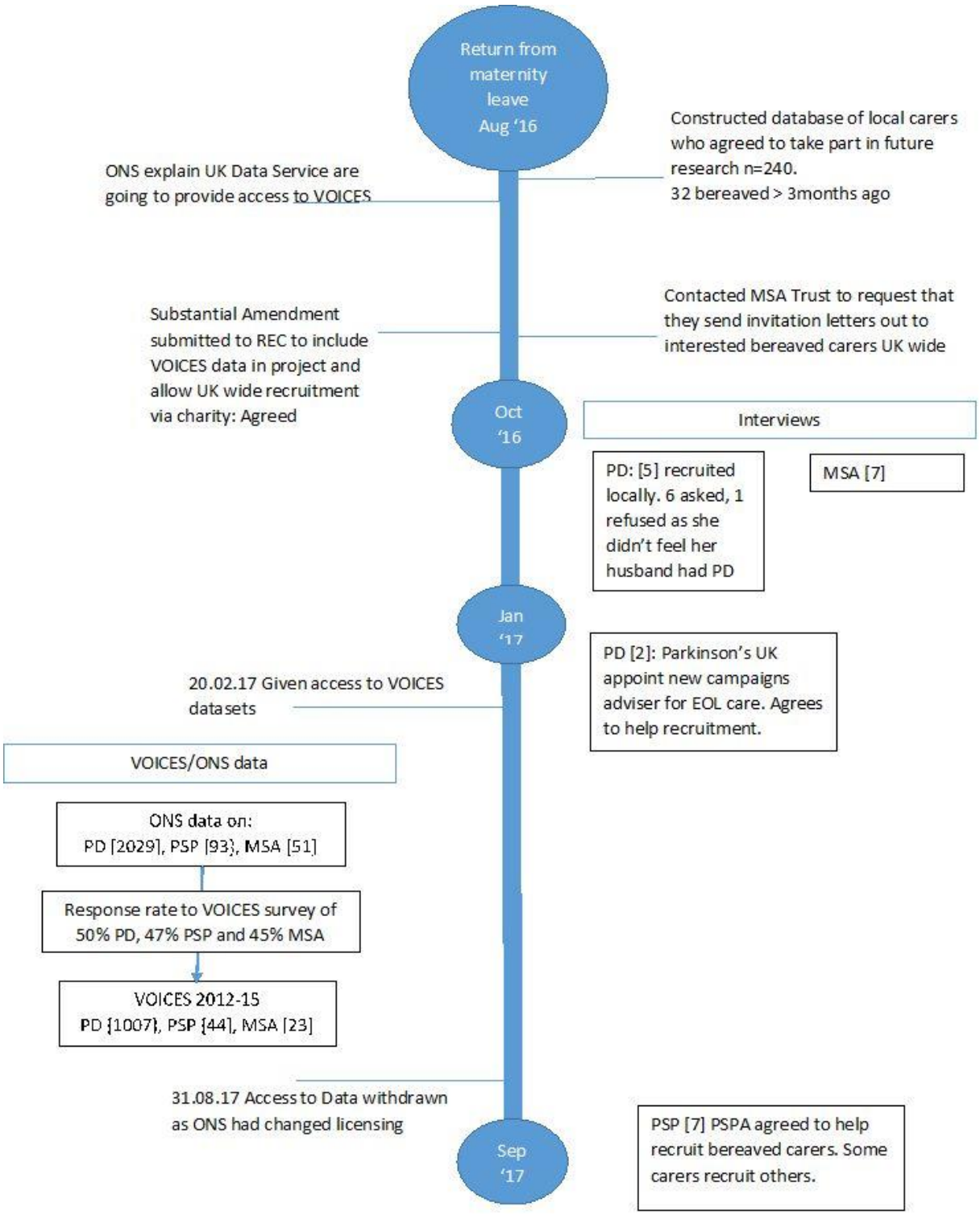

Figure 10 Timeline through the second part of the project

3.6.4 *Eligibility criteria for the qualitative sample*

Any person who had cared for someone who had died from PD, PSP and MSA was eligible to take part. There was no way of verifying the diagnoses before recruitment except for the carers who were recruited locally, as hospital records could be checked. A minimum time of three months after a relative's death was set for sending invitations by post, as this was felt to be in line with studies that had used similar recruitment methods (106, 128). No minimum time interval was set for people recruited through the forums as we judged that because the carers were opting-in to a public invitation they would only take part if they felt ready. This view was supported by a study published in 2015, which suggested that allowing bereaved carers to make their own choice with regard to the timing of participation was beneficial to them and the researcher (129). There was no maximum time of bereavement set because there does not appear to be a consensus over how long is too long in terms of validity, despite suggestions of recall bias over time (79, 130). Some similar studies had opted for a maximum bereavement period of two years (5), but some had accounts from carers who had been bereaved 5-7 years previously (107, 131). Logistically numbers, especially for carers of those with PSP or MSA, would have been very limited by implementing a maximum so we chose not to restrict the sampling by length of bereavement.

Regarding the forums several people joined that were not bereaved carers. Though their views provided additional insight they were not included in the subsequent analysis. Two carers on the MSA forum were based in Australia; their forum entries were included in the analysis as the healthcare systems are not dissimilar and their views still gave insight into the issues that people with MSA and their carers face at the end of their lives.

3.6.5 *Interview Process*

Regardless of the way that carers were informed about the project, all were sent a copy of the disease specific participant information sheets and a consent form. Once a completed consent form had been returned, I called the carer to arrange a time and date for the subsequent interview. This call allowed me to check understanding about the project, ensuring that informed consent had been given, and allowed the carer to ask further questions prior to the interview. At the start of each interview I asked the carer again if they had any questions about the procedure or project and reiterated that they could stop the interview at any point. Although an hour per interview had been proposed, there was no time limit set. Interviews were either carried out face to face or over the phone. All face to face interviews took place in the carers' own homes. They were recorded with a Dictaphone and once the interview had ended this was taken back to North Tyneside hospital. All telephone interviews took place using a speaker phone, in a private room, in the North Tyneside education centre and were recorded using a Dictaphone. Each interview was immediately downloaded onto my secure personal drive within the hospital network at Northumbria Healthcare NHS Foundation Trust and the original recording was erased from the Dictaphone. During the transcription process names of people and places were replaced with an asterisk. Pseudonyms were then developed for each carer and their relative and are used throughout the results sections of this thesis.

3.6.6 *Interview data collection – topic guide*

Interviews were semi-structured using a short topic guide (Figure 11) as an aide memoire, rather than a list of questions. First carers were asked to tell me a little about their life with their relative, and the disease, and then I asked them to focus on the last few months of life. Further questions were driven directly from the carers previous responses. I felt the interviews flowed better this way, allowing me to build rapport with the participants. It also allowed carers to focus on what actually mattered to them, which was especially important for the carers of people with PSP/MSA as end of life care with this group had not been

previously explored. Interim analysis on the forum samples and initial interviews allowed me to add additional areas of questioning for subsequent interviews.

TOPIC AREAS:

- Place
  - Where did your relative want to die?
  - Did the location affect their experience?
  - What were the staff like?
  - Was anything lacking in the services delivered? Was anything especially good?
- Planning/communication
  - Who made the decisions?
  - Prior plans/discussions
  - Did being able to communicate affect their experience
- *What was on their death certificate?*
- *Had they ever suggested ending their life more quickly?*

Figure 11 Topic guide for interviews (italics denote questions that were added later)

3.6.7 *Sample size/data saturation*

20-30 carers was the number we were initially planning for the qualitative arm of the study. This number was chosen because reviews have suggested that the number of interviews conducted should be between 5-25 for studies of experience (phenomenology) and should be at least 15 for qualitative research (132). In addition, 20-30 had been suggested as fitting the requirements of thematic analysis at doctorate level, which was the method we had chosen for analysis (133). We felt that 10 carers in each disease group would give us the ability to compare the diseases and that an overall sample of 30 people would allow an adequate comparison of places of death, especially when combined with the VOICES data. However, there was some in-built flexibility in terms of numbers, as it was not clear at the outset (due to a dearth of qualitative research evidence on end of life among these groups), the numbers required to reach data saturation (134). Recruitment of participants ceased at 36 – the point at which no new themes were emerging following additional data collection.

3.7 Quantitative data collection

3.7.1 *Background of the VOICES survey*

The VOICES survey was developed in 1995 by Professor Addington-Hall and originally consisted of 144 questions targeted around health and social care provision in the last three months of life (84); it was redesigned into a shorter format in 2011 (VOICES-SF) consisting of 58 questions (85). The first half of the survey relates to the last three months of life and asks questions about service provision in the home, care home, hospital and hospice. The latter half of the survey is concerned with the level of care in the last two days of life, regarding symptom control, personal care needs and communication, and 'circumstances surrounding the death' which relates to decision making, knowledge of dying, plans and bereavement.

Between 2011 and 2015 the VOICES-SF was the tool used in the National survey of bereaved relatives, commissioned first by NHS England and then the Department of Health, and administered by the ONS. In 2014, in light of the findings in the Neuberger report 'more care, less pathway'(83), the survey was altered so that the wording and responses of some questions changed (98); two additional questions were added about food and drink in the last two days of life as well as a further three part question about communication with relatives (Appendix B has a copy of the 2014 survey, the additional questions have been starred). A question regarding where the dying person had spent the last two days of their life was removed.

3.7.2 *Sampling methods for the National Bereavement survey*

The ONS used stratified random sampling, stratified by COD, place of death and geographical spread, to post out surveys to around 49000 bereaved carers each year (98). The 2011 sample related to deaths between November and June, whereas subsequent surveys related to deaths that had occurred between Jan and April. The carers had been bereaved 4-11 months prior to the survey being sent out. All causes of death were eligible to be sampled except those caused by accident, suicide or homicide. Place of death had to

be either a home, hospital, care home or hospice. The response rate was around 45% each year leaving a total response of around 110,000 carers across the five years.

3.7.3 *Accessing the ONS VOICES datasets*

In June 2016 the ONS made all five years of the VOICES datasets available for public use through the UK Data Service. However, to protect anonymity the finer detail variables were combined; this meant that COD was limited to a label of cancer, cardiovascular disease or other, with the data for the carers of those with PD, PSP and MSA within the 'other' category. In order to access the ICD-10 codes for causes of death, enabling PD, PSP and MSA to be selected for, the special licence datasets had to be used. To gain access to these datasets I had to be registered with the ONS as an approved researcher and had to have completed a SURE (Safe Users of Research data Environments) course. I was only eligible for provisional approved researcher status and the conditions of the approval were that I had to access the data under the supervision of a fully approved researcher, Professor Richard Walker.

Following project approval from the UK Data Service and the ONS; we therefore had a window of access (under special license) to the VOICES surveys between 20th February 2017 and 31st August 2017, after which all of the datasets were destroyed in line with the request from the UK Data Service/ONS, as access was changing to secure lab only.

3.8 Analysis

3.8.1 *Qualitative*

The interviews and forum extracts were analysed according to the principles of Thematic analysis outlined by Braun and Clarke (135). Thematic analysis was chosen because it does not need to conform to a set of philosophical principles, unlike grounded theory or interpretive phenomological analysis, and so fits within the methodology of pragmatism and mixed methods research.

Braun and Clarke advocated a six–phased approach to analysis (135): the first step relates to familiarising yourself with the data, the second relates to coding the data, the third, fourth and fifth relate to generating, reviewing and defining themes and lastly the sixth relates to writing the report.

Familiarising myself with the data

All but two of the interviews were transcribed by me; the two interviews that were transcribed by a medical secretary were checked for accuracy against the recordings. As well as providing the opportunity to familiarise myself with the data, transcribing the interviews allowed a degree of preliminary analysis to be done which enabled me to explore points of interest in subsequent interviews. Once the interviews were transcribed, these were read and key concepts and points noted.

Generating initial codes

Coding was initially conducted by hand, then using Nvivo software to aid data management. Transcripts were examined line by line and sections of text were assigned a label(s)/code. Initially this was done separately for each disease group. Individual data extracts could be assigned more than one code (see Figure 12 for an example). I took an inductive approach toward analysis, so that the codes that were generated came directly from the data, rather than from a pre-determined list based on prior research. As the analysis progressed it was apparent that some codes needed splitting and others needed condensing, at this point I used Nvivo to aid in their management. Each disease became a project within NVivo with its own data set.

"as I was out of the room whilst they told my mum, I was unaware of the severity of it all. Upon my return, mum pointed out "Bury me". Devastation, total devastation" MSAf2

Coded as

- communication person with MSA to carer
- how was bad news broken
- decision making – patient
- future plans what
- did person know dying
- did carer know dying
- impact of dying on carer

Figure 12: Example of how extracts were coded

Generating, reviewing and defining themes

I collated the codes into themes by using hand written spider diagrams and by generating sets and higher-level nodes[11] on Nvivo. Some codes became collated into a main theme, for example support during disease, support at time of death and support after dying all became 'Support'; some codes became subthemes, for example, staff attitudes. In defining the themes some codes were split, reassigned or abandoned.

Through reviewing the data sets separately it was apparent that almost all of the codes overlapped between MSA and PSP; I could also see that the overarching themes matched across all three disease groups. Therefore, I generated a word document for each theme and populated them with data extracts arranged by subtheme; this allowed me to review the themes and check that they were reflective of the data. I had colour-coded each extract by disease group and this allowed me to compare the diseases within the themes. I then read through the interviews again to ensure that the themes fitted the most pertinent issues related by the carers.

[11] terminology for a code in Nvivo

3.8.2 *Quantitative*

IBM SPSS Statistics (Versions 21-24) was used to analyse the VOICES datasets.

Within the UK data service there was one corresponding SPSS dataset for each surveyed year, and three datasets which combined the surveys of 2011-12, 2012-13 and 2014-15. Each dataset had been generated containing the answers to the VOICES survey and the ONS death certificate data (including age, sex, causes of death, place of death, deprivation level and NHS area) for all decedents whose relatives had been invited to take part, whether they had responded or not. Data cleaning highlighted a coding anomaly[12] in the 2011 dataset, therefore the 2011 set was excluded from analysis. The ONS data and most of the survey questions were identical across the four years and so the 2012-13 and 2014-15 datasets were combined. The question stem and responses regarding support for symptoms and care needs had altered between 2012-13 and 2014-15 and as they were not directly comparable only the 2014-15 data was used for comparisons of locations. A question regarding where the dying person had spent their last two days was only present in the 2012-13 surveys and questions regarding communication with carers were only present in 2014-15.

3.8.3 *Cause of death (COD)*

The data sets were searched for the ICD-10 codes that corresponded to PD (G20), PSP (G231) and MSA (G903) and where these diseases were recorded as the primary/underlying COD by ONS, the label of 'other' in the COD variable, which corresponded to a '3', was replaced with a '4' for PD, '5' for PSP or a '6' for MSA. An additional variable was generated to account for people who had these diseases but were not thought to have died from

[12] The column for 1st COD was completely blank and carers response to place of death showed an oddly high response for dying in A+E and an oddly low response for dying in a care home, especially when compared to subsequent years

them[13], making the diseases contributary but not underlying COD (discussed in greater depth in Chapter 4). This enabled an estimation of the proportion of people felt to have died because of the diseases. As the people who had PD/PSP/MSA recorded as a contributory COD were potentially in an earlier stage of the disease and died from other causes the decision was made to focus only on the groups whose underlying COD was PD/PSP/MSA. This also meant that a comparison could be made between people dying due to PD/PSP/MSA and those dying due to cancer, cardiovascular disease or 'other' causes. Appendix C illustrates how completion of a death certificate would account for an underlying or contributory COD being recorded.

3.8.4 *Place of death (POD)*

POD is represented in the ONS data (ascertained by information recorded by doctors on the death certificate itself) and as a question for carers in the survey data (Q40 of VOICES survey, see Appendix B). For the purposes of analysis, when survey questions were compared according to POD it is the place recorded by the ONS which was used, rather than the POD carers had selected in the survey. This decision was made because it aligns with the way that the ONS themselves analysed the data(98). This could impact on the analysis of survey responses as it is possible that ONS recorded POD as hospital but carers were answering about home. However, when death certificate and carers' POD were compared they matched 96% for hospital, 97% for care homes/home and for 95% hospices for those with PD and 100% in all locations for PSP/MSA. In the 2012 survey carers were asked about where their relatives spent their last two days and again there was some discrepancy. For example, ONS had recorded POD as hospital but the carer had said that their relative spent all of the last two days at home, in these cases it is likely the carers view relates to home but would be recorded as relating to hospital. This question was removed from later surveys and so could not be used to exclude the data of people who had a mismatch. In 2012-13

[13] PD, PSP or MSA were on the death certificate but were not recorded by the ONS as the primary COD

11% of people recorded as dying in hospital were said to have spent all of the previous 2 days elsewhere by their carers. The same was true in 3% of care home deaths, 6% of home deaths and 0% of hospice deaths.

3.8.5 *Comparisons*

Statistical analysis

Every variable (see Appendices B and D for more information) was compared according to the primary COD and POD with frequency tables and cross-tabulations recorded. Comparisons to other conditions were age-matched. Some of the survey responses were nominal, 'yes', 'no', 'don't know', some were represented as Likert scales with either 'outstanding, excellent, good, fair and poor' as the responses or 'strongly agree, agree, neither agree/disagree, disagree and strongly disagree' (see VOICES survey in Appendix B). As it cannot be assumed that the difference between outstanding and excellent, is necessarily the same as the difference between fair and poor, the Likert scales were treated as ordinal data. Clinically relevant distinctions were then used to collapse the categories into nominal variables to allow comparisons to be made; for example, it was felt that good care meant a person was always treated with respect and dignity and so the categories became 'always' or 'not always' treated with respect. Likewise, categories were collapsed into those who agreed or disagreed with statements, or those who received excellent or less than excellent care. This approach has been used in previous studies using the VOICES survey (136). How the variables were collapsed and compared depended on the individual questions. Mostly, because excellence in healthcare should be the aspiration, the top one or two labels were compared to the rest. So outstanding and excellent versus good, fair and poor; strongly agree/agree versus neither agree nor disagree, disagree and strongly disagree, and always versus less than always. Not applicable and don't know were selected out of comparisons as it skewed the percentages and affected the statistical calculations. When the fact that people had answered not applicable was felt to be an interesting and positive finding this was explored separately, for example, when 'not applicable' was

answered regarding food and drink at the end of life. Appendix D includes tables of the variables and indicates the way they were collapsed for comparison. Categorical statistical analysis was performed using binary logistic regression to create odds ratios with 95% confidence intervals. This method was chosen instead of chi squared testing as it allowed ranking of the differing locations and illustrated more clearly where the statistically significant differences lay; rather than showing a more global difference across the group.

3.9 Meta inferences

Because the survey and interviews were looking at slightly different aspects of the experience, they were predominantly integrated after the analysis had been completed. The exception was that once the qualitative analysis had been completed, the data extracts in the support theme were re-examined according to place of death. This enabled a clearer comparison of places of death to be made and allowed patterns in the strands to be explored. A process of abduction (117) then took place where questions were asked back and forth across the two strands with regard to place of death and similarities and differences were brought together and directly compared and explored, in line with the complementarity purpose of the study, to explain the experience in greater detail.

Although many of the points raised in the qualitative strand did overlap with questions in the VOICES survey it was apparent that it had been useful to undertake the analyses separately as some of the main points of importance raised in the qualitative strand were not touched upon in the VOICES survey.

3.10 Summary

This chapter has outlined a background to mixed methods research and explained why the approach taken was one of pragmatism. It has explained the project design, recruitment into the quantitative and qualitative strands, their analysis and integration.

Chapter 4 Demographics

This chapter sets out the demographic details of the people who died (referred to as decedents by ONS), and their carers, for the quantitative data set (the VOICES samples) and the qualitative data set (interview/forum sample). It also presents some descriptive findings regarding place of death for the quantitative sample.

4.1 The quantitative data set

This section first talks through the difference between contributory and underlying causes of death, comparing the demographics of people thought to die because of PD/PSP/MSA (underlying cause) with those who had PD/PSP/MSA but whose deaths were felt to occur due to a different condition (contributory cause)[14]. The next section focusses on the response rates of carers whose relatives were recorded as dying with an underlying cause of PD/PSP/MSA and the factors which affected the responses. The final part of the quantitative section presents the demographic details for the data that was used in the overall analysis when comparing places of death; including age, gender, social deprivation and POD and looks at factors which affected the overall rating of care.

Figure 13 demonstrates pictorially how the final numbers included in the quantitative analysis were reached.

[14] The ONS records up to 15 causes of death as mentioned on the death certificates. Please refer to appendix C for an explanation of the way that a death is recorded as contributory or underlying

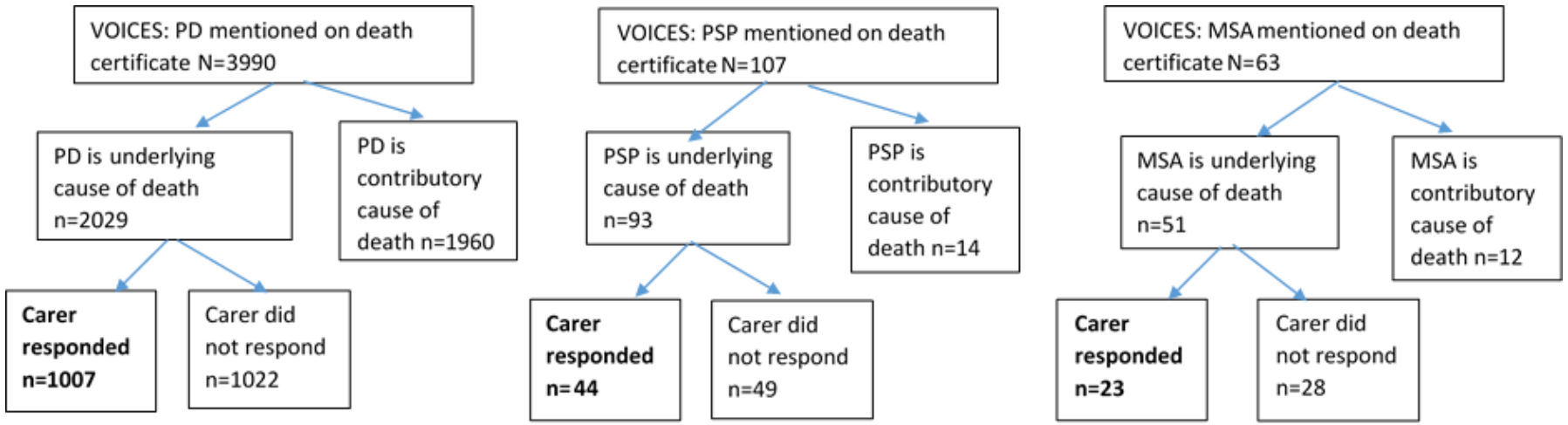

Figure 13 : Flowchart detailing how final numbers included in quantitative analysis (shown in bold type) were reached

4.1.1 *Contributory and underlying causes of death*

The information contained in the VOICES datasets included the demographic data of decedents for every survey that was posted to carers, whether they responded or not; based on the information provided to the ONS at the time the death was registered.

There were 3990 decedents with PD, 107 decedents with PSP and 63 decedents with MSA mentioned somewhere on their death certificate. Of these decedents the underlying COD was felt to be PD in 2029 (51%), PSP in 93 (87%) and MSA 51 (81%). Appendix E includes tables comparing those who died with PD/PSP/MSA as contributory or underlying causes.

Those decedents mentioned with PD as a contributory COD (n=1960) were more likely to be male (63% vs 60%) and to have died in a hospital (52% vs 34%) than those dying from PD as an underlying cause and less likely to have dementia (17% vs 37%) or to have died in a care home (34% vs 52%).

It is difficult to compare the contributory and underlying COD groups for those with PSP/MSA mentioned on their death certificates as the numbers for the contributory groups are so small (PSP n=14, MSA n=12). However, the same trends were seen for those with PSP and MSA in terms of place of death; decedents where the PSP/MSA were felt to be contributory were proportionally more likely to have died in hospital than for the decedents where the PSP/MSA was the underlying COD (PSP 71% vs 28%; MSA 67% vs 41%).

Interestingly, where PD/PSP/MSA were felt to be contributory causes, 19% of those with PD and 50% of those with PSP/MSA were recorded having pneumonia as their underlying COD; given that pneumonia is more common in these diseases this finding does call into question the accuracy of the way that death certificates are recorded.

4.1.2 *Underlying COD PD/PSP/MSA*

Those dying from MSA died younger than those with PSP/PD (49% in 50-74 age group MSA, vs 37% PSP and 11% PD). There were more men that died from PD (60%) and MSA (59%) than women, which was not true for those dying from PSP (male 49%). People dying from these diseases appear to be less likely to have been recorded as living in areas with the most deprivation (31% PD/PSP and 22% MSA of deaths were recorded in most deprived 40%), which may well reflect the fact that these conditions occur in more advanced age as social derivation is linked to reduced life expectancy. Dementia was mentioned on the death certificate for 37% of those dying from PD, 11% of PSP and 6% of MSA. Figure 14 shows the POD according to the underlying COD. It shows that people who died from PD appear more likely to die in a care home than those with PSP/MSA. People with PSP appear more likely to die at home than those with PD or MSA. Those with MSA appear more likely to have died in hospital or hospices than those with PD or PSP.

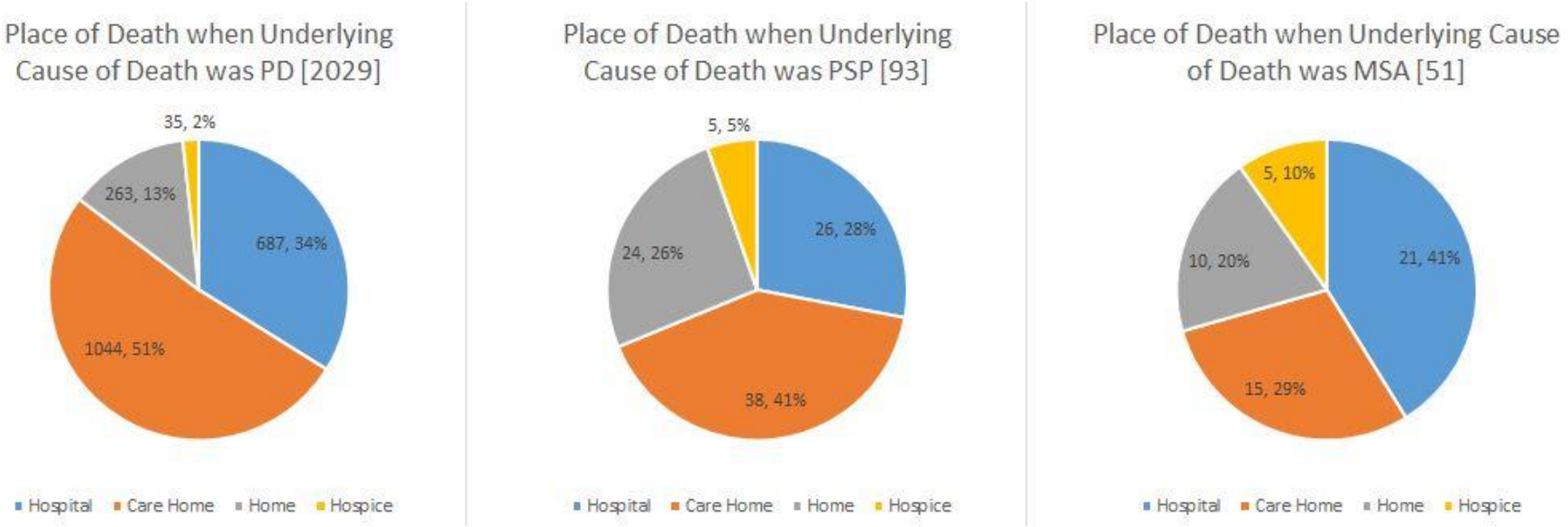

Figure 14 POD recorded by ONS when the underlying COD was PD, PSP or MSA [n], England 2012-15 (n, %)

4.1.3 *Response rates*

Table 3 shows the response rates from carers of those whose underlying COD was felt to be due to PD/PSP or MSA.

Condition	Number of questionnaires sent	Response rates n (%)
PD	2029	1007 (50)
PSP	93	44 (47)
MSA	51	23 (45)

Table 3 Response rates from carers where the underlying COD was PD, PSP or MSA

Response rates were affected by POD, age and deprivation index. PD carers were significantly less likely to respond if the POD was listed as hospital compared to care home [OR 0.81 (0.67 to 0.99) p=0.036] or at home [OR 0.66 (0.49 to 0.87) p=0.004]; the comparison with hospices was not statistically significant [OR 0.62 (0.31 to 1.24) p=0.18]. PD carers were significantly less likely to respond if the decedent was in the most socially deprived 20% when compared to those in the middle [OR 0.60; CI 0.44 to 0.83: p=0.002], 2nd least deprived [OR 0.68; CI 0.50 to 0.92: p=0.012] or least deprived 20% [OR 0.67; CI 0.49 to 0.90: p=0.009]. Response rates for PD carers were not affected by the age, gender or dementia status of the decedent.

Carers for those with PSP/MSA were more likely to respond if decedent was older than 75 and PSP carers were more likely to respond if they were in the least deprived social group; response rates were not affected by gender, dementia status or POD.

4.1.4 *Sample used for comparative analysis*

Table 4 shows the demographic details for decedents whose underlying COD was PD/PSP or MSA, where the carers had responded to the survey. Table 5 shows the demographic details for the carers who responded to the survey.

Demographics of decedent	Underlying COD n (%)			
	PD [1007]	PSP [44]	MSA [23]	Total PDRD [1074]
Age				
50-74	100 (10)	10 (23)	7 (30)	117 (11)
75-84	491 (49)	23 (52)	14 (61)	528 (49)
85+	416 (41)	11 (25)	2 (9)	429 (40)
Gender				
Male	596 (59)	18 (41)	14 (61)	628 (58)
Female	411 (41)	26 (59)	9 (39)	446 (42)
Deprivation index				
Most deprived 20%	105 (10)	4 (9)	3 (13)	112 (10)
2nd most deprived 20%	169 (17)	5 (11)	1 (4)	175 (16)
Middle 20%	237 (24)	14 (32)	7 (30)	258 (24)
2nd least deprived 20%	248 (25)	10 (23)	6 (26)	264 (25)
Least deprived 20%	248 (25)	11 (25)	6 (26)	265 (25)
Dementia				
Yes	377 (36)	3 (7)	1 (4)	381 (3)
No	630 (63)	41 (93)	22 (96)	693 (65)
Place of death				
Hospital	312 (31)	11 (25)	10 (44)	333 (31)
Care home	528 (52)	18 (41)	9 (39)	555 (52)
Home	147 (15)	12 (27)	4 (17)	165 (15)
Hospice	20 (2)	3 (7)	0	23 (2)
Ethnicity[15]				
White	936 (93)	43 (98)	21 (91)	1000 (93)
Religion[16]				
Christian	844 (84)	37 (84)	18 (78)	899 (84)
No religion/other	143 (14)	7 (16)	4 (18)	154 (14)

Table 4 Decedent Demographics

[15] This is answered by carers in the VOICES survey and because some carers did not answer the questions the % figures as a proportion of those who answered are slightly higher than those shown

[16] As above

Demographics of carer	Underlying COD n (%)			
	PD [1007]	PSP [44]	MSA [23]	PDRD [1074]
Relationship to decedent				
Spouse	333 (34)	21 (48)	14 (61)	368 (34)
Child	544 (55)	19 (43)	8 (35)	571 (53)
Other	116 (12)	4 (9)	1 (4)	121 (11)
Age				
18-49	102 (10)	4 (9)	6 (27)	112 (10)
50-59	300 (30)	11 (25)	3 (14)	314 (29)
60-69	279 (28)	13 (30)	4 (18)	296 (28)
70-79	198 (20)	10 (23)	6 (27)	214 (20)
80+	116 (12)	6 (14)	3 (14)	125 (12)
Gender				
Male	331 (33)	23 (52)	8 (35)	362 (34)
Female	628 (62)	20 (45)	15 (65)	663 (62)
Ethnicity				
White	959 (95)	44 (100)	21 (91)	1024 (95)

Table 5 Carer Demographics

4.1.5 *Overall rating for care in the last three months*

The overall rating for quality of care in the last three months was affected by COD, as shown in Figure 15 .

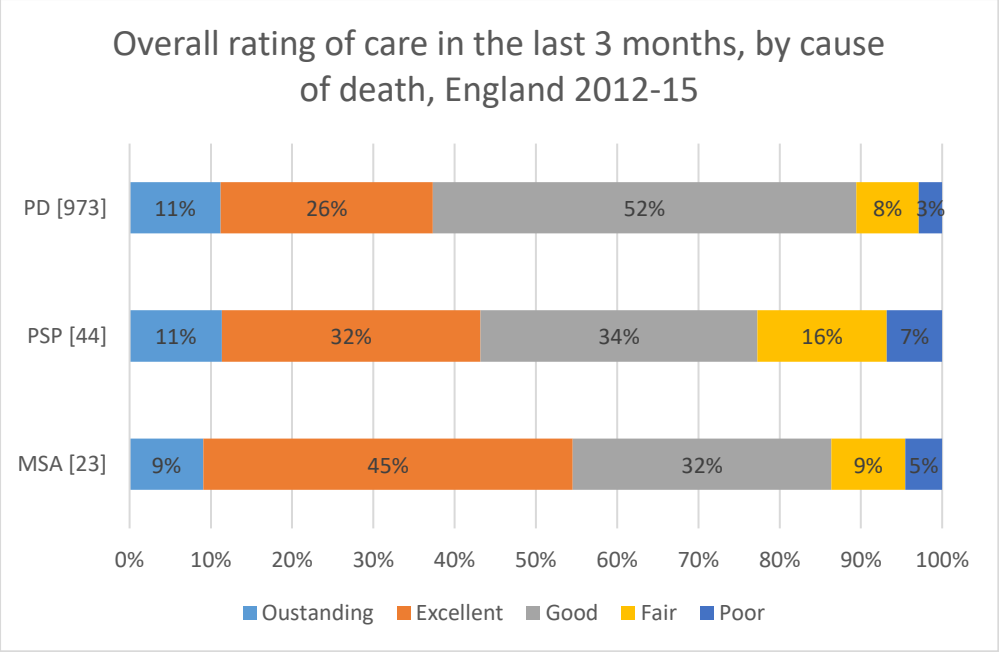

Figure 15 The overall rating for quality of care in the last three months, by COD

Carers whose relatives died of PD were significantly more likely to feel the quality of care was positive (outstanding/excellent/good) than the carers of people dying of PSP [OR 2.48; CI 1.19 to 5.18: p=0.0015]; there was no statistically significant difference between those who died of PD and those who died of MSA [OR 1.33; CI 0.39 to 4.58: p=0.65]. A greater proportion of the carers of those who died from PSP and MSA felt that their care had been outstanding or excellent, compared to those who died from PD, but the differences were not statistically significant.

Other demographics that may have affected the overall rating of care were compared with the diseases combined, because the numbers for PSP/MSA were too small to allow any statistical inferences to be made. Appendix F contains the proportions for the individual causes of death and shows that for most variables the patterns of PSP/MSA followed that of PD. Appendix G details the odds ratios, confidence intervals and p values for the findings detailed below.

Overall quality of care was not affected by the age, gender, deprivation index or religion of the decedent, nor by the presence or absence of dementia being mentioned on the death certificate. Carers who were spouses were significantly more likely to answer that care had been positive than carers who were the decedents' children. The older a carer was, the more likely they were to feel that care was positive; with carers over the age of 60 significantly more likely to rate care positively than those aged between 18-49. Male carers were more likely to rate care positively than their female counterparts.

In terms of POD, there was a statistically significant difference across the group. Carers whose relatives died in hospital were significantly less likely to rate care positively than carers whose relatives died in care homes [OR 0.60; CI 0.43 to 0.85: p=0.003]; there was not a statistically significant difference when comparing hospital deaths to home or hospice deaths, despite the apparent fact the hospices and home deaths appeared to be rated even more highly (Figure 16).

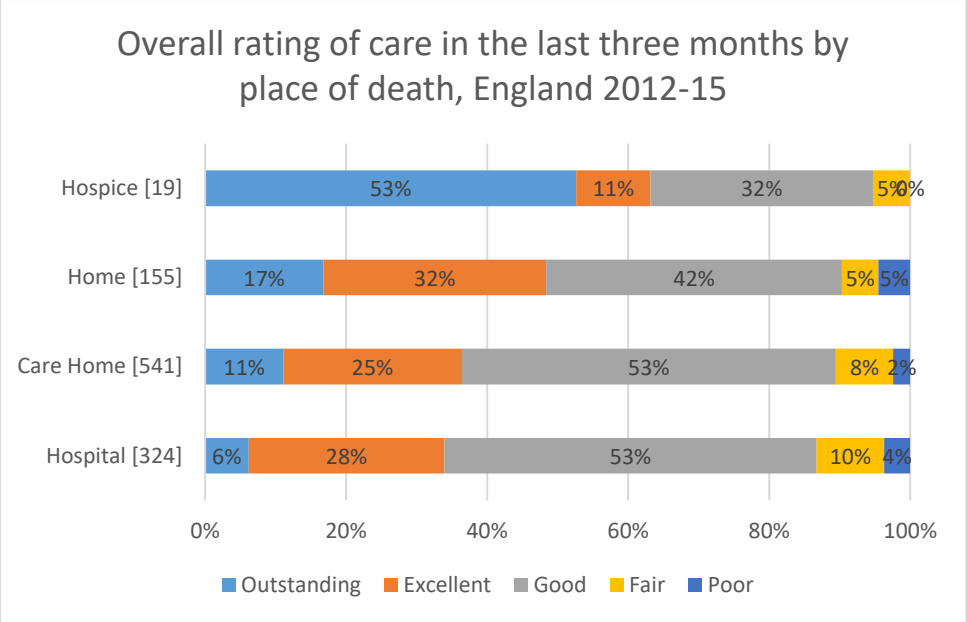

Figure 16 Overall rating of care in the last three months by POD, England 2012-15

However, regarding POD these results should be interpreted with caution because clinically and practically comparing the overall score of the whole of the last three months to the POD makes little sense. As an example, of those who died in a hospice 78% had spent some of their last three months in hospital and 35% of them had spent time at home, so their carer's overall rating of care for the last three months would likely refer to a multitude of places of care and make a comparison based on POD alone difficult. This factor likely explains why in the subsequent results chapter hospice appears to be rated much higher, in terms of excellent care, than this overall rating scale would suggest it performs. When comparing those who answered they had spent all of the last three months in a care home the overall rating went up and for those who had spent all of their time in a hospital the overall rating went down (see Appendix G xi). Chapter 6 compares the different places of death in closer detail and provides more detailed views of the components that make up care in individual places.

4.3 The Qualitative sample

This section presents the details of the qualitative sample. Because the recruitment was undertaken as a convenience sample, aside from those who died locally it was difficult to ensure all places of death were sampled, but there was interview data across all locations for each of the disease groups. Although no-one with PSP died in a hospice (as Table 6 shows), two carers related that their loved ones had spent a couple of months within hospices in the last months of life.

Compared to the VOICES sample, the carers in the interview/forum group were more likely to be spouses and they had, for the most part, been bereaved for a longer period. Interviews were undertaken by telephone in most cases (n=18); the rest were undertaken face to face at the carer's home (n=6).

Demographics of decedent	**Underlying COD n (%)**		
	PD [n=13]	PSP [n=9]	MSA [n=14]
Age			
50-74	2 (15)	3 (33)	11 (79)
75-84	9 (69)	4 (44)	3 (21)
85+	2 (15)	2 (22)	0
Gender			
Male	10 (77)	5 (56)	5 (36)
Female	3 (33)	4 (44)	9 (74)
Place of death			
Hospital	7 (54)	5 (56)	7 (50)
Care home	3 (23)	3 (33)	1 (7)
Home	2 (15)	1 (11)	4 (29)
Hospice	1 (8)	0	2 (14)
Demographics of carer			
Relationship to decedent			
Spouse	10 (77)	6 (67)	11 (79)
Child	3 (23)	3 (33)	3 (21)
Gender			
Male	2 (15)	2 (22)	6 (43)
Female	11 (85)	7 (77)	8 (57)
Average bereavement (range)	18 months (1 to 78)	34 months (3 to 84)	40 months (1 to 96)
Number of interviews	8	7	9
Number of forum entries	5	2	5
Average length of interview (range)	80mins (59-117)	97mins (65-140)	105mins (70-180)

Table 6 Demographics of Decedents

Alias of carer	Alias of decedent	Disease	relationship to decedent	Length of bereavement	Length of interview	Word count	Place of death
Jennifer	Doris	PD	Daughter	3 years	-	6053	Care Home
Sandra	Edmond	PD	Wife	6.5 years	-	3306	Home
Moira	Samuel	PD	Wife	1 month	-	960	Hospital
Pippa	Cedric	PD	Daughter	15 months	-	2039	Hospital
Martha	Fred	PD	Wife	5 months	-	810	Home
Brenda	Eddie	PD	Wife	< 1 month	117 mins	21662	Hospital
William	Pearl	PD	Husband	7 months	64 mins	6650	Hospital
Barbara	Derek	PD	Wife	9 months	78 mins	11091	Care Home
Angela	Graham	PD	Wife	2 years	100 mins	11925	Care Home
Pam	Andrew	PD	Wife	2 years	77 mins	9756	Hospice
Susan	Paul	PD	Wife	16 months	78 mins	10543	Hospital
Simon	Gladys	PD	Son	14 months	65 mins	9488	Hospital
Betty	Donald	PD	Wife	7 months	59 mins	7896	Hospital
April	Janice	PSP	Daughter	6 months	-	3906	Hospital
Samantha	Ronald	PSP	Daughter	3 years	-	1498	Hospital
Peter	Yvonne	PSP	Husband	14 months	82 mins	11362	Care Home
Constance	Thomas	PSP	Wife	9 months	141 mins	16887	Care home
Stephanie	Nigel	PSP	Wife	6 years	87 mins	11361	Hospital
Kate	Marion	PSP	Daughter	7 years	75 mins	12509	Hospital
Margaret	Chris	PSP	Wife	3 months	130 mins	20650	Home
Hope	Dennis	PSP	Wife	6 years	102 mins	11652	Hospital
Colin	Grace	PSP	Husband	1 year	65 mins	9029	Care Home
Charlene	Evelyn	MSA	Daughter	< 1month	-	502	Hospital
James	Rachel	MSA	Husband	3 years	-	1086	Home
Nicole	Jake	MSA	Wife	8 years	-	663	Home
Abigail	Stella	MSA	Daughter	4 months	-	2022	Care home
Cecil	Elizabeth	MSA	Husband	3 months	-	7015	Home
Julie	David	MSA	Daughter	8 years	84 mins	12054	Hospital
Helen	Tony	MSA	Wife	7 years	110 mins	21346	Hospital
Vincent	Beatrice	MSA	Husband	3 years	123 mins	20052	Hospital
Paul	Emmy	MSA	Husband	1 year	76 mins	10265	Hospice
Elaine	Stephen	MSA	Wife	2 years	134 mins	25388	Hospice
Aileen	John	MSA	Wife	4 years	85 mins	12230	Hospital
Charles	Anna	MSA	Husband	3 years	67 mins	6931	Hospital
Philip	Thelma	MSA	Husband	6 years	180 mins	21786	Hospital
Sebastian	Jade	MSA	Husband	15 months	90 mins	10685	Home

Table 7 Information regarding individual carers

The word counts of the interviews and forum samples are provided to give an indication about the amount of data in the forum entries. Although the forums contained less information than the interviews overall, the information they did contain was all highly

relevant to the research questions, especially regarding the experiences encountered in the differing places of death. Appendix H contains mini case studies for each carer's narrative to provide the background for subsequent quotes.

4.4 Summary

This chapter has presented the demographic details of the quantitative and qualitative samples. It also explained demographic factors which affected response rates and the overall rating of care.

Chapter 5 The palliative and end of life needs of people with PD, PSP, MSA and their carers

This chapter presents the main components of the qualitative interviews and forums and allows for a comparison between the views of those caring for people with PD and those caring for people with PSP or MSA.

The principle themes from the qualitative interviews were those of preparation, support and identity (see Figure 17). In this chapter these themes equate to a discussion about the future and ACP (Preparation); co-ordinated care (Support) and knowledge about the diseases/community spirit reflecting collective and relational aspects of identity (Identity).

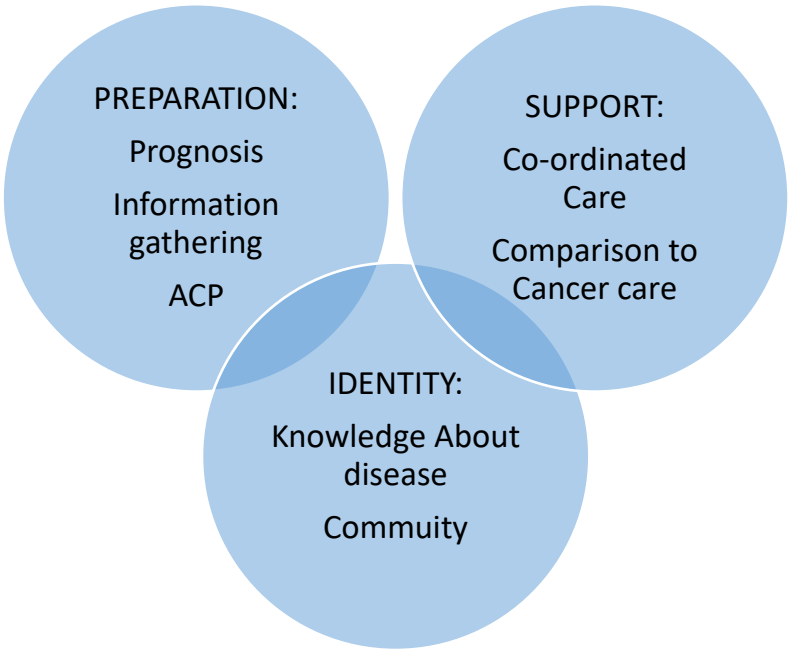

Figure 17 The principle themes of the project and an indication of the ways they are discussed in this chapter

5.1 PREPARATION: Prognosis, Information Gathering and ACP

As stated in the introduction and literature review, current guidance suggests that people should be aware of their prognosis and receive timely information to enable them to plan. This section discusses communication about the future between people with PD/PSP/MSA and their relatives and HCPs. It then discusses how these discussions, or lack of them, can shape ACP. Figure 18 presents this section diagrammatically.

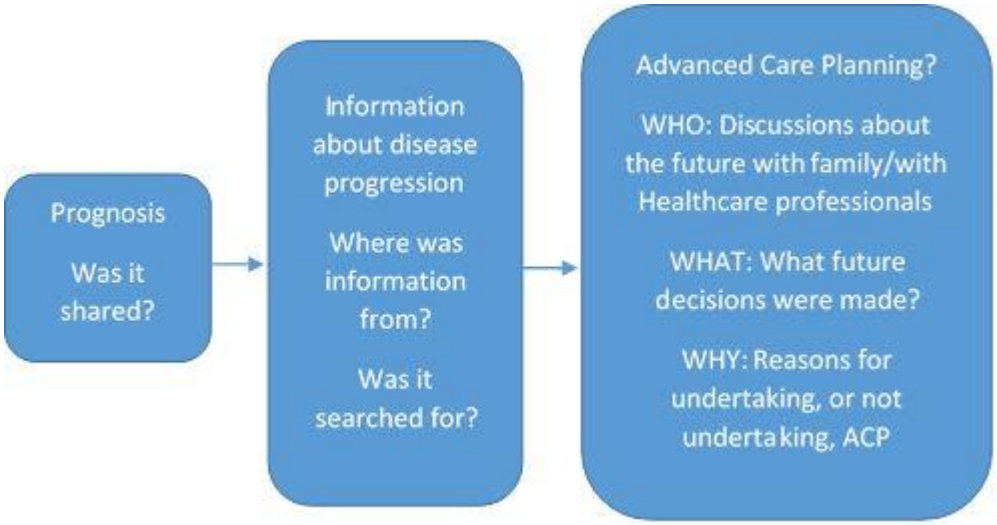

Figure 18 The components of future planning

5.1.1 *Prognosis*

In most cases there was a delay in diagnosis for those with PSP/MSA. Most had to pay privately to see a neurologist and several had been diagnosed with something different beforehand (often PD). Those with PSP/MSA had found this delay frustrating. Some had researched their likely diagnosis themselves and knew time was limited. Others knew something was wrong and wanted to get to the bottom of it, though in retrospect a couple of carers were glad there had been a delay.

> *"you get angry that you're not getting anywhere but then you look back and you think well we had three years when we didn't know what was going to happen, so actually that was quite nice" Helen (MSA)*[17]

Once given a diagnosis, the majority of those with PSP/MSA were told that there was no available treatment to slow the progression of the disease and that they had a life-limiting prognosis.

> *"when I first found out about MSA I knew that I was watching my wife die from the very beginning day by day, week by week, month by month, year by year and I knew she was dying, it wasn't a case of if. I knew there was an around about seven years prognosis" Paul (MSA)*

[17] Each quote is followed by the carer's alias and the curved brackets indicate the COD of the person they cared for

In contrast prognosis for those with PD was seemingly raised rarely by movement disorder teams. This may be due to the heterogeneity of PD, which does make predicting an individual's prognosis difficult. Indeed those in the interview group with PD lived for 5-25 years after their diagnosis; a much larger range of time than those with PSP/MSA (1-5 years). Once the disease had progressed, years later, a couple of those with PD had been told they were in the end stages, but they were in the minority. Most carers felt that clinic appointments centred around medication, whether it was helping or not, whereas they would've welcomed more frank discussions about what could happen with PD.

> *"I think that more information about PD and the various stages of the disease being communicated to the main carer in advance can only be helpful. It will help to come to terms with the situation and also to plan for it... I also think that a conversation about the fact your loved one is dying would also have been very helpful and in particular advance of what you can expect the various stages and interventions to be" Sandra (PD)*

Timing in regard to when conversations about the future should happen was discussed.

> *"CM: anything else you we could do better at the end of life for Parkinsons's disease?*
> *Betty: I think really just keeping people informed of how bad it can get and what it can do to people*
> *CM: when do you think is the right time to tell people that sort of thing?*
> *Betty: at the beginning of the deterioration*
> *CM: so as things start to go downhill*
> *Betty: yeah coz you sometimes think gosh what's happening and then you think maybe this is the way it's supposed to be" Betty (PD)*

Marking the point of decline where it would be relevant to bring up discussions about the future might be difficult, but Pippa's view was that there should be more honesty at an earlier stage to better prepare people for what lay ahead

> *"I feel it is about being honest about the future so people can truly plan their future and live for now rather than hoping that something miraculous will happen and their mobility will improve and their Parkinson's will be cured…there needs to be more honesty amongst professionals about what a Parkinson's diagnosis means. When my father was diagnosed they said you won't die from Parkinson's but you will die with it. There is no doubt that Parkinson's is a killer and this shouldn't be played down" Pippa (PD)*

Pippa had witnessed her father and others put off decisions whilst waiting to get better with their medication. She felt it should be clearer no cure was coming. In the death certificate data supplied by ONS, 51% of those with PD were felt to have died as a direct consequence of their PD and yet even carers who had been told their relatives had end stage PD felt that it was not a COD.

> *"Mum knew she did not want to be resuscitated or have her life extended if she had an accident or went into heart failure or other such conditions. She knew Parkinson's was not terminal" Jennifer (PD)*

5.1.2 *Information about disease progression*

Because those with PD and their carers felt that PD was not a COD and because clinics largely focussed on medication, rather than discussions about decline, there was no suggestion for most that discussion should be had about the future. Pippa felt that by the end of her dad's life the PD team had given up on her dad, "as if they didn't really want to discuss the end of life", and even when people had good access to PD teams and nurses for support regarding symptoms, discussions about how near the end might be and what might happen did not appear to have been had.

> *"The first indication I had that my husband was seriously ill was the telephone conversation I had with the Parkinson's Nurse when I rang to tell her he was in hospital again with bronchopneumonia. This was about 2 months before he died and up until then no-one had even hinted how very ill he was. It was then I realised that maybe he did not have much longer to live" Sandra (PD)*

It could be assumed that those with PSP/MSA had more opportunity to discuss the future as they were told their conditions were life limiting. However, once they had been told their prognosis there was little further explanation as to what the future might bring, or how the end might come; some were told there was nothing the neurologist could offer them and one respondent was even told not to come back.

> *"the neurologist basically said 'you don't really need to come back and see me there's nothing much I can do for you, make sure you're in touch with our Parkinson's nurse at the hospital they'll probably be the best person for you' which um charming; didn't get any information about what that was, what it meant, what it might mean for the future or anything, yeah lovely, charming" Kate (PSP)*

Even though other neurologists were reported to be empathetic and engaged, none had given help with planning for the future, or really discussed it. Those with PSP/MSA were either signposted towards the charities to gain more information or searched the Internet for more information themselves, or their carers did

> *"I got a lot of information off the internet as one does these days, sometimes of course that's not necessarily for the good but, you know, when you have a need to glean information" Constance (PSP)*

The amount of information they sought was very much dependent on their reaction to the news and the way they chose to cope with the diagnosis. Individuals seemed to react with a 'fight or flight' response, that is they either chose to search for information so that they could be prepared for what was coming,

> *"I know he looked it up on the internet and I know he'd got this 'my PSP files' he started this file and I found that out after, so he was aware what a devastating diagnosis it was" Stephanie (PSP)*

or they preferred not to look any further

> *"Gail instructed me not to study the internet, which was a waste of time of course because my two daughters immediately did and told me what it said but Gail wasn't up to speed in many senses, she didn't want to know and that generated its own problems" Colin (PSP)*

This response was true not only for the person with the disease but also for their carers; some carers wanted to know everything

> *"I'm the sort that I wanted to find out as much as I could, I wanted to know what we were up against" Elaine (MSA)*

whereas other carers preferred not to read about what might happen

> *"I looked it up on the internet, I read a little bit of it and I thought I don't want to know anymore I'm just going to take each day as it comes" Helen (MSA)*

The practical (whether they had access to information) and emotional (whether they wanted to access information) ability to find out more about the diseases and their progression had a direct effect on whether plans were discussed. Those with PD were practically more limited in regard to future planning because prognosis was discussed less

frequently; their interpretation of their situation, with regard to planning, was therefore more often related to ageing and their ability to think about their own mortality in general, rather than related to their disease. In contrast those with PSP/MSA were more often confronted with the life limiting nature of their diseases and therefore their emotional ability to search for information and plan was more closely related to their disease.

The discussions people with the diseases had with their families and HCPs, the types of plans made, and the reasons for making them will be discussed in the sections below. They make up the 'who', the 'what' and the 'why' of ACP and we will look at each in turn.

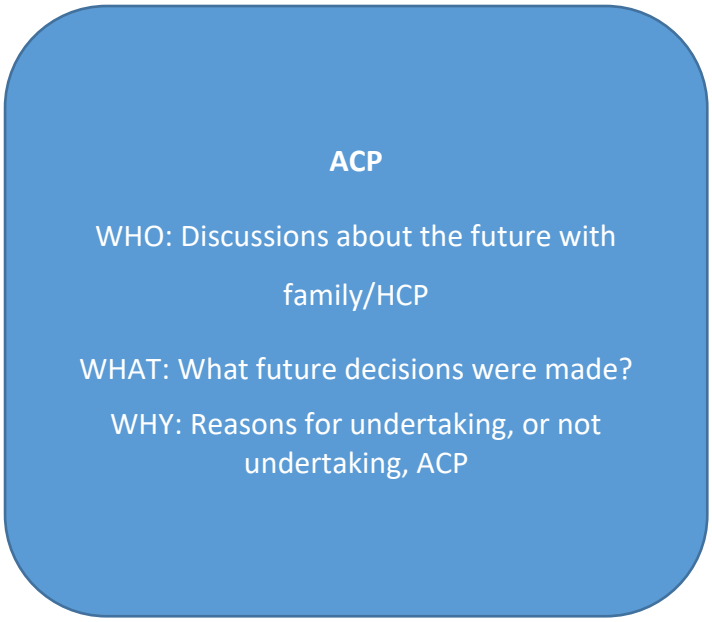

Figure 19 Components of ACP

5.1.3 *ACP (WHO) – within the family*

The ability to think about what the future might bring and whether people could discuss the future had the most impact on plans being made. There was little difference between people with PD, PSP or MSA in this regard. If there was disinclination to discuss the future then conversations about the end of life weren't had at all or they were mentioned only when a prompt appeared, for example, a TV programme about funerals. If there was a reluctance to think about the end of life from a carer's point of view this could shut down discussion and limited the making of plans.

"Helen: the way I looked after Tony was as if he was going to get better and that's how Tony thought, he was going to get better
CM: yeh he was fighting it each day
Helen: yes he did he fought it every day um he never gave in to it so I think for me to say well you know you're going to lose this battle what are we going to do would've floored him again and so, you know, I didn't" Helen (MSA)

Less often a person had made plans for the end of their life but did not want to discuss this with their carer.

"she was concerned for me and I think that's why when it came to issues of death and her condition that it was like getting blood out of a stone trying to raise the subject, so I left it alone" Paul (MSA)

As these quotes show, avoidance of the topic could be generated from either those with the diseases or their carers and often the reason people gave for being reluctant to discuss the future was a desire to protect the other person. There was perhaps also an element of self-preservation, as raising the subject was acknowledged to be difficult.

"it's a heck of a lot easier to avoid the question <where would you like to die?> isn't it and so would I actually have had that discussion or not, I don't know, it's difficult" Simon (PD)

If both parties were willing to discuss the future and what it might bring then plans, or ideas about what people would want, had more chance of being discussed and written down.

"we talked about death all the way through from day one you know and where he wanted to die. I wanted to know what he wanted to happen and he had a DNR put on his file from the very start and he wouldn't've had a feeding tube - he said 'when I get to that point that's it, I want to be gone" Elaine (MSA)

However, even when both parties were willing to discuss the end this didn't always translate into concrete plans; many people just didn't feel they were at the stage where plans needed to be recorded or issues such as POD needed to be discussed, as death wasn't imminent.

"P: well it's like everything else, you look at it and think well there's no problem, we haven't got a problem at the moment, we were muddling along and it didn't feel as if there was any immediate threat at the time" William (PD)

April felt it was this delusion regarding time that stopped discussions being had rather than the emotional difficulty that other carers had implied.

> *"My feeling is that people don't talk about dying because we all delude ourselves that we have plenty of time. Even when my mother was in the final stages of a degenerative disease, I did not grasp that death was so close. I think this delusion stops people talking, rather than fear of broaching a sensitive subject" April (PSP)*

This quote suggests that guidance about what the end of life with these conditions might look like would be useful. It may help people dying, or at least their carers, to know the end is approaching and to discuss the end and what those dying may want. There were triggers that indicated that the end of life was approaching in the narratives that some carers related but these did not appear to have been communicated.

Whether discussions about the future were delayed by a delusion of time, denial regarding prognosis or the sensitivity of the issues, the danger of delay was that by the time thoughts about recording plans came it was too late, the ability for the person with the disease to communicate (PSP/MSA), or make decisions (PD), was gone.

> *"Because she lost her ability to communicate quite quickly and we were slow on the uptake of talking about things before, we didn't really know what sort of care she wanted later on in life" Kate (PSP)*

Therefore, because of disease burden, there is a particularly pertinent timeliness element to making advanced plans for those with these neurodegenerative conditions. This is further evidenced by looking at the question in the VOICES survey that relates to decision making. Those with PSP, MSA and PD appear less able to be involved in decisions about their care in the last three months than those with cancer, cardiovascular disease or 'other' COD (see Table 8).

COD [number answering question]	He/she was not able to be involved in decisions regarding care in the last 3 months [n (%)]
Cancer [24716]	1807 (7)
Cardiovascular diseases [21671]	3452 (16)
Other [35690]	7865(22)
PD [989]	301 (30)
PSP [44]	23 (52)
MSA [22]	5 (23)

Table 8 Ability of the decedent to be involved in decisions about their care in the last 3 months of life, by underlying COD, England 2012-15

In addition, carers who's loved ones had completed ACP felt it was easier to discuss the end of life when you weren't confronted with the end approaching imminently and so earlier discussion was suggested as being beneficial from this point of view also.

> *"Talking about it when it is less critical early on in diagnosis was what my Mum had wanted to do - then it was put aside"*
> *Jennifer (PD)*

5.1.4 *ACP (WHO) – Healthcare involvement*

Discussion, and certainly recording of plans, was more likely when a person external to the family was involved. There were mixed feelings about GPs facilitating ACP. Some had found their GPs very helpful for talking through plans.

> *"The Compassion in Dying charity suggested that you involve your GP in writing the Decision <ADRT>. Mum had an appointment with him to talk it over and he made some suggestions and ensured she understood what she had written and the medical implications"*
> *Jennifer (PD)*

Others felt they did not have enough time or raised issues such as DNAR insensitively.

> *"we had no idea this lady <GP> was coming, she knocks on the door, she comes in with these pieces of paper and she said, 'you fill these in and then we will talk on the phone or I'll see you, no, no we'll talk on the phone'. So we don't know what they are and after we start looking at them it looks like it's some sort of advance care plan, well I know it is now and they wanted to discuss DNR and all sorts of things that Yvonne just did not want to discuss and so she is very upset" Peter (PSP)*

Despite Peter explaining that his wife had not wanted to discuss resuscitation, once she was attending the hospice day centre she was able to discuss the future and make decisions about what she wanted

> *"So what actually happened, we joined the hospice <as a> day patient, a wonderful nurse <name>, we spent 4 sessions with her, we'd take tea and she works her way through advanced care planning and Yvonne agrees a DNR order" Peter (PSP)*

Hospices and SPC services were often the facilitators of recorded plans as they were particularly skilled at navigating difficult discussions. The time, empathy and continuity they showed enabled plans to be discussed even with those who seemed initially reluctant to talk about the future. Some care homes had ACP built in to their admissions process, covering not just the practical elements of future care, such as DNARs or PEG tubes, but also emotional elements such as hand holding and music. When discussions had been had with these services plans were more likely to be recorded at an earlier stage and families were less likely to have delayed decision making. It may well be that specialist nurses help with future planning in some areas but this was not the case with the carers interviewed. Nor was there any guidance in the making of plans from movement disorder clinics, aside from suggestions to claim benefits because 'the illness is not cost free' (Stephanie PSP) and to 'do everything you want to do now' which hinted at the speed of progression for PSP/MSA.

5.1.5 *ACP (WHAT)*

As suggested above, the ability to gather information about the diseases and to discuss what their prognosis meant for the future affected what plans, if any, were made. For those with PD, because often prognosis was not raised, plans were made regarding a general ability to think about death in the distant future and were often not to do with PD but general ageing.

"We had got it <LPA[18] and PPOD> all sorted out well in advance when we made our wills ten years ago. There was no pressure to do it then, it just seemed a good thing to do along with the wills" Martha (PD)

Whereas those with PSP/MSA had been told their prognosis and so their plans were made regarding their ability to think about a time limited life and they were often more disease specific.

"do you know the next main watershed Claire was going to be whether she was going, when her swallow deteriorated enough, that she had to be PEG fed, Thelma didn't want to be, we discussed that with the speech and language lady" Philip (MSA)

DNAR was the commonest advanced decision across the three groups. Three people had ADRTs and several had LPAs, but by no means the majority. There had been some discussion about PPOD but rather than stating a preferred place more often people had discussed that they did not want to die in hospital or go into a care home.

"we promised her she wouldn't ever be alone, or live in a home, or die in hospital" Charlene (MSA)

Those with PSP/MSA were more likely to have discussed a PPOD than those with PD. Those with PSP/MSA had discussed PEG feeding more often than those with PD. This reflected the fact that PSP/MSA progress faster and swallowing issues occur earlier. Therefore, those with PSP/MSA had often been seen by speech and language therapists at an earlier stage and discussions about PEG feeding had been introduced by them. Brain donation was the one advanced decision that did appear to have been discussed in movement disorder clinics, it was discussed regarding future research for a cure. This was raised more frequently for those with PSP/MSA and many of those with MSA had agreed to donate their brains to research, seemingly because the MSA trust had sent out information about it.

[18] Lasting Power of Attorney – these documents allow a named person to make decisions on behalf of an individual should that individual lose the capacity to make decisions for themself

5.1.6 *Reasons for ACP (WHY) – being in control*

There was no difference across the diseases regarding the reasons that people undertook ACP. One of the principle reasons for undertaking ACP was to allow those with the diseases to maintain their autonomy; ensuring that decisions that were made about their care aligned with their wishes.

> *"When she wrote the Advance Decision and End of Life Plan it gave Mum the feeling of being in control - she said Parkinson's had taken so much control from her that the plans meant she could feel that she would be in control of the end of her life - through my voice and her written words" Jennifer (PD)*

Being in control of future decisions was the reason given in all three cases where an ADRT had been made; this and a LPA for health and welfare being the only legal way for a family to refuse treatment and ensure that their loved one's wishes are enforced. As discussed previously this is particularly pertinent in these conditions as the ability to communicate often becomes reduced/absent towards the end of life and advocacy becomes increasingly important. Carers found that knowing their relative's wishes helped them be sure that they were doing what their loved one would have wanted.

> *"If you have those confronting conversations with your loved one before the illness becomes really challenging then it makes things somewhat easier when the time comes. Ultimately for us it was about really listening to mum and hearing what it was that she needed, physically, emotionally, psychologically and spiritually" Abigail (MSA)*

This also allowed them to be advocates and ensure their loved one's wishes were carried out.

> *"I think we were open about it and we talked about it. I think that was definitely a benefit and I knew exactly what he wanted, and you know I made sure he got it" Elaine (MSA)*

However, unless a person's wishes were written down on a legal document such as an ADRT they were not always followed. Doctors' views did not always align with carers' and, unless a LPA was in place, carers' wishes could be overruled.

> *"I remember getting taken into this room and dad was crying and I was crying saying 'look there's just no point in her having it <a PEG tube>, if it gave her quality of life then fair enough' but they said 'no because she's not got any care plan, you haven't mentioned this before, we have to do it*

legally' and dad was like 'well I'm going to put a pillow over her head, don't give it to her' and it was one of these situations where it was really stressful… that's the sticking point in mums care it's the only thing that I felt completely out of control over" Kate (PSP)

In the case of this family and others who had not discussed the end of life, or made specific plans, there was some sense of regret that situations like this might have been avoided if they had been more prepared.

"One of my regrets is that I avoided discussing end of life care. He didn't want a PEG but perhaps two cycles of antibiotics and five weeks in hospital, all to no avail, could have been avoided" Stephanie (PSP)

5.1.7 *Reasons for ACP (WHY) – being ready to die*

Carers appeared to have more difficulties with being prepared for the end to come than their loved ones; almost all of those dying from the diseases, with only one or two exceptions, were ready for their lives to end.

"He had previously told his carer he did not want to live anymore and his quality of life was poor" Sandra (PD)

Therefore, although some plans were used to state a PPOD, or to improve the quality of the end of life through personal touches, one of the main reasons people wanted to make decisions, such as to refuse a PEG or complete a DNAR was because they did not want their life sustained when it had reduced quality.

"he didn't want a PEG put in to help with eating, as he had been advised, as he felt if he couldn't eat or drink without it then there was no reason to be alive" Nicole (MSA)

One of the reasons those with the diseases chose to donate their brains to research was to counteract how much the disease had taken away.

"at that time he could still communicate to a certain extent, he said 'well that's about the only thing I can do that'll be left of me that can do some good, that's the only thing that I feel I could do some good with at the end of all this" Aileen (MSA)

Although these quotes may suggest that hopelessness and loss of self were the main reasons that people were ready to die, there were not always negative thoughts associated with the desire for life to end. Some people found comfort in their faith.

"she had made the decision not to be resuscitated?
P: oh, yeh she did because she was quite a religious person and she never spoke to me um oh maybe up to a year before she died she did tell other people that God was waiting for her" Paul (MSA)

And in the thought that they were protecting their carer.

Sebastian: "she would ask our pastor occasionally and perhaps the week before 'is it alright to ask Jesus to take me now?' <laughs>
CM: but she wasn't saying that in terms of, because it doesn't sound like she was depressed
Sebastian: she'd had enough of it really yeh, no she wasn't depressed
CM: no, she'd just had enough of having it
Sebastian: yeh and I think she was also, according to my sister, a little concerned for me… she didn't want me to have to put up with it that much longer either because she could see that it was quite an undertaking doing what we were doing" Sebastian (MSA)

They were ready to go and therefore did not see the point in being resuscitated or having a PEG and made plans to refuse both accordingly.

5.1.8 *Reasons for ACP (WHY) - wishing to hasten death?*

A small proportion of people with MSA/PSP had mentioned euthanasia to their relatives or HCPs; there were no active mentions of euthanasia for those with PD, though a few had refused their medications in a tacit suggestion that they had had enough and wanted to die sooner. Rachel (MSA) and Dennis (PSP) had actively requested help to end their lives. Other people with PSP/MSA, like John, had planned to end their lives if things got worse.

"he said that he would stockpile pills or something, he would do something, before things got too bad" Aileen (MSA)

A couple of other people with PSP/MSA had mentioned the idea of 'Switzerland' in response to articles or television documentaries. Philip's wife, Thelma (MSA), had said that she wouldn't go to Switzerland but if her doctor offered her an injection the next day 'she would take it'. Interestingly though, he pointed out that her views appeared to change as the disease progressed and she never mentioned it again.

"the funny thing was that it was spoke about fairly early in the proceedings and after a while, probably still with three or four years to go, it was never mentioned again and there was a sort of a serenity about her and she never

ever talked about wanting to have an injection or whatever again" Philip (MSA)

As it happened Philip felt that Thelma had been given an assisted death using increasing sedation.

"CM: the implication you took from that, or the implication was, that they were sort of helping her to die?
Philip: yes
CM: ok that's what I
Philip: well I don't know what else you'd infer that you know when the first one is sort of easing her passage and she's still there and they look surprised and then they come back and they're adamant that this will be quick that its more of whatever it was maybe in a massive dose or whatever and it's to save her just lying in that state for any longer and it did happen quite quickly after that… That isn't something that I'm bitter about" Philip (MSA)

Yet what he was more upset about was that they had been told she was getting better and so her transfer to the hospice, her PPOD, was cancelled. Several other carers felt that their relatives had died under strong sedation. Although they did not necessarily feel it had hastened their death, they felt that if sedation helped their relatives be more comfortable, they did not have a problem with the fact they may have died sooner because of it. One carer, Julie, had joined 'Dignitas' herself having witnessed what her dad had been through with MSA.

Despite many people with the diseases being emotionally ready to die, most had not requested their lives be ended prematurely. There were those who had discussed the issue with their spouses and were against the principle of euthanasia, despite being clear they did not want to live any longer.

"Colin: Grace was absolutely determined she didn't want treatment, she wanted out broadly and that was that
CM: When you were saying she didn't want any more things had she ever brought up the idea of having her life ended early or anything like that?
Colin: no, no, that's an interesting question and it's a question I've asked myself, for myself. She and I had discussed over the years the Swiss thing and all the rest of it, possibilities, but I think, no she didn't want, she had never ever made any reference to that. She could have made some reference on an Ipad or something that would have sent me into a dither and a tizzy and all the rest of it but she didn't want it and she was not in favour of it in fact. I mean when she could discuss things logically she was

very concerned that people should be able, she didn't want people taking a decision for somebody to die, the risk of other people making a decision for the wrong reasons, so she was very much seeing it out" Colin (PSP)

When euthanasia had been mentioned, though it was not acted upon, it was sometimes considered when deciding upon medical intervention at the end of life

"Rachel had discussed with me many times the option of euthanasia, in the last stages she would have taken that option, indeed asking me to help her, which was something I could not directly do, but I was mindful of this when discussing the continued battle against infection with the doctor, and in retrospect, I believe it was the major consideration on our minds when making the decision to discontinue the heavy antibiotic regime she was on at the time. This decision ultimately led to her passing" James (MSA)

Interestingly though, a lack of intervention being attempted was one of the principle concerns of a hospice consultant who disagreed with Chris (PSP) about the wording of his ADRT, seemingly not understanding, from the point of view of Margaret, that her husband had already had enough.

"he wanted to make his own decision about the refusal of treatment, the ADRT form, well we had quite a few tussles with <the hospice consultant> because he said 'well what if he gets something like pneumonia, pneumonia is treatable, if he's in hospital we can treat that'. But Chris' attitude was for what, you know, that's the body's way of saying enough is enough… yes it's treatable but for what, you know, what gain was it going to be for him other than prolong his life, which was becoming more and more unbearable" Margaret (PSP)

The concern of the hospice consultant, regarding giving up too soon, was one of the reasons given for an avoidance of recording plans by a couple of carers.

"I discussed with the GP about circumstances where I might have felt that resuscitation wasn't right but you kind of worry about signing one of those forms where, I don't know, kind of mum had to go into hospital for another reason but say she developed an infection or something whether they'd feel well is it worth the treatment because a DNR's in place" Simon (PD)

And Stephanie explained that her husband had not wanted to donate his brain for research due to the same concern.

"I suppose in a way he's got the feeling that things will be stopped before you've had a, without the extra chance, how can I explain it, that things will

be taken before completely necessary and therefore your chances of living will be impaired you know" Stephanie (PSP)

And so a feeling that HCPs might not put in as much effort if they saw plans had been made was a reason for not wanting to record them, along with the difficulties in having the discussions to make plans in the first place.

5.1.9 *Preparation summary*

This section has presented the elements of preparation that people with these diseases make. There is some difference between PD and PSP/MSA as people with PD are rarely told that it could be life limiting, even when entering the palliative stages. However, even though people with PSP/MSA are aware the diagnosis will shorten their life expectancy the way that they prepare for the future is very individual. This is based in part on the information they are given and the opportunities they have for discussion with their family and/or HCP and in part on their own emotional ability to think about the future. Honest conversations at a reasonably early stage were a key component of allowing individual wishes to be maintained in the face of a decreasing autonomy through a lack of mobility, communication and cognition. Although a proportion of planning was down to the emotional preparedness of those with the diseases (and their carers) more guidance would have been welcomed from movement disorder teams so that they were aware of the type of decisions they might need to make and had more idea about the way the end might come. Whilst hospices were great at facilitating plans they are not always easily accessed (as the next few sections will show) and arguably it should not fall to them to have discussions about the future, when movement disorder teams may have more knowledge of the way these diseases progress and more access to those with the diseases at an earlier stage.

5.2 SUPPORT: Co-ordinated care

Co-ordinated care is vitally important for support, especially in the earlier stages of the disease when people are likely to be living at home. Indeed, a lack of co-ordinated support is one of the reasons that dying at home is achieved less often than might be desired. These diseases all have significant impact including loss of mobility, speech and sometimes

cognition, requiring increasing support to maintain everyday activities. The first part of this section will show the difficulties that people with the diseases and their carers encountered when trying to navigate the health and social care systems. It explains that people with PSP/MSA had a greater difficulty with co-ordination of care because they needed more help more quickly and their rarity impacted on the efficiency of the care provided. The latter half of this section compares those dying from PD/PSP/MSA to those dying from cancer as there were a few carers who had direct experience of caring for someone with cancer, or having cancer themselves, and the differing experiences they encountered were enlightening regarding the provision of services.

5.2.1 *Navigating the system*

This section is divided into healthcare, social care and the co-ordination of services (both within and between). Figure 20 below shows some of the services that people with these diseases might need and provides a guide to the following subheadings. Appendix I contains a chart that the PSP association produced suggesting the services that people with PSP require and the annotations by the carer show the difficulties with achieving their aims in the current system.

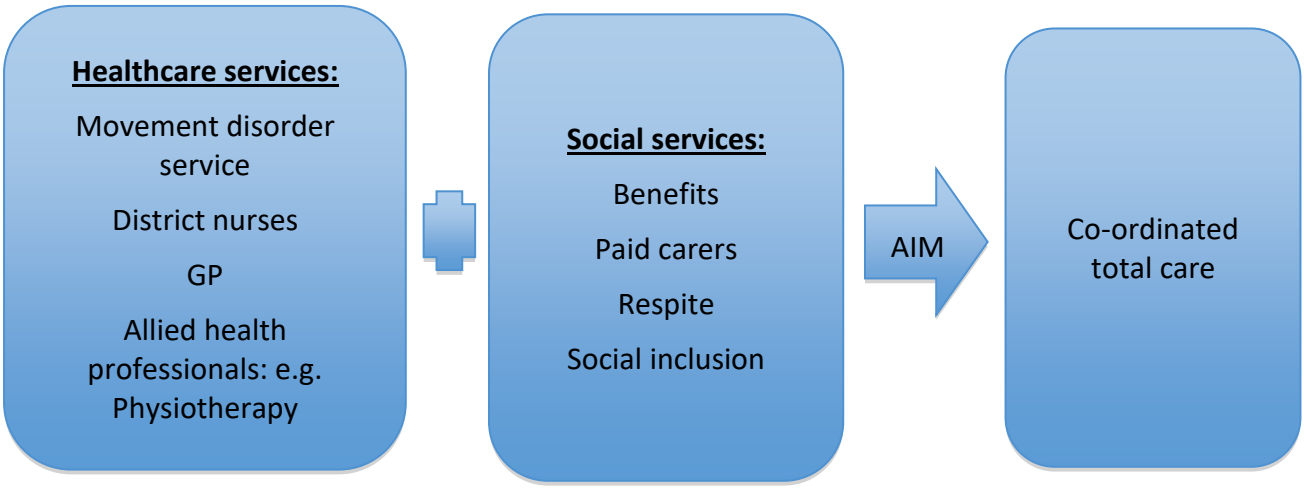

Figure 20 The components of professional/formal care

5.2.2 *Navigating the system – Healthcare*

There was a greater degree of frustration from the carers for those with PSP/MSA with regard to healthcare because the speed of progression meant that more equipment and services were needed, in combination, at an earlier stage than in PD. Some carers felt that

along with the lack of information they received about future progression there was also a lack of guidance about where to turn locally for support from HCPs, which left them feeling bewildered

> *"I feel it was misinformation, lack of information from the people that you thought would point you in the right direction and I just felt all of the time that I had to be the driving force and I was often asked 'what do you want us to do, what should we do' and I thought, I don't know, I've never had PSP, we've never known anyone with PSP, I don't know what to do…it's like being in a maze blindfolded, because you don't know which direction to take, you don't know which direction you're facing and you don't know which way to turn because you've never ever come across anything like it" Margaret (PSP)*

Even when those with PSP/MSA had been told that they would need physiotherapy, occupational therapy, speech and language therapy and help from other services there was a frustration that the NHS was slow to respond and that joined up care did not automatically occur.

> *"the most important thing we got out of the specialists was references to other appropriate specialists, but that required a lot of work on my part because the system was very unresponsive to someone with those needs and getting physiotherapy or whatever required me to be quite proactive which I found to be quite disconcerting" Charles (MSA)*

Only one woman felt that everything was organised for her husband in a smooth fashion and this had occurred because he had been referred to a neurological rehabilitation centre, where all services were co-ordinated from one place. Other carers were grateful for the kindness of the staff they did meet but getting access to them had been a struggle and had taken up valuable time.

> *"when you're at your least fit to do it you have to do all that sort of stuff and it's so time consuming and exhausting and although you could take your anger out on those sort of systems you really just want to spend time with your loved one don't you rather than having to do all of that and being in a battle" Kate (PSP)*

Several relatives took to carrying lists of all of the individuals involved with their loved ones' care, along with a list of their medications, and they handed them out to anyone new who was involved. But it had taken them time to realise it was down to them and that no-one else was going to do it for them.

"it seemed to me and I didn't understand this until I went through the process that it was like a spider's web, a web the connection between all the people and all the medications and all the processes that we went through and we were the spider and we didn't know that we were the spider and that we were controlling the web, no-one else was" Sebastian (MSA)

Quite often the healthcare system was referred to as inflexible, in stark contrast to the transport sector which several carers held in high esteem. Several examples were given of a lack of understanding regarding what it meant to care for a person with PSP/MSA. As PSP/MSA are rare, allied HCPs were often unable to educate carers and those with the disease about how it might affect them and they were not always clear exactly what was needed.

"the one thing <the consultant> said to us was 'you need to get everything in place early, these things take time to organise, people can't just jump when you need a piece of equipment or whatever or alterations to the house, so you need to get that started'. So we did go along that route quite early on but because they hadn't come across PSP they were, we didn't really get the right equipment at the right time" Margaret (PSP)

Those with PD still encountered problems with co-ordination, but this was often at a later stage and more often the issues were centred on social care provision; which was a problem across all three disease groups.

5.2.3 *Navigating the system - Social care*

Paid carers made a huge difference to the experience of those with the diseases and their relatives. They were often relied upon to make staying at home possible. The thing that helped most was co-ordination of carers and the continuity of the care team itself but getting care providers to recognise this was often a battle.

"it took a lot of banging on the door to really get what we needed and force it home to the care provider why we needed consistency of staff and the amount of calls we had and stuff and similarly with the social services team to get agreement for that" Simon (PD)

Social workers helped guide care in some circumstances but in others they told carers they were not eligible for funding and would not provide suggestions of care companies.

"the social worker was pleasant and she was here 90mins doing forms, 30 pages worth and at the end said 'do you have any savings' and when we

said yes she said 'oh we can't help you then' – I said 'you can't help financially but I need advice. If we had no money you'd be throwing things at me and advice costs nothing'. It was like having a door slammed in your face" Margaret (PSP)

Hospital stays often led to an increase in care, at least initially after discharge, but the on-going provision of carers seemed to be strongly influenced by location; because of the way carers were paid, they would sometimes only stay 5-10minutes of a 30minute call to allow for travel time, a particular problem for those in a rural location.

"I suppose it wasn't the carers it was the system; he <the paid carer> would come to us in the morning and his next port of call was half an hour away but he wasn't allowed time to travel so of course he came, looked at Donald, 'are you ok?' and then off again and that wasn't fair because we were having to pay for it" Betty (PD)

Some had services cancelled as they lived too rurally, leading to further isolation.

"the agency that were providing the care pulled the plug on us and said that they didn't want to come out to this, to our rural village, because she could have, deal with more clients in the town without having to allow for travel time. So, from then on, I was totally on my own. Yeh, pretty mean" Angela (PD)

Location, in terms of regional variation was also mentioned regarding continuing healthcare (CHC) funding and it certainly seemed that some people received the funding very readily whereas others battled multiple times and were still not awarded it.

"I mean it is really a postcode lottery as to where you live as to how you're going to be treated at the end of life and she <sister in law also caring for husband with PD> got continuing care allowance, she got good district nurses and I battled for continuing care three times and every time they told me that unless he had skin lesions or that he was going completely mental and violent they wouldn't give it me. But they just took one look at <brother in law> and they didn't even fill the forms out, so she got round the clock care and back up nurses and district nurses. I mean here it takes you four days to get a district nurse, she got one in 20 minutes, so it really is a postcode lottery as to what you are going to get" Pam (PD)

CHC funding was mentioned a lot as being very difficult to get in most places and for all the diseases, with several carers explaining they were only awarded it retrospectively after their loved ones had died.

With mum we did get the continuing healthcare but that was only, we got that after she died and we got money back retrospectively and I only knew about that because by this stage I think I was googling so much stuff and I rang and they said 'oh its highly unlikely you'll get it' so I said 'well I've looked at the prescription online for what you are supposed to qualify and I think she does' and they said 'well it will be very difficult' and I said 'well despite it being very difficult I would like to have a go at it' Kate (PSP)

The ability to get CHC funding was aided by hospices and hospitals, especially if they co-ordinated with movement disorder teams or the charities that represented the diseases.

"the CHC approval had come through, I mean that went through so quickly it was unbelievable. They never questioned it and I think it was beneficial to me in that the hospital submitted the application so they knew exactly how to do it but they also did it with advice from the PSP association helpline nurse because the hospital had not really dealt with anyone with PSP before but they were terribly willing to learn" Hope (PSP)

Given that CHC funding means that all of a person's care provision is paid for by the NHS, getting it awarded had a huge influence on the level of care provided and consequently affected POD. Those awarded CHC funding were able to have a greater number of paid carers coming into the home, or even live-in carers. Despite the problems with co-ordination this brought, these carers were then available for the end of life period, allowing those dying to remain at home.

"we kept her at home and we managed to get carers, or a series of full-time carers using the NHS continuing healthcare system, so that worked very well. They were good kind girls who looked after her very well, looked after her physical needs, including in the end feeding her. It sort of left me free to get on with organisational matters of which there were quite a lot at the time" Charles (MSA)

Whereas those without funding had to rationalise additional care

"I was paying for an overnight sleeper from 10pm to 6am on Monday, Wednesday and Friday, that was basically all I could afford because that was £100 a night and the carer was 7 days a week" Pam (PD)

and watch their savings rapidly decrease.

"in the end the money doesn't matter it's just that there's none left, that's all" Peter (PSP)

On top of that, those in government systems had such little understanding of the diseases, especially for those with PSP/MSA, that benefits were delayed or refused

> *"Aileen: it was just horrendous the things that like the benefits agency put us through and things it was just absolutely horrendous*
> *CM: yeh*
> *Aileen: you know saying that John would be fit to work in a year's time*
> *CM: oh my god*
> *Aileen: you know I had the assembly minister and the local MP involved with that one because it was such a scandalous way to behave*
> *CM: so frustrating*
> *Aileen: yeh, yep, but I was worried, at that time I was worried that he wasn't going to get his pension coz he had to pay stamp so they were insisting that he went into the job centre to sign on <laugh> oh it was just horrendous"*
> *Aileen (MSA)*

One carer, Julie (MSA), even had to declare bankruptcy because of the money she had spent in order to care for her dad at home.

5.2.4 *Navigating the system – co-ordination across services*

Problems with organising and accessing health and social care were intensified because most people, especially those with PSP/MSA, needed access to both. Generally, carers felt that they had encountered a fantastic range of individuals working within the NHS and social care, but what they felt was lacking was co-ordination between them all.

> *"whatever the NHS is, it's very good, it's excellent but it's very slow… I had carers early morning and in the evening to help get her to bed but they only sent one carer so I had to do it as well, the adult services provided a gantry in the bedroom which was good…there was the bowel nurse, the wheelchair service that came out to us a couple of times, the district nurses provided the bed. Why does nobody I ask myself, and one of my big questions is there is no co-ordinator in the NHS and that's really what, I was then a) in a fog but b)I co-ordinated it broadly" Colin (PSP)*

It was common that the person who had to co-ordinate everything, bringing health and social care together, was the carer, which led to further exhaustion on top of the lack of sleep they were often already experiencing.

In addition, because navigating the system of health/social care was such a struggle, carers were concerned about how their loved ones would have coped without them and similarly how anyone with these diseases would cope if they did not have someone to do it for them.

"I must admit I do have sympathy and worry for people with Parkinson's who maybe don't have people around to shout their corner because whilst we did have wonderful care and stuff if we hadn't fought for it, we wouldn't have got it and that's a concern I think, because more often than not, people develop Parkinson's in a later stage of life and so say family have moved away and they don't have people around, it's left to them, and with them fighting against an illness like that as well, it's a lot to ask" Simon (PD)

One of the problems was a lack of any particular person or team to co-ordinate NHS services and Pippa suggested that it would be useful to have a single care co-ordinator to help.

"My mother had two breakdowns as a consequence of trying to care for my father and that was with carers 4 times a day, it is horrific to watch and be left helpless. Perhaps having a care coordinator or an advocate to do this properly liaising with the different services, social service, OT, mental health, Parkinson's nurse/consultant who meets with the patient at home once a month to discuss current condition, monitor status and gain the additional help and resources from other services when needed <would help>" Pippa (PD)

GPs did not always know enough about the diseases to co-ordinate well and when they did their time was limited. Movement disorder teams often saw people 6 monthly at most and were sometimes geographically remote from services that were local to those with the diseases. Specialist PD nurses were often reported to be without fault and relied upon in the latter stages. They were even more highly prized when they helped to co-ordinate services.

"the Parkinson's nurse was very helpful to us here at home…she was very kind, she organized things from the hospital like equipment etcetera she also helped us as far as what was available from the National Health, what was available from everybody else, you know she helped fill in forms and she was great" Vincent (MSA)

But quite often those with the diseases and their carers had not had access to a specialist nurse, either because they had never been referred (PSP/MSA) or because nurses had left and were not replaced.

"Graham's Parkinson's nurse was very good actually but unfortunately she left <8 months> before Graham died, so for the crucial last month I didn't have any help in that respect" Angela (PD)

Some people had community matrons to help. But most often praise was for hospice teams and their day centres, whose involvement led to everything running more smoothly.

> *"For us the key thing is that hospice referral. That made a huge difference. Continuing healthcare we failed. Say we went through that journey and we hadn't had the hospice, I just don't know what we would have done, I really don't know what we would have done without them" Peter (PSP)*

Unfortunately, even here there was a difficulty in accessing the service; often it was word of mouth that led to hospices being contacted by carers.

> *"Stephanie: the hospice has been extremely good and very kind but I wish I'd known about it before because I just thought, I didn't really realise that their remit also included PSP*
> *CM: the GP or the neurologist, they hadn't mentioned the hospice or anything?*
> *Stephanie: no, no-one had, only my sister-in-law, she was the one that went on and on at me about it" Stephanie (PSP)*

Most hospices were glad to help once contact was made but there was a lack of automaticity regarding SPC/hospice referrals.

> *"CM: did you get any help to look after him?*
> *Susan: no, he wouldn't have any…one of the things I used to think was if I could just get somebody to sit just for half an hour so I could get away*
> *CM: did he ever get links into the hospice or day centres?*
> *Susan: no, nobody ever suggested anything like that" Susan (PD)*

This was in stark contrast to experiences some of the carers had had in regard to other illnesses.

> *<at PSPA group sessions> as soon as you hear someone is getting something then you can go off and search for that yourself but it's not an automatic thing… it is available for people but it's not like a necessary, oh you've got this so go to a, b and c and then you'll get d, e and f. It doesn't work like that, whereas it certainly does with other illnesses Kate (PSP)*

5.2.5 *Comparison to Cancer*

Several carers mentioned that they noticed a stark difference between the provision of support for people with cancer and people with PSP/MSA/PD. They had either had cancer themselves or cared for a family member with cancer, and they saw that support services could work well together in a more co-ordinated fashion.

> *"to be quite honest with you Claire, having faced a stage 3 cancer myself and knowing the response of other people and the range of treatments and services and everything, I know which I would rather be diagnosed with to be quite honest, I would you know. I think that there is so much more out there for people with conditions like cancer than there is for the people with the neurological nasties" Hope (PSP)*

Carers who had experienced both diseases compared the battle they had getting help for PD/PSP/MSA to care that just 'flooded in' for cancer.

> *"When my Mum was diagnosed with terminal cancer people came crawling out of the woodwork to help. Community Nurses, MacMillan, Admiral, Hospice, you name it they all made contact - we were even given free parking at the hospitals for appointments! Everything that could be done to make things a little easier, was done, the support network was amazing right to the end. This was a GOOD DEATH. PSP the basics are; no support network, HCP had no idea as they haven't heard of it, constant confusion, lack of structure/guidance. No one even knew if it was End of Life, it took over 10 days to be referred to Palliative Care Team. This is only the tip of the iceberg. This was a BAD DEATH!" Samantha (PSP)*

Whilst this is the perception, this is not confirmed by the VOICES data. Figure 21 presents the data for question 3 of the VOICES survey (see Appendix B). In regard to people who had spent some time at home in the last 3 months there is little difference in services utilised between those with cancer and those with PD/PSP/MSA.

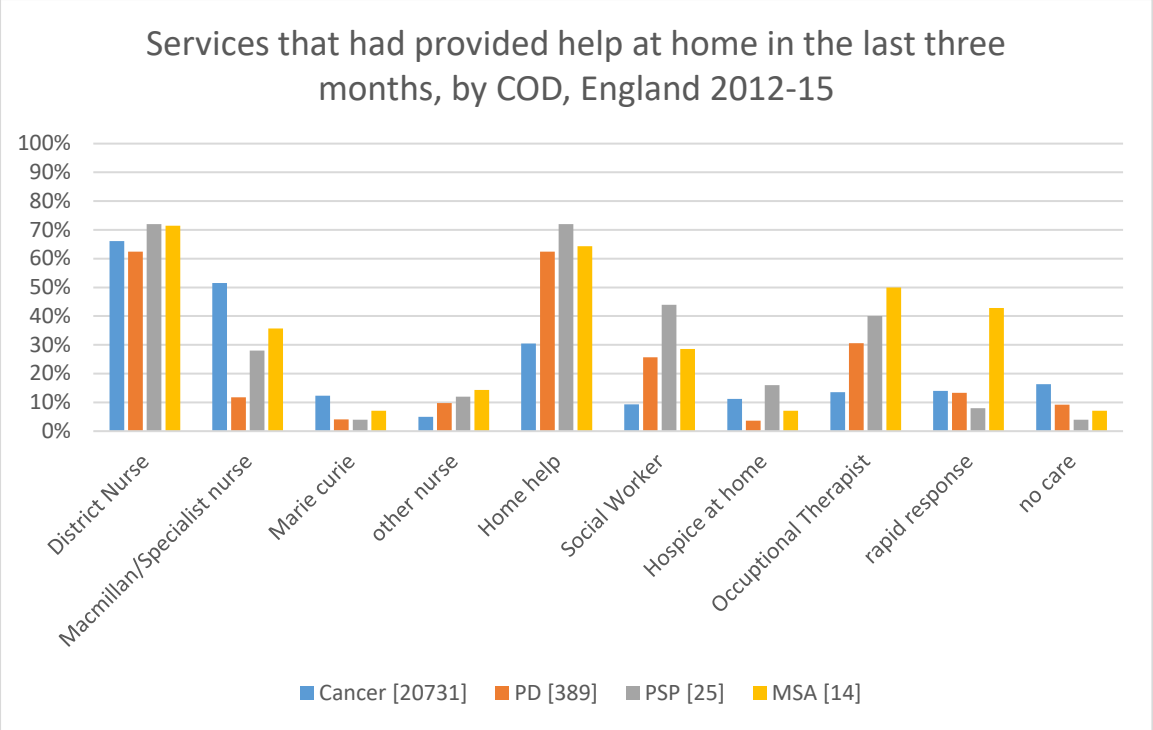

Figure 21 Services that had provided help at home in the last three months of life, by COD, England 2012-15

There were no significant differences between the diseases regarding district nurses. Those with cancer were significantly less likely to have seen 'other' nurses than those with PD. However, this may be due to their increased use of cancer specialist services: Macmillan nurse [Cancer vs PD OR 7.91 (5.81, 10.78) p<0.001; Cancer vs PSP OR 2.73 (1.14, 6.54) p=0.24] or Marie Curie [Cancer vs PD OR 3.28 (1.99, 5.42) p<0.001]. Those with cancer were statistically less likely than those with PD/PSP/MSA to have had Home Help, a Social Worker, or an Occupational Therapist (see Table 9).

Service received	**Cancer compared to:**		
	PD [OR (CI) p value]	**PSP**	**MSA**
Home help	0.26 (0.21, 0.32) <0.001	0.17 (0.07, 0.41) <0.001	0.24 (0.08, 0.73) 0.011
Social worker	0.30 (0.23, 0.37) <0.001	0.13 (0.06, 0.29) <0.001	0.26 (0.08, 0.82) 0.021
Occupational Therapist	0.36 (0.29, 0.44) <0.001	0.24 (0.11, 0.52) <0.001	0.16 (0.06, 0.45) 0.001

Table 9 Likelihood of people with cancer receiving services at home in the last 3 months compared to those with PD, PSP or MSA, England 2012-15

A larger proportion of the carers of those with cancer answered that no care was needed, which may be why this is the case. Carers who had cared for people with cancer and PD/PSP/MSA explained that they felt those with cancer remained able bodied for longer, perhaps explaining the reduced provision of Occupational Therapists, Social Workers and Home Help.

> *"I looked after my mum for 10 months with terminal cancer… looking at caring for her and caring for Stephen, I mean she had terminal cancer and yet it was much easier caring for my mother, it was nowhere near as bad as caring for Stephen coz even though she'd lost so much weight and everything she was still going up to bed every night" Elaine (MSA)*

However, when carers were asked in Question 5 of the VOICES survey if they had received as much support as they needed when at home in the last three months of life, all groups responded similarly, as Figure 22 shows.

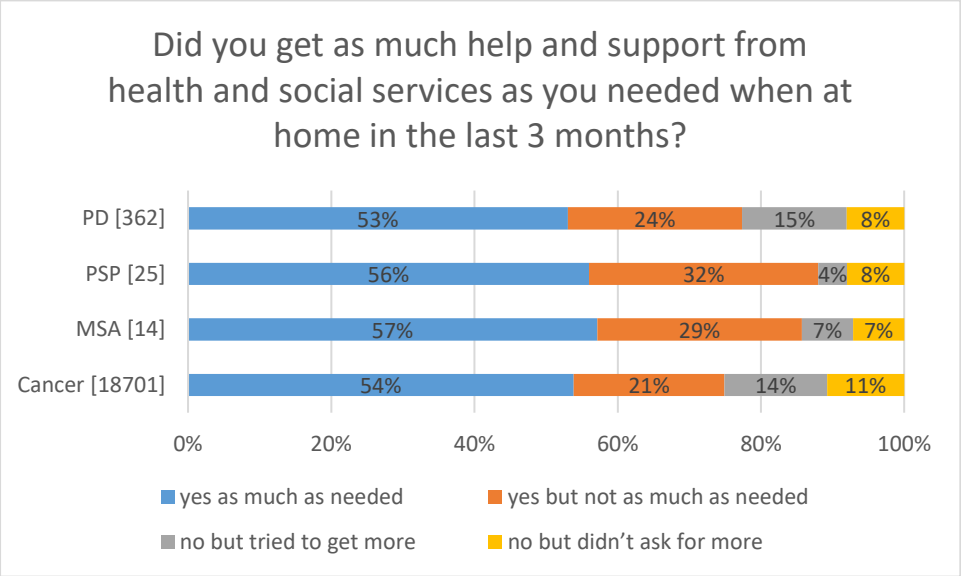

Figure 22 When at home, was support adequate in the last three months of life, by COD, England 2012-15

Here though it is worth remembering that the VOICES survey only looks at the last three months of life and the people still living at home with these conditions, by virtue of the fact that has remained possible, will likely have a lot of help in place.

> *"I had said to Elizabeth when she was first diagnosed with MSA that she would not go into a nursing home if we could possibly avoid it. I didn't know then how difficult this would be. To do it you must have plenty of extra support. Apart from the Carers you need a GP, District Nurse and OT who are all keen to support nursing in the home. This we had" Cecil (MSA)*

It may well be that those who had poor provision of services had already moved to a care home, or elsewhere, by this time. Certainly those with cancer were more likely to have spent some of the last three months at home (88%) than those with PD (41%), PSP (57%) or MSA (70%). In addition, the difficulties relayed by the carers of those with PD/PSP/MSA were not necessarily that they had not got the help in the end, but more that it had been a long time coming.

> *"we had the district nurse coming in every 24 hours to do the syringe driver so we only had that for I don't know six or seven weeks, it wasn't long at all, everything was just too late, you know things could have been perhaps more comfortable for him uh if they had been done earlier" Margaret (PSP)*

Those who had experienced caring for someone with cancer felt that they could be left alone some of the time, whereas caring for someone with PSP/MSA/PD was a 24/7 job, often for years, making the physical, mental and monetary costs larger.

> *"Parkinson's is a very long, drawn out grinds you and them down disease with masses of different little side effects, whereas the people who had nursed people with cancer, it was usually a matter of weeks or months. The person with cancer remained mentally and often physically quite capable of managing themselves, they could be left you know, it was a question of pain management more than anything. They didn't have all the horrendous side effects and caring duties that the people with Parkinson's had to face and for years you know, so I do think it's very different" Angela (PD)*

On top of that there was no way of knowing how long the disease would last and the uncertainty made caring even more difficult.

> *"you know that there's an end to it almost with cancer, you know that, but with Parkinson's you're just sort of living through this on a day to day basis you don't really know what's going to happen, how many years it is going to be, what's coming next. It is a much harder thing to cope with" Pam (PD)*

5.2.6 *Support summary*

Overall carers felt that although the needs that their relatives had were high, there was a lack of co-ordination in place to respond to them in a proactive manner. There was no single person, or service, who co-ordinated care and so the onus was on the carer most of the time and that was a struggle which didn't seem fair when it appeared to occur more rapidly and cohesively for those with other diseases. In addition, cancer funding into

research was felt to be high, as was the publicity surrounding it, so there was no struggle with recognition, whereas some of the difficulties in navigating the system were felt to spring from a lack of knowledge about what those with the diseases needed. This lack of knowledge will be presented in the next part of the chapter.

5.3 IDENTITY: Knowledge of disease and community support

This section presents the frustrations that carers felt about a lack of disease knowledge being present in the healthcare system and discusses support from communities. Chapter 7 explains in detail how these findings have an impact on identity. It is presented in this way within the thesis as the theme of identity was developed more fully after the initial analysis was completed. Though studies often focus on one aspect of identity, such as the personal 'self' or societal views, Schwartz et al (137), in their textbook on identity, explain that each will play a role in the overall identity of a person. They explain that an individual's total identity is made up of their personal, relational, collective and material identity (see Chapter 7.2 for definitions). This section presents data that can affect all these aspects. It also indicates that a disease identity/label can become important in itself, especially when a disease is rare.

5.3.1 *Knowledge of disease amongst HCPs: introduction*

A lack of knowledge was more of an issue for those with PSP/MSA as their rarity meant there was little understanding in existence about the diseases; most people had not even heard of them. In contrast most people had heard of PD, even if they were not always aware of the challenges that having the disease brought. Carers felt more knowledge about the diseases, would have allowed HCPs to provide better care. When HCPs had knowledge about the diseases, confidence grew, and when HCPs did not know, but tried to find out, their effort was appreciated. Carers also found that empathy grew when knowledge increased. When no effort was made carers were upset by the lack of interest in their loved one, and what they were going through, and they became scared to leave their relative.

They felt isolated and frustrated due to a lack of knowledge which caused problems both during the time they were caring for their loved one and during their bereavement.

Knowledge about the diseases therefore affected service provision, education, empathy and support, as shown in Figure 23.

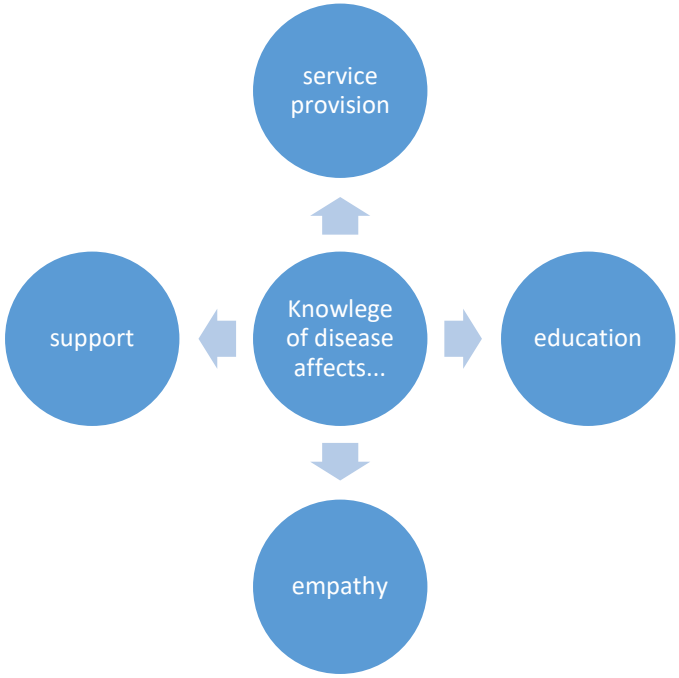

Figure 23 Aspects of care affected by knowledge of the diseases

5.3.2 *Knowledge of disease amongst HCPs*

One of the reasons that PSP/MSA carers wanted there to be more awareness amongst HCPs about the diseases related to a desire to get an earlier diagnosis to enable proactive planning.

> *"what they <people with PSP> do need is to get in front of a speech therapist and to be looking out for falls… so I think there are amelioration aspects of those who have it which mean an early diagnosis is important and an early diagnosis is only possible if the relevant people know enough" Colin (PSP)*

However, even with proactive planning, the lack of knowledge about PSP/MSA amongst HCPs often affected the quality of any support that was received, because it did not meet requirements.

> "when you have clinicians who don't have any understanding you really are on an up-hill battle with it. It's very, very, very hard. There just isn't enough known about the business and the impact that it has… It was the same as when they are talking about care in the home, they think that the patient sits in an armchair all day or lays in bed all day. They've got no concept of how PSP affects you, they have absolutely no idea, the same as physiotherapy and so forth*" Constance (PSP)*

For those with PD, knowledge was felt to be lacking regarding specific issues such as medication, with the importance of timing and the differing preparations frequently misunderstood.

> *"I said 'well I brought them in, you can't get hold of these Parkinson's drugs that easily', 'oh well we'll get some tomorrow' and I said 'well that's not good enough he needed them now'; some nurses actually understand about Parkinson's drugs but a lot of them don't" Pam (PD)*

The other area where lack of understanding was frequently mentioned, across the groups, was regarding mobility; several PD carers explained their spouses had lost their mobility in hospital.

> *"they didn't keep him on his feet and then he just went off and at the hospital it used to take three of them to see to him because he just couldn't stand on his feet properly" Susan (PD)*
> *[Prior to being admitted to hospital Jacob used to walk with Susan to the shops and back]*

Indeed, the only negative comments about hospices were regarding problems with mobility during respite stays. Jade (MSA) had lost her mobility because she had not been helped to walk in case she fell and Tony (MSA) had developed a pressure sore through not being moved. Both instances were felt to be due to a lack of knowledge about the disease.

Happily, for those with PD, knowledge was growing through PD nurses providing education within hospitals and that had improved the situation somewhat.

> *"having our nurse based at the hospital has made a massive difference because all the wards have got information packs about Parkinson's and if anybody has a planned admission she can go up to the wards and prepare them in advance as well" Brenda (PD)*

The PD nurses also helped carers and those with PD to learn more about it, as did a range of other people.

"I learned about end stage Parkinson's and what to expect through PUK factsheets, speaking to a Parkinson's nurse and The GP who cared for Mum at the nursing home, and also the Nurse at the nursing home and the carers there who were very Parkinson's aware" Jennifer (PD)

In contrast there was limited information that carers and those with PSP/MSA could learn from the HCPs that they encountered.

"just about everybody we spoke to they were just as much in the dark as I was basically and we just didn't fit into the mould of cancer, Alzheimers, all these things that everybody knows about" Margaret (PSP)

This lack of knowledge meant that the majority of PSP/MSA carers became experts themselves, through the internet and the charities, and had to spend their time being educators to professionals.

"I had a book and every time she had to go to <local hospital>, various people would come and I'd say 'have you heard of MSA?' and they'd say 'what's that?'
and I'd say 'multiple system atrophy'
'no'
so I'd give them a book… I was dishing these books out like confetti almost" Paul (MSA)

Some carers found this frustrating and the lack of continuity present in the healthcare system, discussed in more detail in Chapter 6.1.2, only made it worse.

Not all carers found the lack of knowledge frustrating. Several pointed out that the rareness of the diseases did make awareness difficult, it was the apparent reluctance to learn more about the diseases that carers sometimes encountered that caused the most anger.

"what annoyed me Claire is that neither of the doctors were prepared to just, I know they were busy, I know they were pulled out and all the rest of it but I thought just for the sake of a phonecall <to the neurology team> you know you can understand more what my husband's going through coz nobody had a clue" Elaine (MSA)

An increase in sensitivity was noted when HCPs knew more about what the illness might bring.

"I mean, you would go into your GP and you get your 7 minutes and out. It's not good. I said to the GP, 'PSP explains it' she said 'what's that?', but when

they knew that she had what would be considered a terminal diagnosis and it was serious, then they actually became kind" Colin (PSP)

But when HCP's understanding remained lacking, seemingly affecting the ability to empathise with what those with the diseases were going through, carers were reluctant to leave their loved ones in healthcare settings as they felt their needs might not be met. This meant that confidence went down as the sense of being alone and unsupported increased.

"We encountered many GPs who had little or no knowledge of the illness, it only added to my sense of isolation" Stephanie (PSP)

What helped were the places and people who tried to learn more about the diseases. Several services, including hospices, care homes, GP practices and care team managers sent staff on courses to learn more, which was highly appreciated.

"the care was absolutely wonderful and they even set up an afternoon for their staff in staff training for dealing with PSP" Hope (PSP) [regarding a community hospital]

Places where knowledge of the diseases was high, such as neurological hospitals or research centres, were found to be more supportive early on because of the increased empathy they showed and the confidence they brought. Interestingly, however, one carer with experience of a specialist neurological care home found it to be impersonal and too concerned with health and safety.

"When its meal time, you will have to hang on and it may be 15 or 20 minutes before we can take you to the bathroom, but 'no your wife can't take you because of health and safety issues'… it's dehumanising for anybody" Constance (PSP)

She felt they knew of the disease but could not see the individual through it enough to change their set routines, which was in stark contrast to her husband's previous hospice stay. Another lady, Gail, had tried respite in a neurological care home but preferred the 'normal' care home she'd been to instead as it was more personal and had a less clinical environment.

"what she didn't like about it actually was a) it was bleak, that's to say there were no carpets, which is intelligent really for a hospital but nevermind, it doesn't feel like home" Colin (PSP)

Colin also felt that empathy wasn't as forthcoming in the specialist home as at the place his wife chose suggesting that inherent knowledge of a disease does not necessarily improve empathy, and that when an environment becomes more clinical it may in turn become less homely. Striking the right balance may be difficult.

It seemed that the type of knowledge needed altered as the diseases progressed, with personal identity outweighing disease identity as the end of life drew closer.

However, even after a person had died knowledge of their disease seemed to be important to some carers. Moira (PD) mentioned that it might have been useful to speak to someone with knowledge of PD after her husband died. Certainly it seemed that a discussion with someone who knew about the diseases may have been useful for others carers as well. For example, Vincent (MSA) was shocked when he discovered, in the course of his interview, that sudden death was a feature of MSA, but he appeared to be pleased to have found out.

> "I mean the fact that you've enlightened me over this sort of dying without any notice has helped me a lot it really has, that was like winning the football pools if you like because I was sad and annoyed and disappointed and all of the negative things that you think about that I wasn't there and I blamed all sorts of people, not face to face, but in my mind I blamed the doctors and the nurses, why didn't they phone me earlier etc etc etc but it's quite possible she put her head down on the pillow and went to sleep… and that to me, you know, you have helped me tremendously*" Vincent (MSA)*

If someone in the hospital had known about MSA and been able to explain that death could occur suddenly, it may have eased aspects of his grief, whereas he was actually faced with a doctor who had not heard of MSA and so was not going to write it on the death certificate and, in his eyes, didn't seem to care that it might be important to him.

> *"I mean even then, nobody seemed to care… if that makes sense to you, she hadn't done any research, she didn't know what I was talking about…but it's this lack of um interest you know just another person, just another bed number and you're talking about end of life and that hurt me probably as much as the doctor asking me if, or telling me they wouldn't probably, resuscitate her if if she got to that stage" Vincent (MSA)*

Vincent felt MSA should have been on the death certificate to reflect the battle Beatrice had been through, he was proud of the way she had fought. A couple of other carers shared this

view and felt that the diagnosis was only put on the death certificate because they requested it.

> *"CM: what was your sort of rationale for it needing to be on the death certificate?*
> *Kate: I think I just wanted it to be recognised that mum didn't die just because she was of an elderly age and I think I wanted it to be shown that she had an illness… she didn't just get pneumonia and not get well from that, the reason she couldn't get better and because she was for so long, I mean I'd actually forgotten what my mum was like for ages, it's taken me a long time to remember better days because it's so consuming and so awful at the end…I'll never forget how difficult that was so I think probably it is linked to that, you want it acknowledged that the last bit was really difficult" Kate (PSP)*

It seemed therefore that having the correct diagnosis on the death certificate mattered to some carers because it helped to preserve the identity of their deceased relative. Alongside acknowledgement of what a battle the illness had been Kate, and others, felt getting the correct diagnosis on the death certificate was important to further raise awareness of the diseases themselves.

> *"CM: So they hadn't put PSP on the first death certificate?*
> *Constance: No, no and my understanding is that quite often this is the case*
> *CM: what is your feeling about that?*
> *Constance: Well I think it's wrong because unfortunately if you get a diagnosis say of bronchitis or pneumonia or COPD then you are never going to get the right statistics, you are never going to know whether its PSP or whether its Parkinson's you know, MS, unless you actually get the first cause of death then you will never really get the root cause of the effect that these illnesses <have> and the number of deaths that are linked to these illnesses" Constance (PSP)*

5.3.3 *Knowledge of disease: summary*

There were definite differences related between the diseases when it came to professional knowledge. Those with PD were able to be educated by professionals they met, not just movement disorder specialists but care home staff, GPs and paid carers who had previous experience of caring for others with PD. The only area that was mentioned as lacking, predominantly amongst hospital staff, was an understanding regarding the importance of medication timings and mobility. In contrast, PSP/MSA carers felt that almost all of their

encounters with health and social care professionals were affected by a lack of understanding with regard to the disease, which increased isolation. So, where PD carers might fight for knowledge about aspects of their disease, PSP/MSA carers fight for a knowledge of the disease's existence.

When HCPs had knowledge of the disease identity it could help maintain an individual's identity in several ways. Practically it meant that they were often able to remain independent for longer if the right help/medication/equipment was in place, maintaining their sense of self (or personal identity). It also meant they were more likely to be able to stay at home, maintaining some material identity and relational identity. Emotional support was more likely when HCPs had knowledge of the disease as they showed more empathy and a disease label allowed carers to maintain the identity of their relative as a strong independent person who was battling an awful disease.

5.3.4 *Community support: introduction*

The first part of this section explains that because services did not always react proactively, or with empathy, carers relied on their community of friends and neighbours for support. This helped them to keep their loved ones at home or show them that they still mattered once they were in care homes, helping to maintain relational and collective identity. However, this section also explains that some carers noted a reduction in visitors as their loved one's deteriorated, which Chapter 7 will show could have impacted on their sense of self. The lack of knowledge encountered, by those with PSP/MSA especially, meant there was little public understanding about what they were going through. The latter part of the section therefore explains that the respective charities became lifelines in terms of information, guidance and camaraderie and several of the carers continued to attend their group meetings after their loved ones had died, as if they had gained a sense of collective identity from them.

5.3.5 *Community support*

Due to the difficulties in navigating the health and social care system and a lack of HCP's knowledge, those with the diseases and their carers relied on their community to help them manage.

> *"we cared for him for so long at home with not much support other than friends and family because doctors and specialists didn't know what the hell MSA was" Julie (MSA)*

Local services, such as transport providers, were relied on to get by and quite often they responded more quickly, and showed more empathy, than HCPs. There were many examples of friends and neighbours who helped and reduced the isolation that the diseases could bring.

> *"we were very lucky in so far as we had really really good neighbours who had helped me on a number of occasions because he had fallen in the garden and they helped to get him up" Stephanie (PSP)*

Some friends made efforts to include those with the diseases in their usual activities, for example they moved the locations of coffee mornings into their houses. Unfortunately, however, there were also several carers who explained that there had been a reduction in callers because people could not handle facing the disease in front of them.

> *"I think along the way, some of the symptoms they can be quite difficult, and I know mum and dad lost lots of friends really because they just found it too difficult to see mum the way she was and so your world gets very small" Kate (PSP)*

This avoidance by some friends and family added to the isolation brought about by the diseases themselves, due to immobility and loss of communication, and persisted beyond the death for carers because they did not want to reconnect with the people who had let them down.

> *"So many people just disappeared but funnily enough reappeared at his funeral all balling their eyes out and all that and I just couldn't give them the time of day I'm sorry, no way… you weren't there when he was alive so don't start crying now" Aileen (MSA)*

This was potentially detrimental to their grief as it was predominantly family and friends that carers relied on to help them in their bereavement (discussed further in Chapter 6).

PSP/MSA carers felt that a lack of public awareness about the diseases reduced the support and empathy they might have been automatically shown if their loved ones were suffering from a better publicised disease.

> *"I think it would be nice for people to know what the illness is, just for, you know, like everybody knows about motor neurone don't they, but when you say you had PSP it's nothing really, because it's just a collection of letters isn't it" Stephanie (PSP)*

PD carers also felt that more empathy might be shown if public information about the condition was more representative of the actual problems that occurred.

> *"when Parkinson's is publicised both through charities like Parkinson's UK and through the NHS and other means so much of the emphasis is put on sort of the more common symptoms such as stiffness of movement, freezing, tremor all those kind of things but so many other symptoms, like dementia, like swallowing problems, drooling, constipation all of those kind of things which really have a massive effect on quality of life never get really discussed in as much detail as potentially I think they should… if people think it's just living with something that causes difficulty getting to the shops, maybe they don't fully understand what an illness it can be"*
> Simon (PD)

The importance of increased publicity about the diseases was mentioned multiple times and several of the carers actively campaigned for the charitable trusts and spoke at meetings to raise awareness for the public and professionals. A lot of these meetings were organised by the charities and, although it may be a quirk of the recruitment process for the study, it appeared that many of the carers relied heavily on the charities for support.

The charities provided knowledge, advice and empathy through information packs, online/telephone support and local face to face support groups. Interestingly carers seemed to be keener on the support groups than their loved ones had been. People with the diseases appeared to have been more ambivalent about the groups. Some found them useful and attended regularly. Others understood why they helped their carers and went for them.

> *"he wasn't keen to go to them initially, which I could understand, but I wanted to find out as much as I could, I wanted to know what we were up against and he agreed in the end to come" Elaine (MSA)*

But several did not like seeing what the future might hold and so went to one meeting and then declined to go again.

> *"he didn't want to go to anymore because there were people there who were further on with PSP than him and he said 'I don't want to get like that' because there happened to be a man there who was in an electric wheelchair and he was just making these gurgling noises all the time and grunting and choking and we hadn't reached that stage. We did eventually, but that horrified Chris to think that that's what might happen I guess and he didn't want to go anymore" Margaret (PSP)*

Carers found the support meetings were sources of empathy, as other carers could understand what you were going through, without the need to have the illness explained to them.

> *"I know people coming to the group they get a lot of comfort from, well I always say to them you never have to explain here, everybody here knows what it is all about you never have to explain, because you get tired of explaining" Hope (PSP)*

In addition, the advice other carers in the group/forums could give about finances, downstairs living, wet rooms, care companies etc was invaluable and facilitated planning and managing the home environment.

> *"it's just as well we started going to these carers meetings because I got most of my information from other carers…there was a lot of things that I started to claim for that I didn't realise I could because no one told me I could" Paul (MSA)*

The support groups tended to be most useful shortly after diagnosis, when the need for information and advice was greater. They became more difficult to get to as the diseases progressed and quite often support then dropped off, which reinforced the isolation for some of the carers.

> *"my parents had attended Parkinson's support groups until my dad became too unwell to go. But more should be done for the carers during end stage Parkinson's and after that person has died. When my dad deteriorated and was unable to go and see the consultant no one came to see him. You get the feeling that everyone gives up and you're just helplessly watching this person deteriorate and no one helps them or their carer" Pippa (PD)*

Some groups continued to supply support. Hope explained she sent out a newsletter so that information shared in the meetings was available to all. Other carers used the internet forums on the charity websites, or carers groups on social media sites, which lessened the isolated feeling.

> *"a few months before he died, there is PSP unlocked… on the website and I sort of I looked at that every day and that was quite comforting in a way to think that I wasn't the only person that was having to put up with it"*
> *Stephanie (PSP)*

Elaine (MSA) made such close friends with people on social media sites that she continued to keep in touch with them after Stephen had died, suggesting that the illnesses could in fact lead to new community relationships forming.

A lot of the carers continued to go to the support groups after their loved ones had died or set up groups if they were lacking in their locations, in order to protect others from the lack of support they had experienced.

> *"they didn't have the support groups and things around when mum was alive which is why I've done one because I just know I wouldn't want anyone else to be on their own like we were really" Kate (PSP)*

Helping with the charities provided carers with a sense of purpose in the face of life without their loved one.

> *"I found myself dragged kicking and screaming into becoming a coordinator but to be quite honest I wouldn't change a thing because I have found it very very rewarding and in a weird way it's given me a sort of purpose that at age 75 I would never have expected to have at this stage of my life. Sometimes I sort of think oh it's all too much, its taking over, but then people say things that make you realise that they get something out of it and they appreciate it and you think oh well I'll plod on a bit longer"*
> *Hope (PSP)*

As well as helping them to still feel connected to the support network they had valued so much

> *"I mean everybody from Parkinson's who's rung me or written to me has done it from, not just from a professional point of view but from a friend's point of view as well, it's been really nice. It's been lovely, coz we're one big family us Parkinson's lot"*
> *(PD)*

Some carers continued to attend support groups but felt they should let go.

> *"I still carried on <going to the local MSA group> after she died but I'm going to have to stop because uh I'm seeing people getting to the stage my wife was and I just find it all too distressing so I'm going to stop…I'm just going to go to the Christmas do but I'm not going to go back again because I just, I, I've gotta look forward I've got go forward I can't keep looking back because that's not going to solve anything" Paul (MSA)*

Others met with people from their support groups during their bereavement as they felt it was helpful to speak with someone who could understand what they had been through. Aileen felt continuing to attend the meetings was of more use to her than any bereavement counselling would ever have been, suggesting a potential role for the charities in bereavement.

> *"when John was alive I would've welcomed more support, I would've loved to have had the contacts that I have now with MSA and how much we help one another through, like the bereavement side was helpful, but we've chosen who we want to do it with but if they'd offered me bereavement counselling or anything else after John died I'd've said 'no' "*
> *Aileen (MSA)*

Aileen was not alone in highlighting how much more support there was available now compared to when she was caring for John. Many carers said they found it gratifying that times were changing and support, at least from the charities, was improving.

5.3.6 *Community support: summary*

The above section incorporates the main points carers made regarding the support they, and their loved ones, received outside of the health and social care sector. Nearly all the carers relied heavily on the support of their friends and family, with several stating that if they had not been there to help, there was no way they could have kept caring for their loved one at home. The charities for these diseases, especially for those with PSP/MSA appeared to be incredibly important in supporting carers and enabling them to care with more confidence. However, some carers still felt that the support dropped off as the diseases progressed and finding a way to keep that support flowing was a challenge, especially because as the level of care required rose, the time available to search on the internet to find alternative support decreased.

5.3.7 *Identity summary*

This section has discussed HCPs knowledge of the diseases and community support. It has suggested how these elements can impact on the identity of the person with the disease and their carer, though this will be explored in much greater detail in Chapter 7.

5.4 Overall summary

Figure 24 shows how the factors influencing end of life care fit into the overall themes of the project in regard to preparation, support and identity and shows that there are emotional and practical components within the themes.

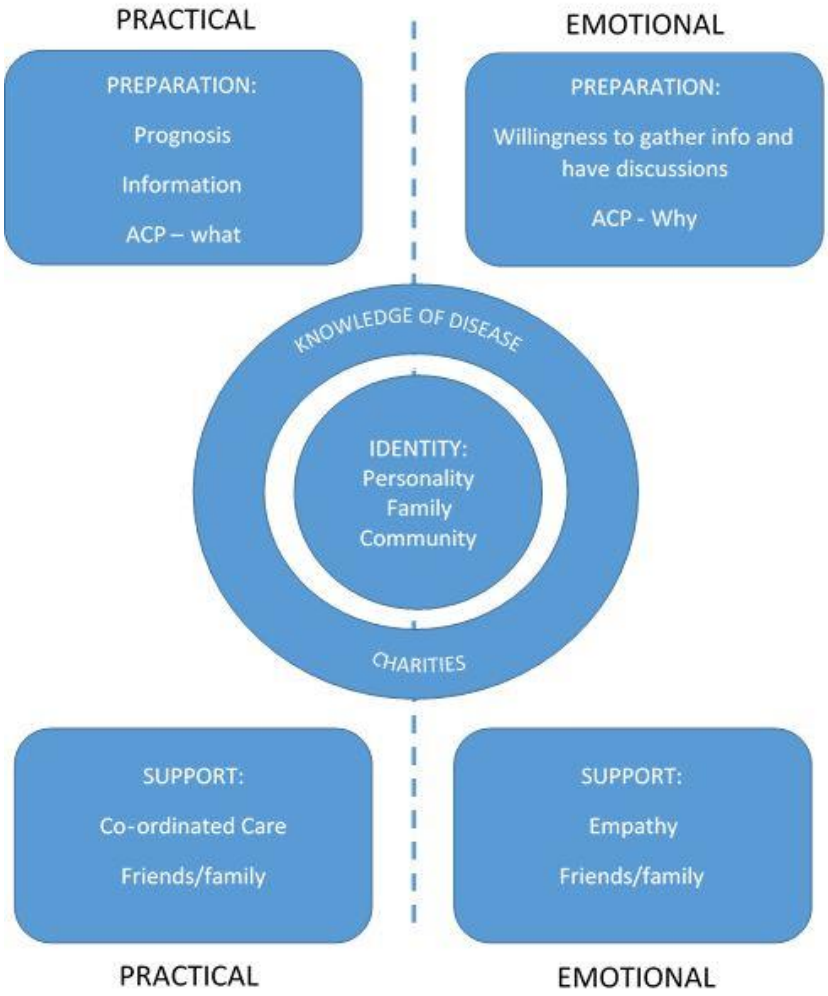

Figure 24 The principle themes of the project and their representations within this chapter

From the excerpts presented it is clear that the personal characteristics and preferences of the individual with the disease (personal identity) and the relationships they had with their

carer and wider networks (relational/collective identity) shaped their experiences in terms of the preparation they undertook and the support they wanted/received. Emotional preparation is dependent on an individual's nature, preferences and the way they are supported by others. Knowledge about the biological disease label, is also central to the support and preparation that can be undertaken/provided and means that the charities, who know more about the diseases, can therefore help. Desire for people to have knowledge about the diseases came across most strongly from the carers of those with PSP/MSA because they were faced with such a lack of awareness.

Though practical elements are often the easiest to target for intervention, without awareness of the underlying emotions involved, practical planning may fall flat. Here no advanced planning could take place if those with the diseases did not want to think about what the future might bring. This stood true for those with PSP/MSA and those with PD. Practically however, those with PSP/MSA had been told their prognosis and so they potentially had more opportunity for planning for the future than those with PD. Those with PSP/MSA were also more likely to have had hospice involvement and hospices were excellent at providing support for planning, on a practical and emotional level. Both of these factors, an awareness of prognosis and increased hospice support, may explain why more of those with PSP/MSA had made plans and more had indicated a PPOD both in the interview and VOICES samples.

Co-ordinated support was lacking for all of the diseases, with regard to social care especially. CHC funding was difficult to access and, along with provision of funded carers, was linked to geographical location. There was a feeling that CHC funding was easier to obtain when services with a greater knowledge of the diseases, such as the charities, intervened. Co-ordinated health care was more of a problem for those with PSP/MSA because they needed more concurrent services at an earlier time but unfortunately provision often fell short of what was needed.

The next chapter considers place of death in greater detail and highlights the aspects of care that affect experiences across the differing locations. The elements set out in this chapter can affect the location of death, as without honest information to plan, support to deliver

care at home (from professionals and communities) and practical knowledge about the diseases, achieving death at home becomes more difficult.

Chapter 6 Experiences of the end of life in different locations

This chapter concentrates on the last three months of life and explores the different components of service provision across the four locations: hospitals, care homes, homes and hospices. Four areas are covered: aspects of staff care that are important to those with the diseases; support for symptoms and needs; awareness of dying and PPOD; and finally support for the carers themselves. These are summarised in Figure 25.

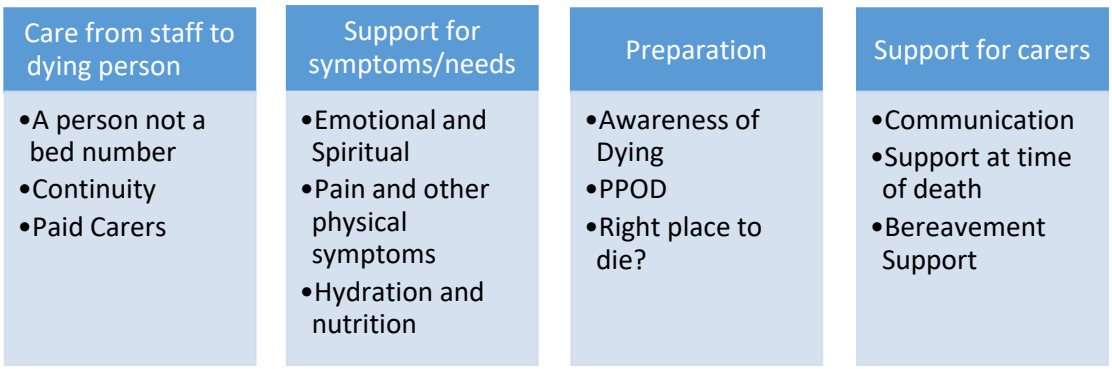

Figure 25 The elements that affect end of life care

The conclusion to the chapter relates the aspects of care that were felt to be important back to the main themes of the project.

6.1 Care from staff towards those who were dying

This section outlines the aspects of staff care that impacted on the overall experience in the different locations. It outlines the importance of the dying person being seen as an individual, continuity of care and then comments on paid carers, as they impacted on the experience of people in their own homes.

6.1.1 *Seeing the dying person as an individual: 'a person not a bed number'*

The most important aspects of staff care in the last three months were that staff saw the person who was dying as an individual, spent time and tried to communicate with them.

"what do the people who really made a difference to us do, they spend time and they talk to us as friends and human beings" Peter (PSP) [Care Home][19]

This is particularly relevant for those dying with PD/PSP/MSA as their ability to communicate is affected so much in the latter stages of the diseases; indeed, the majority of the carers in the qualitative sample (20/36) stated that problems with communication were present at the end of their relatives' lives. The ability to communicate was somewhat intertwined with being seen as an individual and when the effort to attempt to communicate wasn't made by healthcare staff, greater isolation occurred.

"I think the biggest thing for John was that he lost the ability to communicate and that people didn't, if he couldn't, then it was almost like he didn't exist and that was really heart-breaking for him" Aileen (MSA) [Hospital]

Several carers mentioned that their relatives still "had their minds" and could understand everything that was happening and so it was crucial that people tried to communicate with them.

"when the nurses came out <to our house> they would ask me, but with multiple system atrophy the person's still there...they're locked in this body that's let them down" Helen (MSA) [Hospital]

In all locations there were particular staff that recognised the importance of the 'patient' as a person, but most carers felt that there was more emphasis placed on communication and seeing the individual in hospices, which in turn meant that those dying had built up relationships with staff.

"you have a dedicated nurse there <at the hospice> and that worked because she knew Chris, she knew how things were deteriorating, it wasn't seeing someone different every time and that really really helped" Margaret (PSP) [Home]

Although some hospitals also managed this well, there were far more comments regarding hospitals that suggested personalised care was lost.

[19] Square brackets indicate POD

"in the local hospital you're a bed number. You come in, it's a bit of an inconvenience, but you're here for a period so we'll feed you and water you and whatever else" Vincent (MSA) [Hospital]

Vincent, stated that the difference between the local hospital and the smaller community hospital, or the neurological hospital, was like 'chalk and cheese'; he further explained that in the neurological hospital 'you were a person' and he felt that should be the case in all hospitals, for all diseases. He was not the only carer to suggest that being an inpatient on a neurological ward led to a better experience for those with neurological disease. However, these comparisons were comparing the end of life in a local hospital to an earlier time, where the focus on the neurological hospital stay was for research or a change in treatment and therefore somewhat more positive. Only one person, Ronald, died whilst on a neurological ward and his daughter related the same troubles that were reported generally about hospitals.

"There was a constant change of staff, always something going on and no real calm…It was impersonal" Samantha (PSP) [Hospital]

Generally acute hospitals were felt to be chaotic and the lack of continuity of staff was frequently mentioned. However, some carers pointed out that staff were overstretched, suggesting that at least some of the inadequacies in care may be related to the time that staff had available to spend with individuals.

"I cannot fault the staff they were absolutely marvellous, but it was just there was so few of them, there were just so few of them trying to do so much" Betty (PD) [Hospital]

Certainly, in areas of the hospital where there was more of an emphasis on one to one care, like in intensive care, recognising the importance of the individual person was not overlooked, regardless of their ability to communicate.

"they were really talking to him…it was lovely, it wasn't just a case of oh well this patient's totally unconscious so we'll do this that and the other, they were <talking> as if they were expecting him to participate in the conversations" Brenda (PD) [Hospital]

Recognising the importance of meeting an individual's needs and communicating with them about their views equates to showing that person dignity and respect. There are several

questions in the VOICES survey that ask about the degree of respect and dignity shown by HCPs across the various locations (see Appendix Di).

Figure 26 shows that hospice staff were felt to show the highest levels of respect and dignity towards those dying of PD/PSP/MSA in the VOICES survey, in the same way that the carers in the interview sample had felt hospices showed the greatest care for the individual as a person.

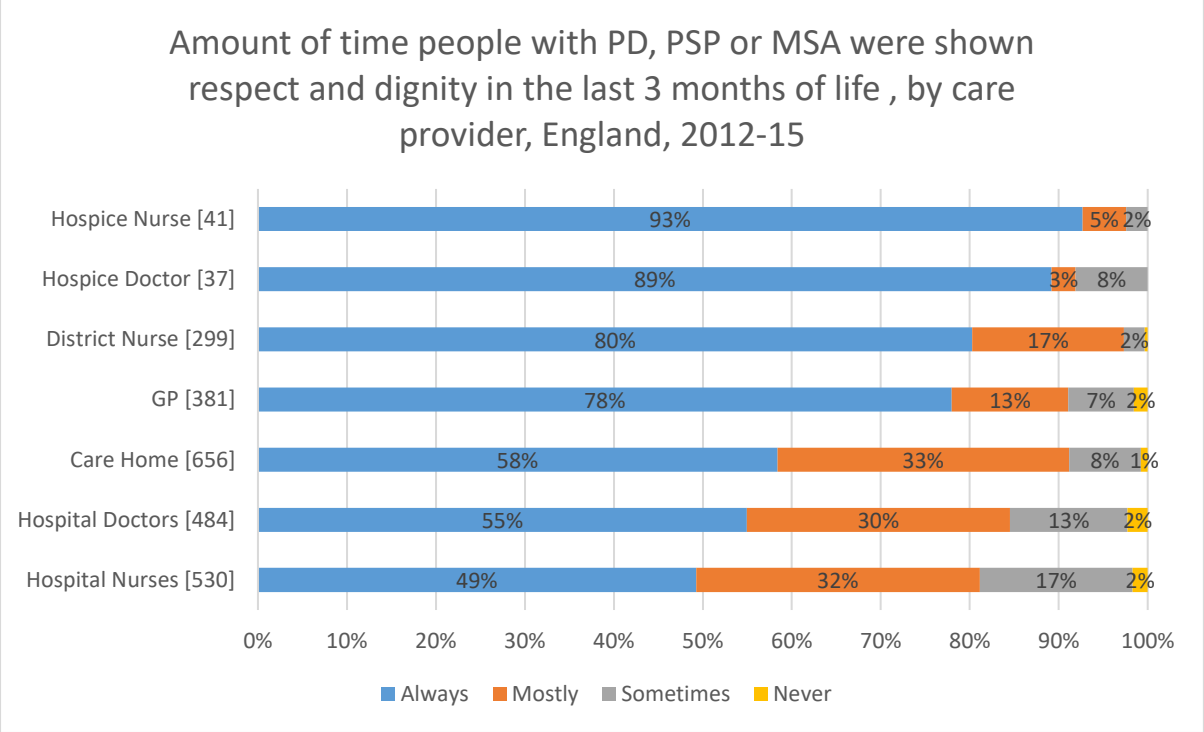

Figure 26 A graph demonstrating how often a person dying from PD, PSP or MSA was treated with respect and dignity by care providers in the last three months of life

There was a significant difference across the group, with hospital nurses statistically less likely to always show respect and dignity in the last 3 months when compared to all other services, with the exception of hospital doctors (see Table 10).

Likelihood of hospital nurses always treating a person with respect and dignity in the last 3 months, compared to other services			
	OR	95% CI	p-value
Hospital nurses	1.00		
Hospital doctors	0.80	0.62, 1.02	0.069
Care home	0.69	0.55, 0.87	0.002
GP	0.27	0.20, 0.37	<0.001
District Nurses	0.24	0.17, 0.33	<0.001
Hospice Doctor	0.12	0.04, 0.34	<0.001
Hospice nurse	0.07	0.02, 0.25	<0.001

Table 10 Likelihood of hospital nurses always treating the decedent with respect and dignity, compared to other services

There was no difference between those with PD, PSP, or MSA except in the case of care homes, where people with PD were significantly more likely to always be treated with respect and dignity than those with PSP [PD 59% vs PSP 33% OR 2.906 (1.225,6.891) p=0.002; see Appendix J ii for other comparisons]. This may relate to the fact that people with PSP are more likely to have cognitive impairment than people with MSA and are more likely to have speech problems than those with PD.

When comparing those with PD/PSP/MSA to the other COD ('Cancer', 'CVD' and 'Other') it appeared that those with PD/PSP/MSA were less likely to always be treated with respect and dignity in institutions such as care homes and hospitals and more likely to always be treated with respect and dignity by GPs, and hospice nurses (see Appendix J iii for graph and statistical comparison). It is difficult to know why this should be the case but again it may be due to the difficulties in communication more common to those with PD, PSP and MSA than people without neurological conditions.

Though most of the interviewed carers relayed positive experiences of care homes overall, the few negative comments expressed were related to dignity.

> *"Derek would be not dressed properly, because he liked to be smart…we were asked to fill a form in about what he was like, you know he'd been a very clever man with a good job and everything but they didn't know all that; so I think that he was treated with dignity but not the same as you would've liked" Barbara (PD) [Care Home]*

Barbara also related that because Derek had dementia, and mobility problems, he was not able to take part in many of the activities that were provided for the residents in his care home, meaning quite often he was on his own.

In hospitals, issues with dignity related to a lack of privacy, lack of effort to maintain mobility and cleanliness

> *"<the hospital ward> weren't getting him up, they weren't moving him, he was laying flat in the bed all the time, getting worse and worse, because he needed to be got up and moved around. I went in some days, obviously he couldn't get up and go to the toilet, so I was going in some days, soaking wet sheets, he wasn't on a catheter and I said 'you know this is ridiculous', 'oh we were just about to change that bed' and I said 'oh come on if I didn't come in he'd have just laid here all day' it was a geriatric ward and it really wasn't, the lady next door to me said 'this is the last chance saloon this ward' and it was so awful and that's why I didn't want him in that place to die. The care was awful" Pam (PD) [Hospice]*

Interestingly the proportion of providers felt to always show respect and dignity towards those dying increased in the last two days of life, with hospital nurses showing the largest increase from 49% to 70% (see Appenidix J iv); so there may well be a conscious improvement in care when it is clear that a person is imminently going to die.

> *"I did find that when the staff appreciated the seriousness of the situation, certainly when they realised mum wasn't going to make it at the end, they were very good" Simon (PD) [Hospital]*

However, it is also worth mentioning that some carers had removed their relatives from hospitals, before the last two days of their lives, because they were so disappointed in the care shown and therefore the apparent improvement in respect and dignity seen may not necessarily reflect improvements in care. For example, Pam whose quote above explained that she had found her husband Andrew lying in

urine soaked sheets in the hospital was so disappointed in the dignity he was shown on the ward that she requested that he was transferred to the local hospice, where he later died.

Nursing needs and privacy were more often achieved in the last 2 days in hospices than other locations, significantly more so than in hospitals and care homes (and home for nursing needs*).* Hospices were more likely to definitely offer enough help for personal care needs as well, though this only reached statistical significance when compared to care homes. Overall care homes were proportionally the least likely to have enough help to meet an individual's personal and nursing needs (see Appendix J v, vi, and vii for more details).

6.1.2 *Continuity*

Due to the complexities of medication regimes for PD and the rare nature of PSP/MSA there was often a lack of understanding present (as discussed previously in Chapter 5.3) and this was perpetuated at the end of life through a lack of continuity of care.

> *"The biggest problem here was the lack of knowledge or even awareness in the GP community with regards to MSA and the use of Locums for home visits being the norm, which was not suitable due to the need to "educate" different GP's every time they visited"*
> *James (MSA) [Home]*

This may well explain why out of hours (OOH) teams were considered significantly less likely to provide excellent care than all other services (see Figure 27), though comparison with hospital doctors did not reach statistical significance (see Table 11).

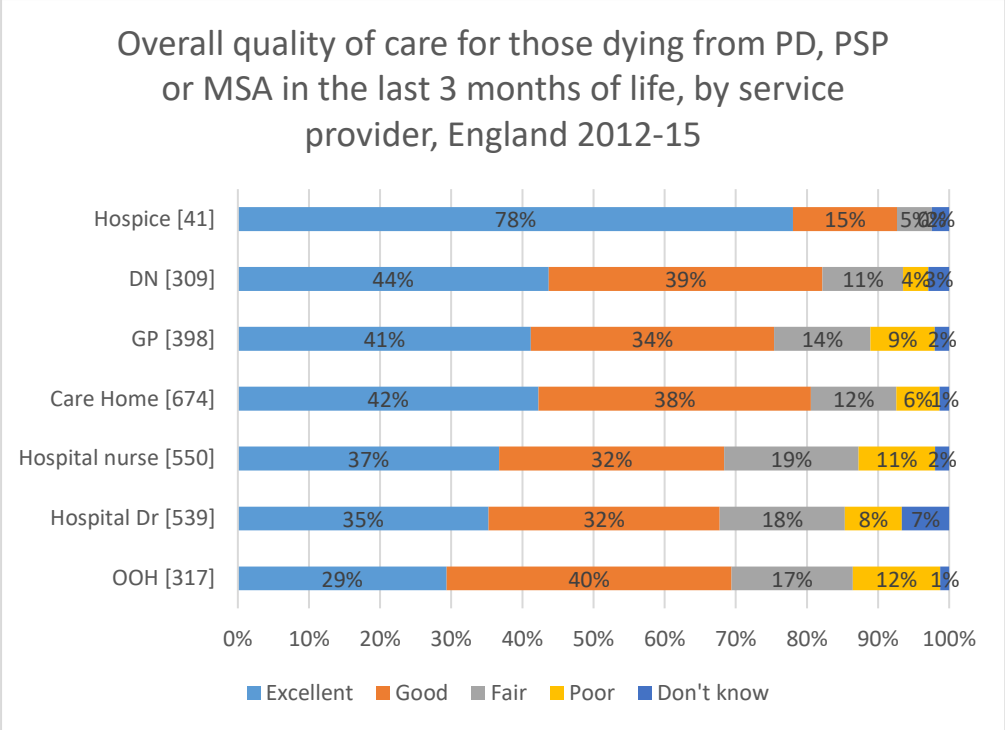

Figure 27 Overall quality of care in the last 3 months by service provider

Likelihood of OOH team providing excellent care in the last 3 months compared to other services			
	OR	95% CI	p-value
OOH	1.00		
Hospital doctors	0.763	0.565, 1.029	0.076
Hospital nurses	0.715	0.531, 0.963	0.027
GP	0.592	0.433, 0.811	0.001
Care Home	0.567	0.426, 0.754	<0.001
District Nurses	0.535	0.385, 0.744	<0.001
Hospice	0.117	0.054, 0.254	<0.001

Table 11 Likelihood of OOH team providing excellent care in the last 3 months compared to other services, England 2012-15

OOH teams were rated as excellent 14% of the time for MSA, 17% for PSP and 31% for PD and although this difference was not statistically significant (see Appendix J ix) there did appear to be a greater degree of frustration with OOH teams from carers of people with PSP and MSA because the complexity and rarity of the conditions meant a lack of continuity was felt more keenly.

> *"you felt as if you were just repeating yourself all the time and you'd feel like screaming 'why doesn't anybody understand what MSA's about' you know" Aileen (MSA)*

Compared to other COD regarding the overall rating of care, care homes and hospitals were rated as excellent proportionally less for those dying of PD/PSP/MSA. GPs were rated excellent significantly more often for those with PD/PSP/MSA than those who died from CVD/'other' causes. Interestingly this was also true for OOH services, though carers of those with PSP and MSA rated OOH care excellent proportionally less than all other groups (see Appendix J x).

In the interview sample it seemed that the provision of care improved when continuity of care was provided because this allowed for knowledge about an individual as a person ***and*** knowledge about their disease to be present. Continuity was a problem in acute hospitals, due to both changes in wards and changes in staff.

> *"I'd spent ten minutes explaining to this nurse about the medication, when it had to be taken all this that and the other and then she turned round and said 'ok, but I'm off tomorrow for five days' and I thought why'd I bother" William (PD) [Hospital]*

It was less of a problem in community hospitals because stays were longer, which perhaps explains why carers were more positive about them than acute hospital trusts. Community hospitals also seemed more willing to find out more about the conditions and contact specialists.

> *"they were willing to learn from me, they asked me to get information for them, they contacted the helpline nurse on one occasion" Hope (PSP) [Hospital]*

Whereas in acute hospitals there was a feeling that the underlying diseases were pushed to the background, with less apparent effort shown to learn about them.

> *"it was like banging my head off a brick wall, I was saying 'just ring neurology' but they never did, they never did bother because as far as they were concerned Stephen was in for a urine infection and that was it" Elaine (MSA) [Hospice]*

Continuity was relevant regarding care homes, as when people had lived in the care homes a longer time and staff had got to know them care was felt to be better.

> *"The Nursing Home staff and her GP knew her well and we knew them well too. I believe it made a huge difference to her experience - and mine… the care in hospital/respite nursing home who didn't know her or about PD was not nearly as good as when she was cared for in her nursing home by those who got to know her and were very PD aware" Jennifer (PD) [Care Home]*

One carer, Angela felt her husband Graham's transition to stay in a nursing home was made easier by the fact that he had attended the day centre there and had got to know the staff. Several carers mentioned that the strength of hospices was the continuity that had been formed through day care and respite stays.

> *"Thelma liked going to the day care, she did like the people there, she had bonded with them and they'd explained to both of us that that's what it was all about that she should feel at home there, it shouldn't be somewhere she should dread" Philip (MSA) [Hospital]*

Alongside their efforts to maintain continuity, hospices were praised for their compassion and time, with most carers stating that they went out of their way to help.

> *"<the hospice> were very kind, very generous with their time and of course very, very caring" Constance (PSP) [Care Home]*

Although no location was devoid of positive comments regarding the caring nature of staff, the degree of praise for hospices was great. There were only four negative comments made about hospices, far fewer than the other locations; all relating to respite stays earlier in the disease process.

6.1.3 *Paid carers*

One of the interesting things about the VOICES survey is that paid carers at home are not referenced in regard to the way they treat individuals, or the quality of care they

provide, yet 30% of people dying from cancer, 45% of people dying from 'other causes' and 66% of the PD/PSP/MSA sample had 'home help' (Appendix B: VOICES survey p2 question 3).

In the interview sample, many people that had spent time at home in the last few months had paid carers. They were mentioned more frequently than GPs or district nurses and they were vitally important to the experiences that people had at home;

both positive

> *"we were very lucky with the caring company we had round here all the carers you couldn't fault them they were very very caring and very gentle with her and in fact several of them became more friends than carers really" Paul (MSA) [Hospice]*

and negative

> *"We eventually had carers come to this house and a couple of them were good but some of them were awful. I mean they really were awful. I mean they would be shouting at Yvonne, 'you're not making an effort, you're not making an effort!' She can't do it, she can't roll in the bed, you know" Peter (PSP) [Care Home]*

As the quotes above show, when continuity was present, carers often became friends, but when continuity was absent, there was little understanding about how the diseases affected people; again reflecting the attributes of care most valued across the locations.

6.1.4 *Summary*

This section has explained how attributes of staff across the locations affected the end of life experience. Locations where continuity of care was shown and carers felt their relative was seen as an individual person, rather than a patient/statistic, were felt to deliver better care.

6.2 Needs

This section outlines the support offered for emotional and spiritual needs, symptom relief and eating and drinking. The figures used in this section relate to the 2014-15 VOICES surveys only[20].

6.2.1 *Emotional and Spiritual*

Figure 28 shows the degree to which carers in the VOICES sample felt their relative's emotional and spiritual needs were considered. It appears that emotional and spiritual needs are best met in hospices, however this should be interpreted with caution as the number of respondents was very small. Emotional needs were significantly more likely to be supported in care homes and at home than in hospitals [Hospital vs Care home OR 0.403 (0.241, 0.672) p=0.001; Hospital vs Home OR 0.432 (0.213, 0.878) p=0.02]; but there was no statistically significant difference regarding spiritual needs (see Appendix J xi). A large proportion of carers in the voices sample answered not applicable to the spiritual/religious question (32-43%), perhaps suggesting that they took this to be religion rather than a more overarching view of spirituality.

[20] The question responses changed between 2013 and 2014 and were not comparable. The 2012-13 surveys did not ask about hydration or nutrition.

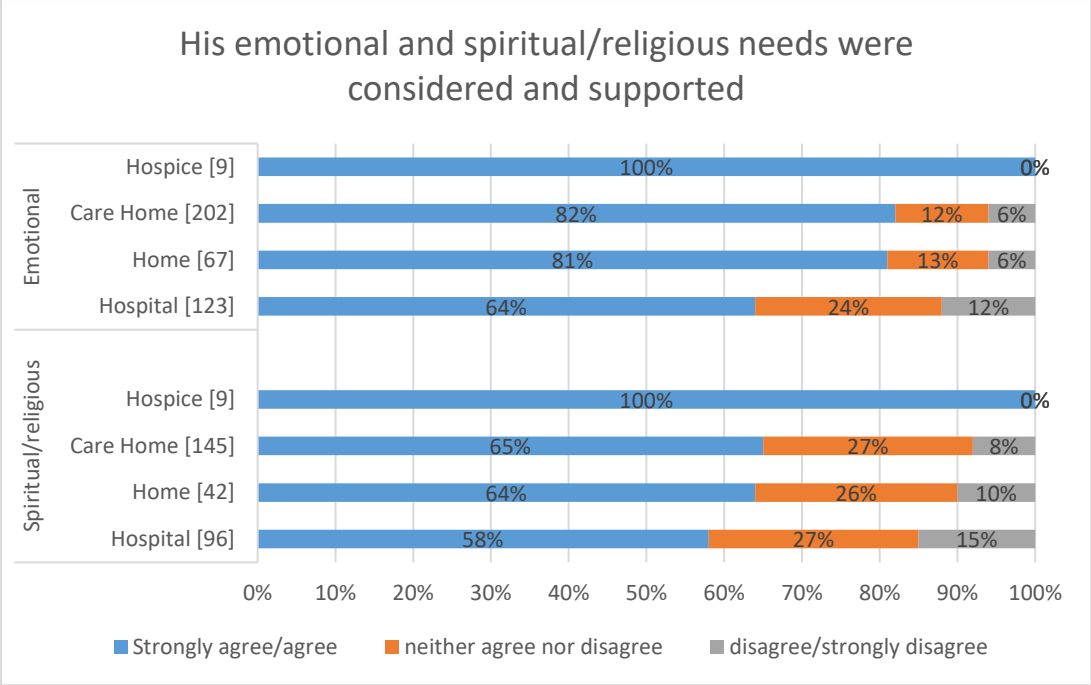

Figure 28 Support for emotional and spiritual needs for those dying from PD/PSP/MSA by place of death, England 2014-15

When comparing the disease groups across the differing locations there was no statistically significant difference between support offered for emotional or spiritual needs for those dying from PD compared to those dying from PSP, MSA or other COD (see Appendix J, xii and xiii).

In terms of the interview sample emotional support did seem to be achieved more often in care homes and hospices than hospitals. Both locations allowed dogs to be brought in and showed high levels of human kindness.

> *"I thought the night staff might be less interested but they talked to her and I used to try and make her smile when one of them said 'come on Grace give us a smile' and so on so they were quite human, they were very human and looked after her" Colin (PSP) [Care Home]*

The main thing that carers mentioned as a positive across all locations was the ability to have music playing for their loved one when they died. Some care homes had undertaken ACP for people when they moved there, specifically for the emotional elements of their care.

> *"they kept her bed turned towards the window, so she could look out, even though they had to move it every time they had to attend*

to her nursing needs. She may never have opened her eyes, but if she did, she'd be able to see out. The plan also covered things like having her favourite music on, and that she would like to be treated with dignity and respect, she wanted people to talk to her and touch her and she wanted her hand held, and to be given a bath if it was possible and she wanted to have her hair combed… from everything I saw, they followed it" Jennifer (PD) [Care Home]

There was no mention of visiting hours in care homes or hospices and friends were welcome to visit alongside family. Visiting for a larger number of people was more restrictive in hospitals; even family found it difficult unless their relative was in a side room where they could spend time freely together.

"if he'd been in the side ward earlier on it would've been easier for us to go and visit, but you had just such a little space and you just felt as though you daren't move, daren't speak" Betty (PD) [Hospital]

As with staff attitudes not all hospitals were the same and certainly community hospitals seemed much more able to provide for emotional needs. Again, they let dogs in and the continuity of staff meant that rapport had been built. Alongside the lack of space acute hospitals were felt to be busy and chaotic, the food was not always good and on shared wards there were problems regarding peace.

"this is something you can't help but before he was put in the side ward we had a couple of Alzheimer's patients, well not actually in that bay, they were in a different bay, but the noise was terrible, it was terrible. But I mean poor things can't help it but it doesn't help and they did have, they were ringing the buzzer a lot of the time" Stephanie (PSP) [Hospital]

In contrast the carers noted the environments themselves were supportive in care homes and hospices. A room in a care home allowed 'home' to be recreated in a different location.

"in the nursing home he had his own room with his you know personal possessions around him, photographs, things like that, it was the nearest probably to him being in his own home" Gail (PD) [Care Home]

And hospices were often set in beautiful locations and provided home cooked food and cakes.

"it's set in a beautiful place as they usually are and I couldn't speak highly enough of them…he continued <in the last few days> to eat ok because the food at <hospice> was all obviously home cooked beautiful food" Elaine (MSA) [Hospice]

Those dying at home, were able to have a closeness with their relative that they did not get elsewhere.

"at least when she was at home at night, I would be in the bed next to her and I could touch her and stuff… in the hospital she'd be in bed on her own, sorry I'm saying hospital I mean in the bed in the nursing home" Charles (MSA)[Hospital]

However, the main support, in addition to family, came from paid carers. GPs and district nurses did call daily, but usually to provide symptomatic relief rather than emotional support.

Spirituality/religion was alluded to less frequently. Personal pastors came to all locations for those that had religious beliefs and hospices had chaplains who were felt to be very supportive.

6.2.2 *Pain and other[21] symptoms*

Several carers referred to symptoms of pain and other things, such as breathlessness, but mostly with a comment that support had been given to control them.

"The lady sorted out some extra pain relief that evening dad went to sleep and never woke up. I'm not suggesting the extra meds killed him just took the pain away" Pippa (PD) [Hospital]

"So we used Midazolam and they titrated the Midazolam up. There was also something, you know, for the strange breathing towards the end of life and they used a drug to try and control that" Peter (PSP) [Care Home]

Only two people were felt to have died with uncontrolled symptoms, John (MSA) who died with intractable pain in hospital and Chris (PSP) who died struggling to

[21] problems apart from pain, thirst and hunger'

breathe at home. Likewise, Figure 29 indicates that for the majority of those dying from PD/PSP/MSA pain and other symptoms were well controlled at the end of life. Regardless of POD less than 10% of carers disagreed that sufficient support for symptoms occurred.

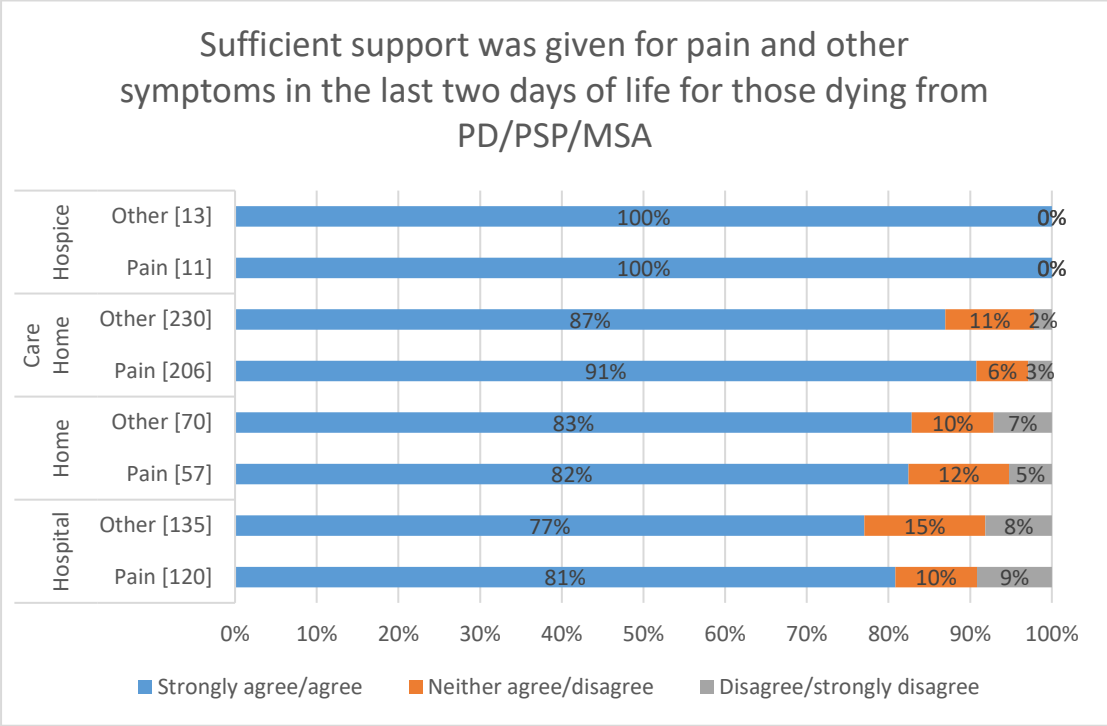

Figure 29 Support for the relief of symptoms in the last two days of life, by place of death, England 2014-15

Although support for symptom relief was good across the locations, it was significantly better in care homes than in hospitals [Hospital vs Care Home 'pain' OR 0.429 (0.223, 0.825) p=0.011; Hospital vs Care home 'other' OR 0.488 (0.281, 0.846) p=0.011]. There was no statistically significant difference between hospitals and home environments (see Appendix J xiv).

The interview sample suggests several reasons that might account for this difference. Firstly, although the majority of carers felt symptoms were controlled by the very end, they spoke of their frustration at the delay in the treatment of symptoms that they witnessed in hospitals, with several of the carers suggesting that it was only because they acted as advocates for their relatives that pain relief occurred in a timely fashion.

> *"I had to make myself unpopular by starting to nag the nurses 30 minutes before the next shot was due to start getting the morphine ready. Otherwise, the shot would have been even further delayed" April (PSP) [Hospital]*

There were no reports that a delay of this kind occurred in care homes or hospices, or suggestions that carers needed to act as advocates for their loved ones in these locations. However, John's wife, Aileen, refused to allow him to be transferred from the hospital to a care home because she felt that if the hospital SPC team could not control his pain then a care home certainly could not. Therefore, the severity of symptoms may keep a person in hospital and the more severe a person's symptoms, the more difficult they are likely to be to control, which may also account for hospitals appearing to offer less support to control pain than care homes. A few carers mentioned that the reason that their loved ones left their homes and went to hospital was because their symptoms could not be controlled at home, often because they related to acute events such as pneumonia.

> *"without being in hospital, my mum would have died in a great amount of pain" Charlene (MSA) [Hospital]*

This may also account for some of the apparent improvement in symptom control at home; when pain was asked about in regard to the last three months it was the home environment that seemed least able to manage pain (see Figure 30) yet Figure 29 suggests an improvement in symptom control at the very end of life.

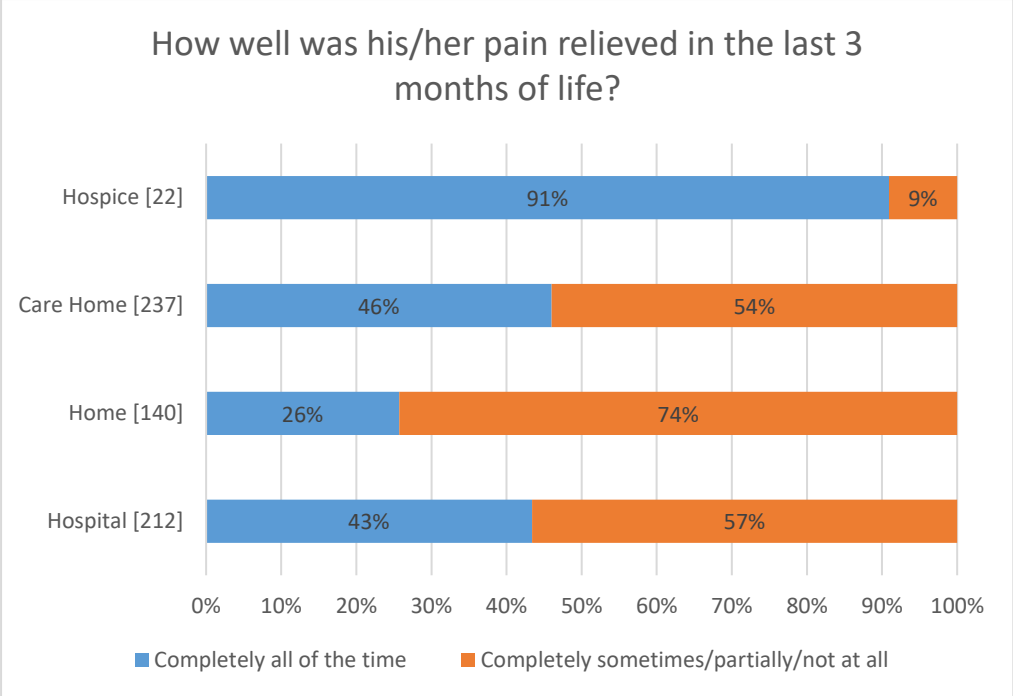

Figure 30 Degree of pain control for those dying from PD/PSP/MSA by location, in the last three months of life, England 2014-15

Carers in the interview sample did state that when the end was apparent district nurses and GPs called daily at home to manage symptoms, which may also contribute to the difference.

> *"The GP, who was calling daily, arranged a battery-operated driver to inject her with steady amounts of a drug called Hyoscine which had the effect of drying up excess mucus. Within an hour or so her breathing had become much easier and more regular. The District Nurse came in daily to refresh the Hyoscine in the driver" Cecil (MSA) [Home]*

As with the levels of respect and dignity shown by staff, this again demonstrates that once it is clear a person is close to death, service provision may alter for the better.

Interestingly, carers of those dying from PD agreed that care homes offered enough support for pain significantly more often than those dying from Cancer, CVD or 'other' causes [PD vs cancer OR 1.962 (1.171, 3.287) p=0.01; PD vs CVD OR 2.082 (1.244, 3.484) p=0.005; PD vs 'Other' OR 1.781 (1.075, 2.950) p=0.025]. There was no significant difference when comparing COD in other POD. There was no significant difference between PD, PSP or MSA for pain control, though PSP seemed

to have support offered proportionally less often. There was no significant difference regarding 'other' symptoms when comparing PD to the different COD (See Appendix J xv and xvi).

6.2.3 *Hydration and nutrition*

In terms of support to eat and drink there was a significant difference across the locations. Care homes and home environments were significantly more likely to be supportive than hospitals, where only 67% of carers had agreed that enough support was offered (Figure 31) [drinking Hospital vs Care Home OR 0.231 (0.127, 0.419) p<0.001; eating Hospital vs Care Home OR 0.285 (0.154, 0.529) p<0.001. Drinking Hospital vs Home OR 0.303 (0.130, 0.707) p=0.006; eating Hospital vs Home OR 0.346 (0.145, 0.824) p=0.017]. There were no significant differences when comparing those dying from PD to those dying from other causes across the locations (Appendix J xvii and xviii).

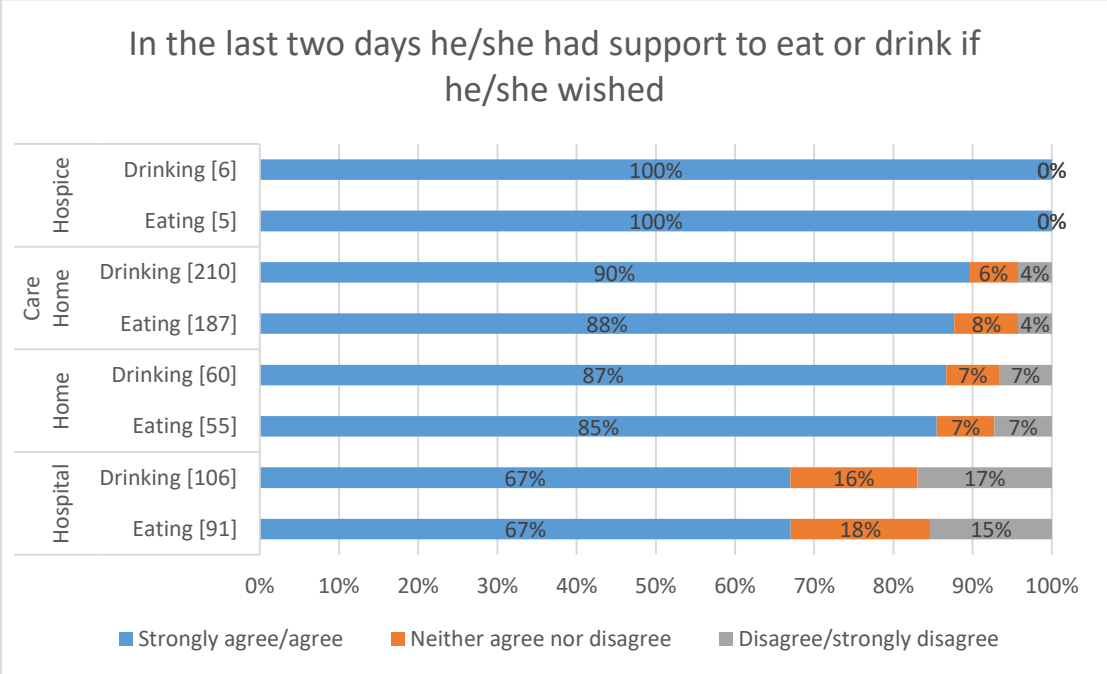

Figure 31 Support for hydration and nutrition for those dying from PD/PSP/MSA according to POD, England, 2014-15

Many carers in the interview sample stated that they needed to be present to help with eating and drinking in hospital environments.

"Because of swallowing difficulties he was becoming dehydrated. I was visiting him twice daily and staying as long as I could to help with drinks and food. He was in hospital for a month, slowly getting worse and unable to eat or drink at the end…The only fluid given was by a stick sponge" Moira (PD) [Home]

Support for eating and drinking is a particularly pertinent issue for those dying of PD/PSP/MSA, 22/36 of the qualitative sample mentioned problems with swallowing existed by the end of their relative's lives.

Home you would think might be less of a problem, but this likely reflects carer provision. One lady was left reeling because she had been told to stop all food and drink at the end of her husband's life and then years later heard the negative press about the Liverpool care pathway and felt guilty that he might have suffered.

"The District Nurse told me and his carers "no fluids, food or medication" on day two. I did not question it at the time, but wish I had…I thought it was the right thing to do but after a few days I wondered whether it was. I could see he was desperately thirsty. Now with end of life care reaching the headline news I regret that fluids were withdrawn and also all of his Parkinson's medication" Sandra (PD) [Home]

Interestingly, the proportion of carers who answered 'food/drink was not needed varied widely across the locations (see Table 12), which was not the case for the other needs surveyed.

Location [number of responses]	Food/nutrition was not needed (%)	Drink/hydration was not needed (%)
Hospital [168]	66 (39)	53 (32)
Care Home [289]	82 (28)	53 (18)
Home [81]	25 (31)	20 (25)
Hospice [15]	10 (67)	9 (60)

Table 12 The necessity of nutrition/hydration in the last two days of life according to place of death, England 2014-15

It is difficult to know why this difference exists but it may come down to communication about food and drink and its necessity at the end of life, which did appear to be better in hospices.

The difference between hospitals and hospices may also relate to the focus of care. In hospital, where treatment and improvement are often the aim, not giving food may be perceived as a failure rather than an active choice due to the distress that choking could bring. Equally, those in a hospice were often there with the purpose of dying.

> *"he was whisked basically from that ward across the road into the hospice and they said he would only live for three days" Pam (PD) [Hospice]*

Therefore, they may have been more likely to be unconscious than those dying in other locations, making the provision of food and drink seem less possible/necessary.

6.2.4 *Summary*

This section has discussed the support offered for emotional needs, spiritual needs, pain relief/other physical symptoms, eating and drinking. Hospitals were felt to meet these needs least often, though were better at supporting physical symptoms such as pain than emotional needs or nutrition/hydration. Even then carers felt they had to be present to advocate for their relatives. Across all needs (apart from spiritual) care homes were significantly better than hospitals at offering enough support. Hospices were felt to offer enough support for all needs by all the respondents, but the numbers answering were very small. Looking across the other COD, where sample sizes are larger, hospices still appear to meet needs more often than the other POD, especially regarding emotional and spiritual needs.

6.3 Awareness of dying and PPOD

This section outlines the extent to which people with PD/PSP/MSA were aware that they were imminently likely to die. It then discusses whether a PPOD had been chosen and the impact such a choice had on the actual POD. Lastly it explores whether carers felt their relatives had died in the 'right' place or not and the ways that dying in the 'wrong' place affected those dying and their carers.

6.3.1 *Awareness of Dying*

There were mixed views regarding how much carers felt their loved ones were aware that the end was imminently approaching. Some people were clearly aware and equate to those in the VOICES sample who 'certainly knew' that they were dying (see Appendix B: VOICES survey question 38).

> *"there was no hope and the doctor came in at one point and we told Nigel what we were doing and he <doctor> said you know that's what we think is best and Nigel put his thumb up, so he obviously, you know in a way at least he knew, because there was no way that he was going to come back from it you know" Stephanie (PSP) [hospital]*

For others, carers felt sure that they knew but they had not openly discussed it, mirroring the probably aware group.

> *"I think he knew, he never said anything to us to indicate that he knew, but I think he knew definitely" Elaine (MSA) [hospice]*

In the cases where more uncertainty was present, matching the 'probably not aware' group in the VOICES survey, the reasons for a lack of awareness were often due to confusion because of dementia/delirium, more likely in care homes and hospitals, or a reduced level of consciousness, common for those transferred to hospices or admitted to intensive care.

> *"CM: was Andrew aware that he was dying at this point?*
> *Pam: um he was very very ill at this stage; he wasn't really talking then" Pam (PD) [hospice]*

In other cases, carers were sure their loved one had not been aware, because they were not aware either; this was usually because death had been sudden, or appeared sudden because HCPs themselves were not aware how ill/close to death a person was

> *"CM: you were saying he was sick at that point. Did you have discussions about whether he was to go into hospital or not?*
> *Constance: No, the doctor, who was a locum, said 'well I could send him to hospital, but you know antibiotics will do the trick and he will be fine again'*
> *CM: Ok, so with that doctor at that point*

Constance: There was no hint that his passing was imminent"
Constance (PSP) [care home]

There are several questions within the VOICES survey that allude to sudden death, or a lack of awareness that death was approaching. Sudden deaths were more likely to have occurred in hospitals (25% of hospital deaths vs 7-12% other locations[22]) and carers were also more likely to answer that it was unclear their relative had been dying when their death occurred in a hospital (15% vs 5-10%[23]).

The acuteness of deterioration in hospitals, the levels of confusion in care homes and the reduced levels of consciousness in hospices may explain why those who died at home were perceived to be significantly more likely to be aware that they were dying, than those dying in other locations [Home vs Hospital OR 3.534 (2.246, 5.562) p<0.001; Home vs Care home OR 2.169 (1.476, 3.187) p<0.001; Home vs Hospice OR 3.689 (1.051, 12.953) p=0.04]. Figure *32* represents the differences graphically. It is also likely that those who were aware they were imminently likely to die chose to stay at home or asked to go home; especially if home was their PPOD.

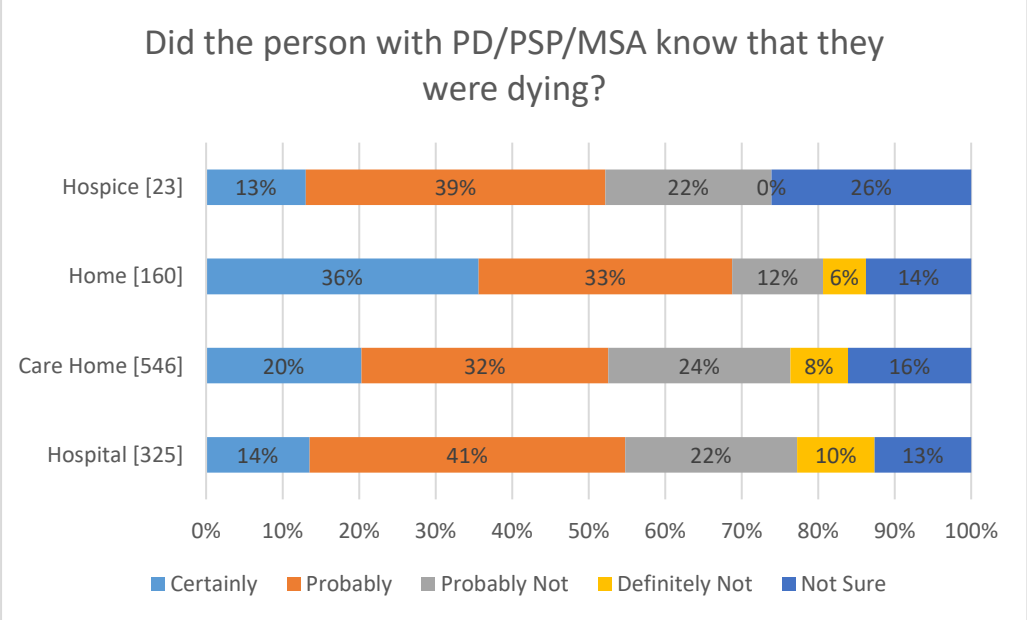

Figure 32 Awareness of dying, by place of death, England 2012-15

[22] Derived from VOICES survey question 45 (see Appendix B)

[23] Derived from VOICES survey question 39, 40 (see Appendix B)

There was no statistical difference in awareness between those who died from PD/PSP/MSA, but those with PD were perceived to be less aware across all locations. Those who died from PD were statistically less aware than those who died from cancer in all locations, less aware than those dying with CVD/'other' COD if they died in a hospice and more aware than those dying from CVD in home locations, likely due to large proportion of sudden death in CVD (see Appendix J xxi for graphs and statistical analysis). Figure *32* shows that a greater proportion of the hospice group were unsure whether their relatives knew, which perhaps reflects reduced conscious levels, or the difficulties that carers had communicating with their loved ones, and this in turn may explain the difference between those dying with PD/PSP/MSA and other COD.

Certainly, in the interview group, carers related that by the time of hospice admission communication/consciousness was markedly reduced.

> *"I knew in my heart of hearts she wasn't going to come out. Whether she did or did not, coz by then communication with her was very very difficult, she wasn't really talking and it was all these squeezes of hands" Paul (MSA) [hospice]*

This may also explain why a large proportion of those dying in hospices had apparently not been told that this was the case (78%). Given the high quality of communication that was frequently related with regard to hospices we might have expected they would have been more likely than the other locations to have informed a person that they were dying, but this was seemingly not the case (see Figure 33). There was no statistical difference across the locations (see Appendix J xxii).

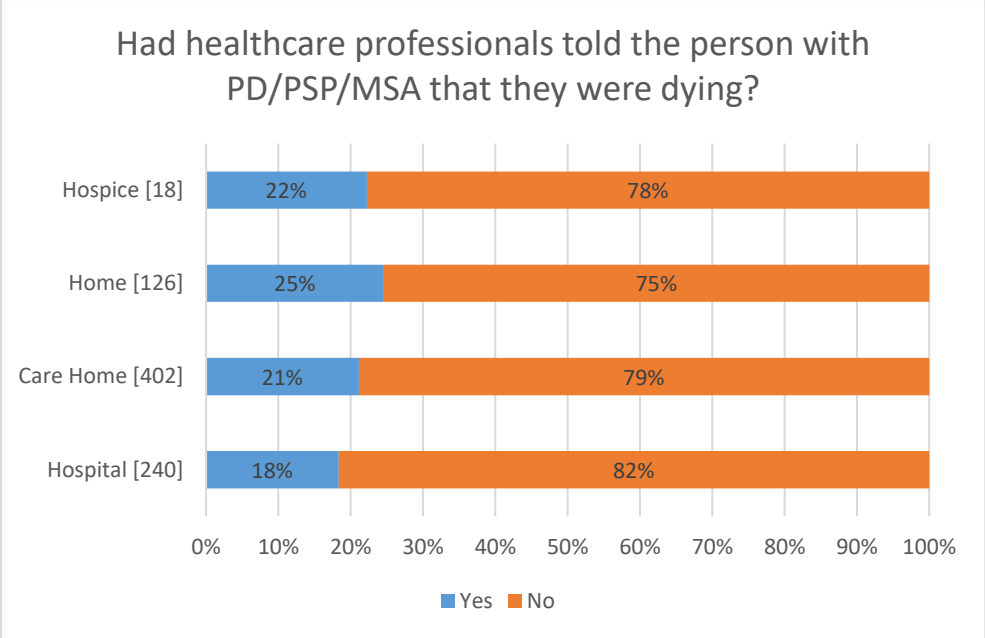

Figure 33 Communication regarding approaching death, by POD, England 2012-15

Figure 33 suggests that a minority of those dying had been told this was the case by HCPs. There were no significant differences between those with PD/PSP/MSA. People dying from cancer were significantly more likely to have been told that they were dying in all locations compared to those dying from PD. Those dying from CVD were more likely to have been told when at home or in a hospice, when compared to those dying from PD and those dying from 'other' causes were more likely to have been told at home, in hospices and hospitals (see Appendix J xxiii).

The interviews suggested that the considerations above, such as levels of consciousness, confusion and the ability to communicate easily, may have prevented staff from telling a person that they were dying.

> *"two doctors in particular were just wonderful in so far as they would speak to John in the room with me there and talk about end of life stuff. We weren't always 100% sure whether he understood or not, whether he was with it or not, but they did it so that he was included" Aileen (MSA) [Hospital]*

But there were certainly instances mentioned in the interviews where carers had been told and the implication was that those dying had not, even though they were cognizant.

> *"When the doctors finally withdrew treatment, I told my mother that she was dying because I know she would have wanted me to. I do acknowledge that this must have frightened and shocked my mum but I did not feel that I was entitled to withhold that information from her in her final hours of consciousness. I am sure that many people would think I did a cruel thing, but nobody knew my mother better than me and I know she would not have wanted me to withhold the facts. This is one thing I DON'T feel guilty about. But because I hadn't anticipated that I would have to tell her, maybe I didn't have the words and could have explained it better." April (PSP) [hospital]*

April felt that her mother should have been told that she was dying, suggesting that she had thought the HCP might have done this. Conversely, Philip was angered by the appearance of the SPC nurse at his wife's bedside, perhaps echoing April's suggestion that making someone aware that they are dying may be cruel.

> *"Suddenly at the side of the bed, bear in mind that although Thelma couldn't talk very easily, she was cognizant… 'I'm the palliative care nurse'… most people know palliative care as being alarming and of course Thelma in the state she was I thought that that was not on, to come to her bedside, with her saying that 'I'm the palliative care nurse and I've been sent along to chat over a few things with you'. And it wasn't with Thelma and me, it was with me but in front of Thelma and I said 'well excuse me' and I took her away from the side of the bed 'can we go and talk somewhere' so I thought that wasn't very good" Philip (MSA) [hospital]*

These extracts allude to a societal view that informing someone they are imminently going to die might be cruel, which might further explain why few HCPs appear to have done so. They also show that carers act as advocates for their relatives regarding information sharing and may affect the information that their loved ones receive; as well as reinforcing that carers feel their loved ones should be the centre of the medical encounter, however ill they might be, rather than being ignored.

6.3.2 *PPOD*

Within the VOICES survey, only 27% of those dying with PD/PSP/MSA had stated a PPOD; whereas around half of the carers in the qualitative sample suggested a PPOD had been discussed. Many of the conversations about PPOD that the interview

sample related had come about through informal discussions over the years between spouses. This may explain the difference in proportions as most of the interviews were with spouses, whereas a greater proportion of the VOICES responses were from children.

There was no statistically significant difference between those with PD/PSP/MSA in the VOICES sample, though the proportions suggest those with PD had discussed a PPOD less (36% PSP, 32% MSA and 26% PD). This likely reflects the differences in discussion of prognosis related in chapter 5.1. The likelihood of those dying from PD having a PPOD is equivalent to people with CVD (26%) and 'other' causes of death (26%) but significantly lower than for people dying from cancer (53%) [PD vs cancer OR 0.309 (0.267, 0.357) p<0.001] (see Appendix J xxiv for further graphs/statistical comparisons).

Overall 47% achieved their PPOD and having a PPOD did seem to affect the eventual POD. Those who died at home were significantly more likely to have stated a preference than those who died elsewhere (Figure 34) [Home vs Hospital OR 6.42 (4.205, 9.810) p<0.001; Home vs Care Home OR 8.17 (5.496, 12.158) p<0.001; Home vs Hospice OR 5.096 (1.869, 13.897) p=0.001].]

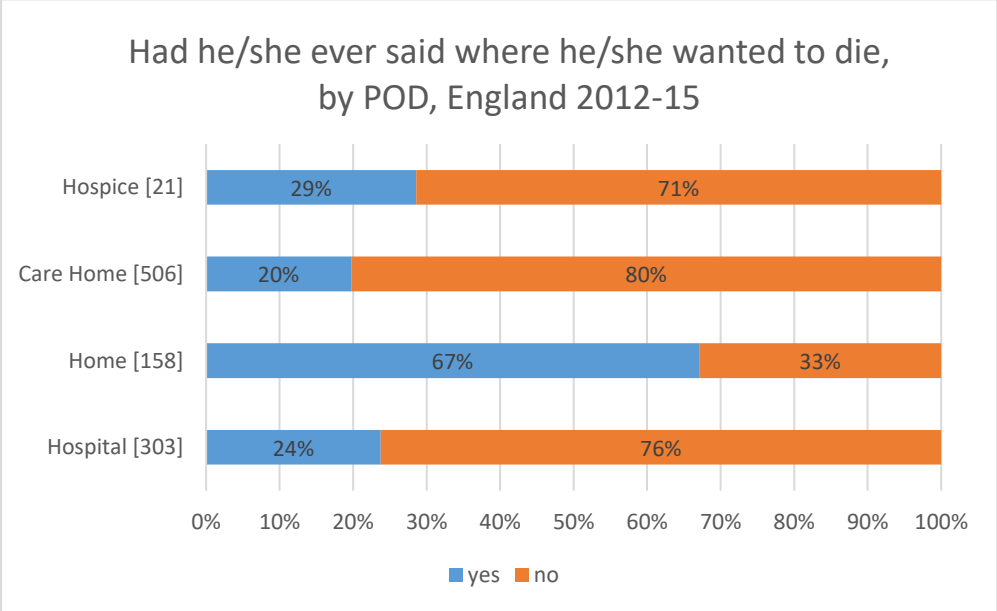

Figure 34, Statement of PPOD, by POD, England 2012-15

It is not that surprising that those dying at home were more likely to have stated a preference; home was the most likely choice for PPOD in the VOICES sample for all COD (74% for those with PD/PSP, 88% MSA – see Appendix J xxvi for more information). Most of the interview sample who had stated a PPOD had also chosen home and certainly for some who had recorded their preference, efforts were made to get them there.

> *"On the Power of Attorney OH had stated that he wanted to be at home and cared for there. P" Martha (PD) [Home]*

However, it was not always possible for people to die in the place that they had chosen. Either acute events had taken people into hospitals,

> *"we promised her she wouldn't ever be alone, or live in a home, or die in hospital. I learnt the hard way that you shouldn't promise people things beyond your control…she was rushed into hospital on Wednesday morning, and she was told she had pneumonia and that she had a couple of hours left" Charlene (MSA) [Hospital]*

or there were logistical reasons cited that prevented those dying from being transported home.

> *"just before we were about to bring mum home the ambulance staff realised that actually her bed was upstairs so how would they get her upstairs and the only way really would be to put her on a board which they thought would probably be a bit undignified and we discussed that and we agreed that given that situation, plus the fact that mum really was very ill, the last thing we'd want was perhaps for her to pass away when she was being transported in the ambulance or something like that" Simon (PD) [Hospital]*

Or a point had been reached where carers were no longer able to continue to care for their loved ones at home and they had moved to a care home, making their previously stated preferences impossible to achieve.

These reasons probably explain why only 44% of the people who had wanted to die at home achieved their aim in the VOICES sample (Figure 35).

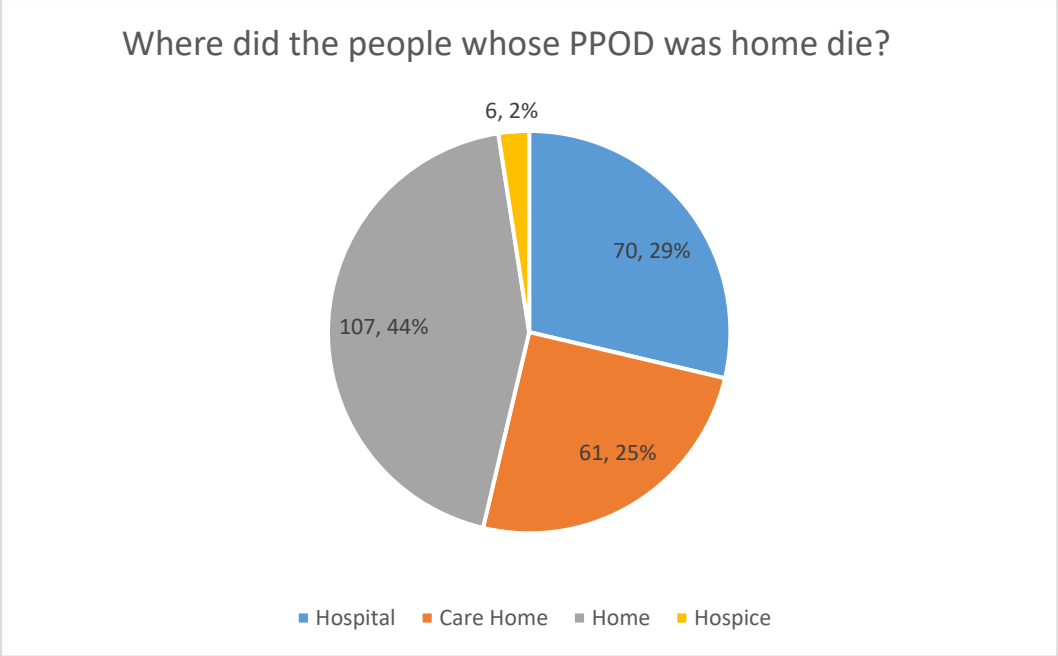

Figure 35 Actual POD for those whose PPOD was at home, England 2012-15

6.3.3 *Right place to die?*

Regarding the VOICES sample, irrespective of whether a PPOD had been stated or not, PD/PSP/MSA carers were more likely to feel their relatives had died in the right place if they died at home [Home vs Hospital OR 17.484 (4.203, 72.727) p<0.001; Home vs Care Home OR 5.018 (1.188, 21.205) p=0.028; Home vs Hospice OR 12.474 (1.959, 79.442) p=0.008]. However, the confidence intervals when comparing locations are wide and reflect the fact that most carers were satisfied that the actual POD was right, whatever the location (see Figure 36).

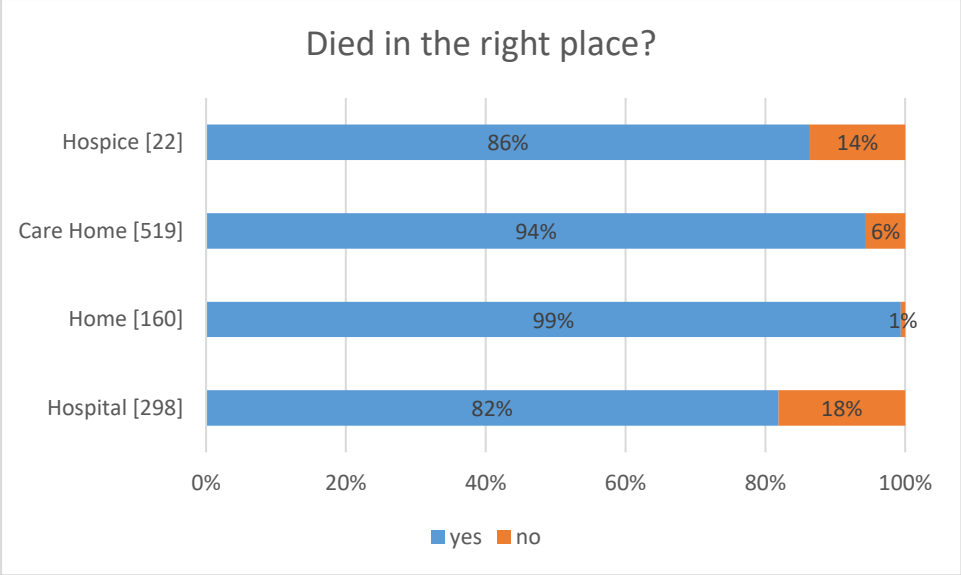

Figure 36: Did the person dying from PD/PSP/MSA die in the right place, by POD, England 2012-15

PD carers were statistically more likely than cancer or CVD carers to feel care homes were the right place for their relative to have died, more likely than CVD carers to feel home was the right place but less likely than CVD carers to feel hospice was the right place (see Appendix J xxviii for other comparisons). It is interesting that a few carers in the VOICES sample felt that the hospice was the wrong place; all had stated their relatives wanted to die at home and so perhaps the feeling was that the hospice should have facilitated this.

This finding would appear to be at odds with the interview sample, where carers had only positive things to say about hospices and certainly felt they were the right place, even when their loved ones had wanted to die at home.

> *"he was on the books that they would help him die at home but basically, that wasn't going to happen…our local hospital isn't the greatest and I was very relieved that he wasn't going to die in there… I'm glad really that he was surrounded by nice people and I was there, yes that was the right place" Pam (PD) [Hospice]*

These carers felt going home from hospital would not have been possible and, that being the case, hospice was preferable to the hospital they were in or to going somewhere else.

> *I spoke to her in the hospital I said to her you're going to the <hospice> because you're too ill for me to look after you at the*

moment…coz there's no way uh I made a promise to her that I'd never stick her in a home <broken voice> Paul (MSA) [hospice]

Despite the negative views that a few carers had about care homes, for those that had experienced them and had relatives who had died there, the majority were felt to have died in the right place. Certainly a few of the carers mentioned that they had not wanted their relatives to be transferred to hospital; they were grateful that palliative care had been provided in the care home and that their loved one was able to stay in a familiar environment.

"I think most people are more nervous or disorientated in a hospital situation rather than being in your own bed in what had become his own room with things around him, even if he wasn't fully aware of it just the idea of it was nicer...he was with particular people who knew him and had cared for him and we were close by and everything ran very smoothly" Angela (PD) [care home]

For several of the carers, their main wish was that their relative did not die in hospital, there was not so much a right place of death as a wrong one. It may therefore seem surprising that 82% of those who died in hospital were felt to have died in the right place according to the VOICES survey. Even when focussing on the people who had wanted to die at home but died in hospital, 61% of carers still felt their relative had died in the right place.

In the interview sample, a hospital seemed to be the right place when alternative options were thought likely to risk the comfort of those dying.

"This lady came to see my dad the day before he passed away, <hospice> had no spaces but I was glad in a way, I don't think he would have tolerated being moved" Pippa (PD) [hospital]

Several carers stated that they would have liked to have taken their loved one's home but that it wasn't possible and that being the case, they felt it was better to keep them where they were comfortable.

"I wanted him to be at home that's what I would've liked but it just wasn't on and they did offer to transfer him to the hospice at one point but they put him in a side room and I just feel that was better than going in the ambulance" Stephanie (PSP) [hospital]

The reasons given for it not being possible seemed to stem principally from exhaustion in carers and increasing care needs that they, or hospital staff, felt they would be unable to manage. There is perhaps here a question about whether more support could have been offered to allow people home and certainly there was a feeling that people could have stayed at home longer, and been supported there better, if continuing care funding had been in place.

> *"Had I known then what I now know about um being able to get continuing care to have support at home I might have given that a try because I did feel, I felt terribly that I had let him down by not being able to keep him at home and I never knew, because he never accused me, but I always wondered whether he felt that as well" Hope (PSP) [hospital]*

Hope's words also highlight one of the problems with having PPOD, the guilt and upset that carers can be left with if it is not achieved.

> *"I was very unhappy that she died in hospital because that is something we had discussed, that she didn't want to die in hospital" Vincent (MSA) [hospital]*

It is also worth asking who is the place of death right for? In the interview sample, home was always reported to be the right place for the person who had died.

> *"so it was peaceful really and it was what we had wanted for her, it was at home" Sebastian (MSA) [home]*

However, although some people had died at home where they wanted, it did not always follow that this was the right place for their carer.

> *"he was looking at me so beseechingly because he was at home, he wanted to be at home, they had offered him a hospice bed in the last week um but he had turned it down he said he wanted, he had always said he wanted to be at home and when my daughter asked him she said 'squeeze my hand dad if you would like to go to the macmillan hospice' and she got no response and she said 'squeeze my hand if you want to stay at home' and that's what he did and so it was horrible right up to the very end" Margaret (PSP) [home]*

Margaret found watching Chris die at home with limited support very difficult and another carer, Nicole, had symptoms of PTSD associated with finding her husband Jake (MSA) dead at home.

6.3.4 *Summary*

This section has discussed whether people dying from PD/PSP/MSA were aware that was the case and had been told that they were dying, whether a PPOD had been discussed and whether carers felt their relatives died in the right place or not.

A minority were aware that they were dying, less so than people dying from other causes, particularly in a hospice environment. In all locations people with PD/PSP/MSA were less aware than those dying of cancer. Communication difficulties at the end of life may set these diseases apart somewhat from other COD but carers still felt that an effort should be made to inform their dying relatives and expressed satisfaction when open communication was shown.

A small proportion had discussed a PPOD but it is difficult to know whether this is because people with PD/PSP/MSA do not think it is important or whether they had just not been asked. Expressing a preference meant that death at home was more likely. Irrespective of preference most people were felt to die in the right place, though this did not mean carers themselves were spared feelings of guilt if preferences weren't met or that caring for a dying person was necessarily easier when it was in the 'right place'.

6.4 Carers

This section discusses how carers themselves were treated across the four locations. It discusses communication with carers and the support they received at the time of their relative's death. It then outlines the support carers were shown immediately after death and the provision of ongoing bereavement support.

6.4.1 *Communication*

Regardless of location, the most important thing to carers in the interview sample, was that their loved ones were treated well and that their worth was realised.

> *"they <hospital staff> realise someone is sick but they don't realise the person who is sick may still have a good quality of life…they don't realise the sick person is somebody's loved one. I loved her dearly*

and I still miss her terribly, they don't realise they are someone's mum" Philip (MSA) [Hospital]

Worth, in many instances, equated to HCPs seeing the dying person as an individual, as discussed previously, but there were also comments that suggested HCPs were perhaps not putting in as much effort as they could.

"the feeling which I had at the end of it was oh well we've tried this but we don't think it's worth the effort to do anything else, if you know what I mean, and that made me feel a lot more upset" Simon (PD) [Hospital]

One carer, Helen referred to this when she compared her husband's treatment to that of Stephen Hawking.

I mean to be fair I did get angry because of course you've got Stephen Hawking who has a chest infection at the same time and he comes out and I was saying 'yeh they wouldn't pull the bloody plug on him would they?' <laughs> and yet they were just happy to switch it off for Tony because they said 'oh well he'll probably have brain damage give the amount of time without oxygen' Helen (MSA)

Some carers felt that there was an automatic assumption that their loved ones must have a poor quality of life and therefore it was a life that was not worth saving.

"he <consultant> said 'I'm sure you'll agree Mr Edwards if your wife goes into a deep sleep, we're not going to resuscitate her'
I said 'why not?'
'well, because of the disease'
I said 'well what do you know about the disease?'
'well it's Parkinson's isn't it, she's not going to have a very good quality of life'
I could've hit him across the room, I really could, you know it's this attitude that for some of these people you know they're so righteous they act like bloody gods sort of I'm in control, I can sort of control life or death… I mean I just think some of these people have no idea, no finesse if you like, no idea how to treat people they're just ignorant, completely ignorant" Vincent (MSA) [Hospital]

Vincent explained that when the above conversation occurred his wife, Beatrice, had just been rushed into hospital and he was stood at her bedside shaking with shock. It was not just the judgement regarding Beatrice's quality of life that upset him, reinforced by the fact that the consultant had talked about her as if she was not

there, but also that the consultant had not appreciated how shocked he was feeling himself. Several other carers likewise related instances where they were not adequately prepared for the bad news that followed; there had been an assumption that they would know what was happening and understand the seriousness of the situation because they were caring for someone with a life limiting disease. They felt that more empathy could have been shown

> *"maybe they had no idea that I wasn't expecting something like this, I don't know, but I think that basically I was being told that mum was a heck of a lot sicker than what I thought and that mum probably wouldn't pull through so obviously that's very difficult news to communicate and I don't feel that there was that much empathy if I'm honest with you at the time" Simon (PD) [Hospital]*

These problems were usually encountered in hospitals, predominantly in A+E departments or medical admissions units; once on the wards more empathy was shown, especially when it was apparent that the end was close.

> *"I remember watching the doctor reading my mother's notes in another ward and preparing himself to come and tell me that she was dying and we should withdraw treatment. He clearly had to compose himself carefully and he communicated it clearly but sensitively. I don't think this could have been better managed in a hospice" April (PSP) [Hospital]*

There is no question in the VOICES survey that relates to the empathy shown by staff when breaking bad news to carers, but there are questions that relate to communication. Figure 37 shows that staff in hospices were felt to communicate with carers best and staff in home environments the worst. There was no statistical difference between the locations when comparing those who strongly agreed/agreed to those who did not. There was no difference when comparing PD to PSP or MSA. When comparing PD to other COD across the locations, PD carers were significantly more likely to feel they were informed and had time to discuss issues in hospital compared to carers of people who died from other causes. This may be because they were more often present to advocate, or because staff communicated with carers more than they did with their patients with PD. There was no significant difference when comparing the COD across other locations,

though PD carers were proportionally less likely to feel informed, or that they had time to discuss issues, when at home (see Appendix J xxx and xxxi).

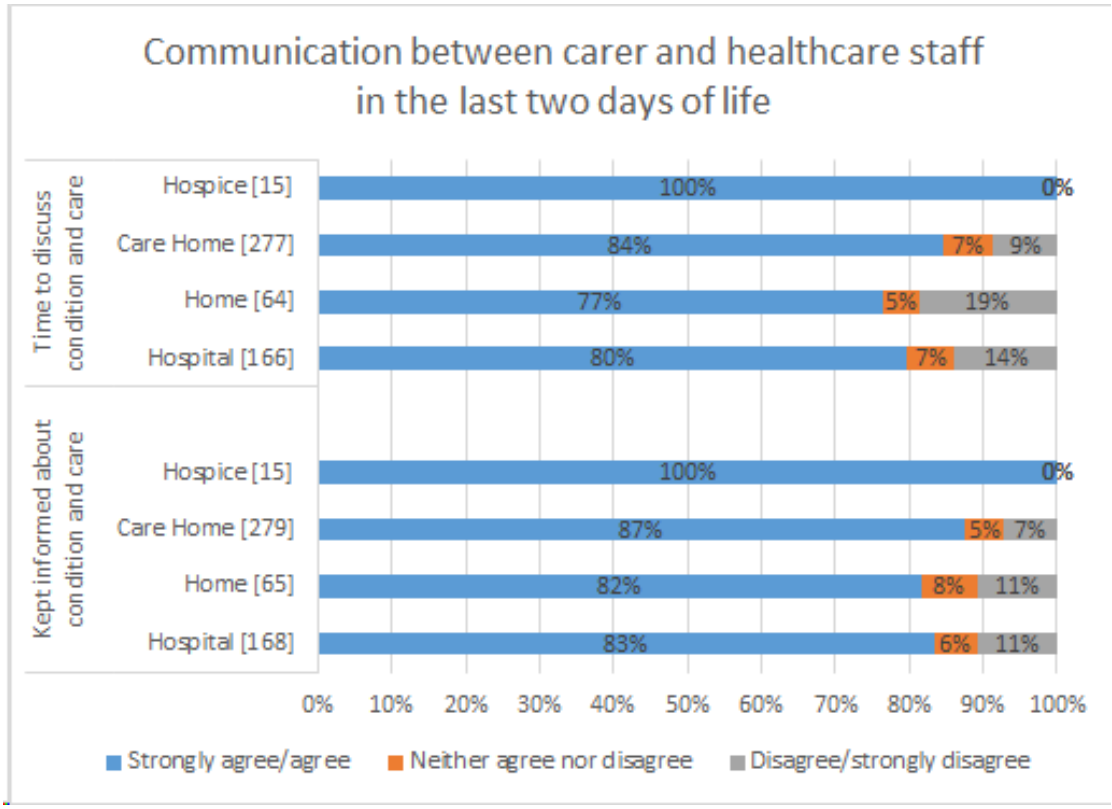

Figure 37 Communication between carer and HCPs in the last 2 days of life, by POD, England 2012-15

Carers in the interview sample felt hospice staff were well informed and had time to discuss their relative's care. For those that had experienced both hospitals and hospices, the continuity of staff, the time available for discussion and the communication skills shown in hospices allowed carers to feel better supported.

> *"the hospice you know it was the same team, the doctors came round regularly, they talked to me, basic communication was so much better <than in hospital> and although it's an awful situation when someone's dying at least you feel much more confident that the person is being looked after properly" Pam (PD) [Hospice]*

Nevertheless, many carers related that hospital staff did put time aside to speak with them. Indeed, one of the reasons that breaking bad news was found to be problematic more often in hospitals was that carers were told clearly that their loved ones were imminently dying more often in hospitals than they were in other locations; this was true even in hospices, as carers were usually aware that death

was approaching prior to transfers occurring. When at home, carers saw HCPs less frequently. This perhaps explains why 19% of carers in the VOICES sample, when POD was home, disagreed they'd had time to discuss their relative's condition (Figure 37). Even if staff were attending the house regularly, it was rare that the nearness of death was discussed.

> *"I think the professionals they did know but they didn't communicate that to me, maybe they thought because I was so involved with his care that I had picked that up for myself and yes I knew he was going to die but I didn't think he was going to die that soon" Margaret (PSP) Home*

Outside of hospitals and hospices the approach of death might have been inferred but if it was communicated at all it was done so less clearly, as indicated in the case study below (Figure 38).

Angela found Graham in his room at the care home vomiting altered blood, a care assistant ran in and said 'oh no, coffee grounds'. Angela was later told by the care home manager and the visiting GP to 'call the family'. The situation was not made clearer, she was told by one member of staff that he would jump up and be fine and despite asking, no-one would tell her what 'coffee grounds' meant, even her own GP. No-one spoke to her again about the approach of his death.

Figure 38 A case study of Angela and Graham (PD)

The uncertainty of knowing that death was imminent then left carers unprepared for the end.

> *"I would have liked to have been told in no uncertain terms, if you like, exactly what had happened, what was going on or that it was the end and to prepare ourselves; because I don't think we were prepared really. I think I should have been more proactive, but I suppose in a way I was too nervous, you know, you almost don't want to hear it I suppose but at the same time you need to hear it" Angela (PD) [Care Home]*

As Angela suggested, for some carers it may have been their own wish to deny that the end of their loved one's life was approaching that stopped them from fully realising the end had come and even in cases of clear communication this denial was sometimes present.

> *"I was just trying to sort of pretend you know he was going to get better even though the palliative care consultant had come to see us on the Friday night and said 'you know this is probably going to be the end, is there anything you want to ask me?'" Elaine (MSA) [Hospice]*

The difference though was that when people had been clearly told that the end was coming, whether on some level they denied it or not, they were more likely to be present and prepared for the end when it came. Conversely, when communication was seemingly less blunt and did not contain the words 'he/she is dying' carers would not always realise the end had come, were less ready for the death to occur, and had more unanswered questions afterwards.

> *"the nurses must have seen something and as I say the only thing I can rely on is the fact that nurses know about these things and it would be nice for me to have known, or would it, did they keep it from me, I don't think they would keep it from me specifically because nobody knows when anybody is going to die" Colin (PSP) [Care Home]*

As Colin alludes to, prognostication of the exact time of death is very difficult and this may account for some of the perceived lack of clarity regarding the approach of death. However, in several interview accounts my interpretation was that the staff had probably known but had not communicated to relatives in a way that they understood. As communication at the very end of life principally relates to conferring that death is approaching, that it was less likely to be done in care homes and at home probably accounts for the carers in the VOICES survey who disagreed that they were kept informed (Figure 37). Though hospitals did inform carers that death was approaching, the busyness of staff sometimes meant carers felt they were being a nuisance when asking questions, which may explain why hospitals were not felt to be better at keeping carers informed.

> *"I felt as if they were all terribly busy and having to answer questions. I was being a pest and go away and sit quietly and don't bother us <small laugh>" Angela (PD) [Care Home]*

Being made to feel a nuisance, the busy nature of hospitals and the lack of empathy that was sometimes shown when bad news was broken are examples of the lack of

support carers sometimes felt hospital staff showed. Figure 39 illustrates the degree of support that carer's answering the VOICES survey felt they had received in the different locations. There was no significant difference between the locations for those that strongly agreed/agreed that they had support (Appendix J xxxii). There was no significant difference between PD, PSP and MSA across the POD either. When comparing PD to other COD (cancer, CVD and Other), PD carers were statistically more likely to agree that they had been supported in hospitals; there was no difference in the other POD (see Appendix J xxxiii)

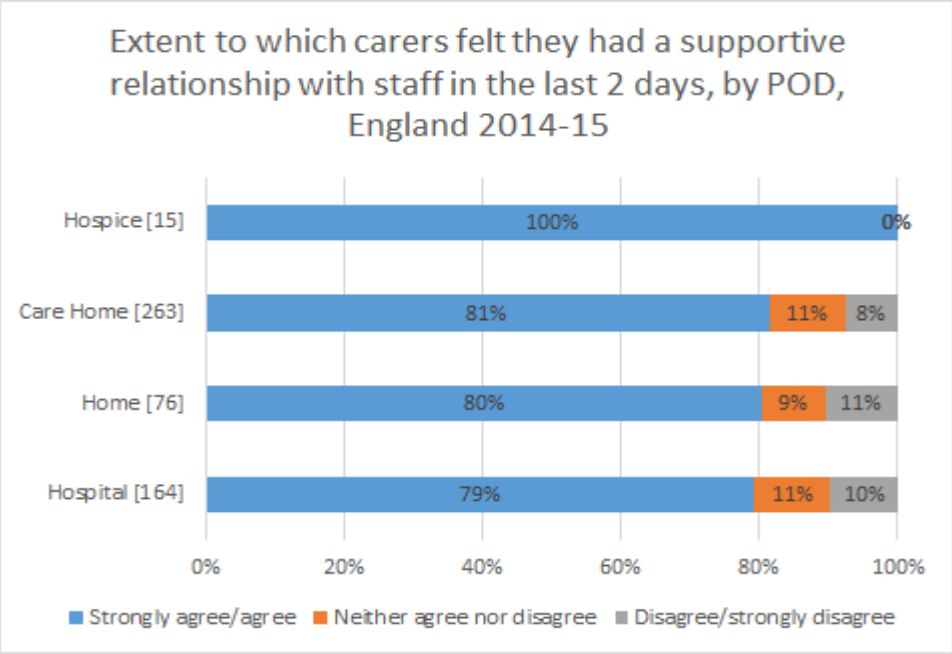

Figure 39 Support from HCPs in the last 2 days of life towards carers of people who died from PD/PSP/MSA, by POD, England 2014-15

Though there was no significant difference across the groups, a slightly greater proportion of carers felt unsupported by staff when their relative died at home. This was mirrored in the interview sample, with carers spending much of their time alone with their dying relative.

> *"a Marie Curie Nurse came for 3 nights out of the ten that he was so ill, but sadly not on the night he died" Sandra (PD) [Home]*

Although some carers welcomed the chance to be alone with their relative at the end of life in hospitals, care homes or hospices, support was there if they needed it, which was often not the case at home.

In locations other than home, aside from good communication, support for carers was provided through food, tea and space, with care homes and hospices both praised for the way they looked after the needs of carers.

> *"The aged care facility provided us with a quiet room where we could also sleep and offered us meals and endless cups of tea and coffee, biscuits and bowls of fresh fruit. Those small gestures did not go unnoticed and were deeply appreciated by us" Abigail (MSA) [Care Home]*

Though food and drink were provided less in hospitals, aside from on intensive care units, most carers stated that hospitals were happy to allow them to stay by their loved one's bedside, making it more likely that they would be present when the end came. Being present was one of the most important things to carers in the interview sample, almost all stated that they had been glad that they had been there

> *"you know if there is one thing I will always be grateful for it was that I was there <slightly teary>, I was there holding his hand…and I'm always glad of that, coz not everybody gets that comfort" Hope (PSP) [Hospital]*

or sad that they had not.

> *"I was very unhappy about the fact that I didn't say goodbye to her" Vincent (MSA) [Hospital]*

Many carers in both the interview sample and the VOICES survey were able to be with their relative when they died. Figure 40 shows that this was more likely to be the case if death occurred at home or in a hospice, principally because carers were already there; with carers significantly less likely to have been present when death occurred in hospitals compared to all other locations [Hospital vs Care Home OR 0.66 (0.499, 0.877) p=0.004; Hospital vs Home OR 0.218 (0.132, 0.359) p<0.001; Hospital vs Hospice OR 0.249 (0.071, 0.870) p=0.029]. When comparing COD, PD carers were more likely to be present than CVD carers when death occurred at home or in a care home, more likely to be present than 'Other' carers at home but less likely in hospital, and less likely to be present than Cancer carers at home or in hospital (see Appendix J xxxiv for graphs and statistical comparisons).

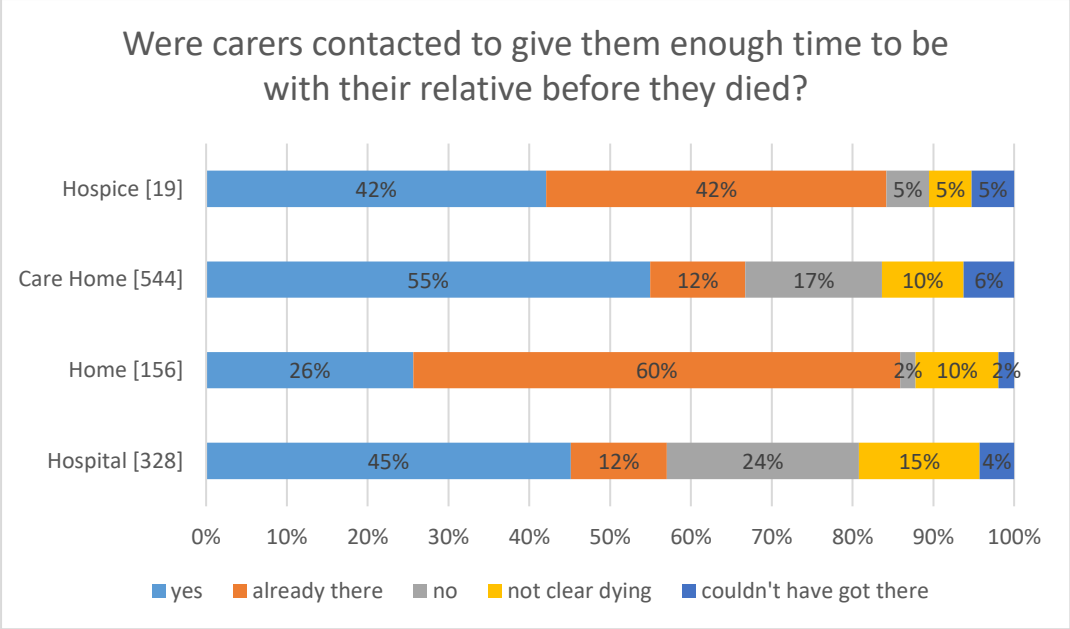

Figure 40 Were carers present when their relative died? By POD, England 2012-15

Although the uncertainty of the exact timing can make it difficult to be there, when carers were aware that the end was close, they were more likely to stay with their loved ones. Hope (PSP) was wavering between staying in the community hospital or going home, the staff said they would make her up a bed on the floor of the physio gym and so she decided to stay; twenty minutes later Dennis died. This reinforces why supporting carers and explaining that death is approaching is important.

In the interview sample, when carers were unable to be there it was principally because death had been sudden in hospitals or because it had not been made clear that their relatives were dying in care homes. In the VOICES sample, carers were more likely to be present at the end in care homes than hospitals however, perhaps because geographically they were nearer to the homes of carers and sudden death was less likely.

6.4.2 *Support at time of death*

In terms of the support that the differing locations offered at the time of death, hospices appeared to be most supportive, followed by care homes (Figure 41). Carers of people with PD/PSP/MSA who died in hospital were statistically less likely to answer they definitely felt supported than the carers of those who died in

Hospices or Care Homes [Hospital vs Hospice OR 0.264 (0.087, 0.799) p=0.018; Hospital vs Care Homes OR 0.635 (0.477, 0.844) p=0.002].

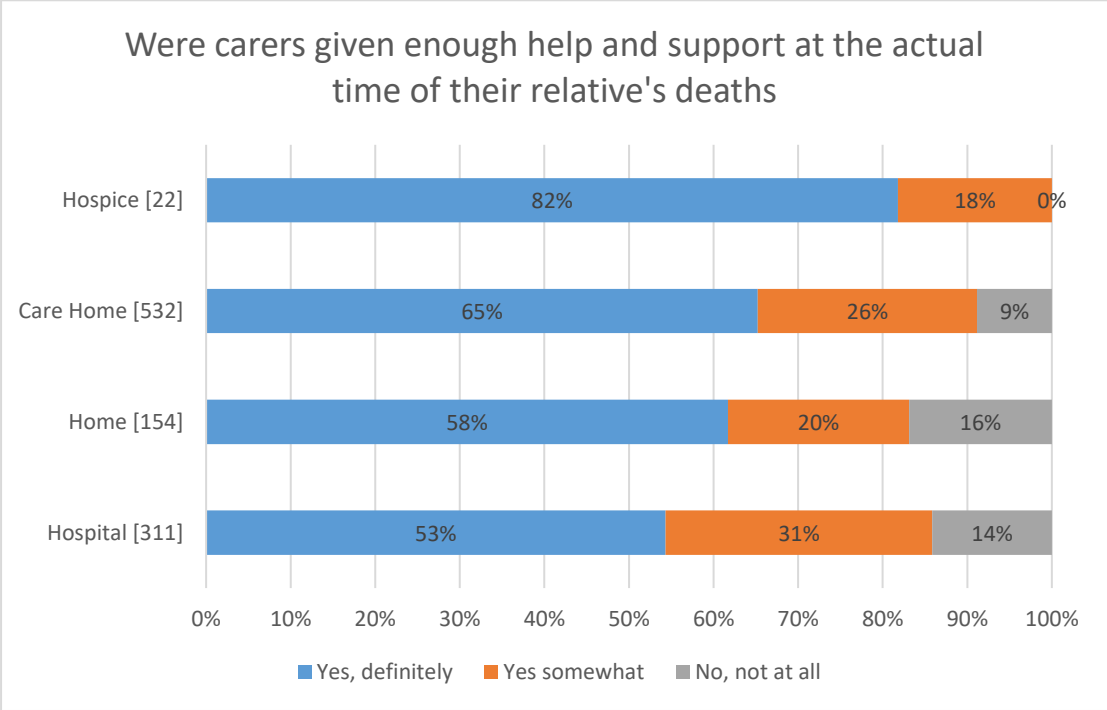

Figure 41 Support for carers at the time of death, by POD, England 2012-15

Carers whose relatives had died at home seemed more likely to have felt they were definitely supported than those in hospital, but this was not statistically significant [Hospital vs Home OR 0.739 (0.498, 1.096) p=0.133]. There were no significant differences between the responses of PD carers compared to carers whose relatives died from other causes across all POD (Appendix J xxxvii).

As Figure 41 shows, carers whose relatives died at home were more likely to have answered that they were not given enough help than those in other locations. In another question regarding the sensitivity of staff after death[24] 16% of carers whose relatives died at home answered that they had no contact with staff after their relatives' deaths, suggesting that they were alone, as carers in the interview sample had related was often the case. In other locations, help and support again equated

[24] Derived from VOICES question 48, see Appendix B

to touches of humanity, such as cups of tea being offered, and to being able to spend time with their loved one after they had died.

A point that carers in the interview sample mentioned, which may well differ from those dying of other causes, was the importance of ensuring that brain donation was accomplished at the time of death, if those dying had previously indicated it was their wish. When the process was dealt with well, carers related how gratifying they had found the experience. But sometimes staff were not aware about the details of brain donation.

> *"this is another thing that we were quite upset about, it was about half an hour after the machines had been turned off and we said 'right he was a brain donor', 'oh, it's too late now you should've told us', 'beg your pardon', 'yeh, you need to be kept alive' we were like, right" Julie (MSA) [Hospital]*

When Julie later found out that what she had been told was not true, it would not have been too late, she was even more frustrated and felt that more awareness about brain donation should be present. Even if staff were aware of the process, in the acuteness of the situation carers sometimes forgot to mention it, prompting Charles (MSA) to suggest that hospitals should actively record donor status on admission.

> *"I regret to say that when she went into hospital dying that was the last thing on my mind…I made a suggestion to the MSA trust that they should use their influence with the NHS that if someone goes into hospital you can complete a long form of all your history and details and so on but a question they ought to add to that is do you belong to any donor bank" Charles (MSA) Hospital*

6.4.3 *After death*

After their relatives had died, most carers in the VOICES survey felt that staff dealt with them in a sensitive manner (Figure 42).

Place of death [total answering]	Staff dealt with carer in a sensitive manner (%)
Hospital [314]	291 (93)
Care Home [531]	514 (95)
Home [128]	122 (97)
Hospice [23]	23 (100)

Figure 42 Sensitivity of staff towards carers after death, by POD, England 2012-15

This was significantly less likely to be the case in hospitals when compared to care homes [OR 0.418 (0.220, 0.796) p = 0.008], and less likely to be the case in hospitals than at home, though this did not reach statistical significance [OR 0.622 (0.247 to 1.566) p=0.314]. In hospices all carers in the VOICES survey felt that they had been dealt with sensitively.

Much of the interview sample felt that they were somewhat supported across all locations, with carers explaining that they had been seen by SPC teams in hospitals and care homes who were very helpful.

> *"the palliative care team at the <hospital> were great as well, they came and spoke to me before mum died, but after they were really empathetic, very supportive" Simon (PD)*

Some GPs were great, seeing carers weekly after their relatives had died and one care home had set up a celebration of life service. Elaine (MSA) mentioned that the hospice had provided her with pre and post bereavement counselling, which helped her immensely.

April (PSP) mentioned that one of the most helpful things that occurred after her mum died was that she was able to speak with the doctor who completed her mum's death certificate.

> *She <doctor> explained that she had considered carefully how to record the cause of the death and had decided to put PSP as the primary cause and pneumonia as the second cause. This was because if my mum had not had PSP, she should have been able to overcome a small patch of pneumonia. But because her breathing was so weak, she couldn't fight it. This explanation helped me*

enormously, because I had felt - and still feel - that I should have noticed her chest infection earlier. I am really grateful for those five minutes with the doctor; if I hadn't turned up slightly early, I would have just been handed the death certificate without explanation April (PSP) [Hospital]

There were a few carers who mentioned the guilt they felt due to their relative's acute deterioration and several others who suggested that some kind of discussion, or debrief, would have helped them to process the events of the final few days because they were left with a lot of unanswered questions. Brenda (PD) explained that she was due to return to the ICU to speak through Eddie's admission, so it appears that in some hospitals at least, a sort of debrief sometimes occurs.

"apparently in a couple of weeks' time we get invited in to talk to the sister if anything, if they could've done anything different, or was there anything we didn't like them doing or was there anything we thought was really good" Brenda (PD) [Hospital]

The only comments that carers suggested were insensitive occurred when HCPs seemingly found it hard to understand why a carer would be shocked that their loved one had died.

"Tony's doctor came out and I said 'I thought I'd have him for a little bit longer' and he just said something like 'well it happens to us all you know' and I went 'yeh, but I just wasn't expecting it at that time' and he said 'but you knew the illness what did you think was going to happen' " Helen (MSA) [Hospital]

Helen explained that she knew the end would come one day but that she had been expecting drifting away, not the sudden choking that occurred. She had practically prepared for life after Tony, for example he had taught her how to use the lawnmower and she already did the finances, but the emotional preparation was something different and several other carers echoed this sentiment.

"Even though we knew that eventually this would come to an end you really are not prepared for it and I really don't think that anyone who has not been through something like this can honestly help you because I feel very differently now that he's gone than I did before, even though I knew it would eventually happen, and I wasn't ready for it" Margaret (PSP) Home

In several cases carers had willed their loved one to die to relieve their suffering, but this was different to being emotionally prepared to live without them. A few carers were ready in both senses, those whose loved ones had agreed to withdrawal of further treatment and the spouses who had been aware the end was coming from day one and witnessed a steady decline.

6.4.4 *Bereavement support*

Unsurprisingly a carer's awareness and acceptance regarding the end of their loved one's life was related to their bereavement. Death that was unexpected, for emotional or practical reasons, was harder for relatives to come to terms with and these carers appeared to have more unanswered questions and more expressed regret after their loved ones had died.

> *"I now have physical disabilities due to caring for him as well as flashbacks of the morning I found him dead… I don't think any amount of counselling will ever get me over this, people and family think I have come to terms with it but I haven't" Tina (MSA) [Home]*

Sudden death did not always lead to increased grief, Susan, for example, took comfort from the fact that Paul had died suddenly.

> *"it sounds horrible but I was pleased the way he died because that's the way he would've wanted to go" Susan (PD) [Hospital]*

Paul had not wanted to linger in bed and despite Susan promising that she would never let him go into a care home, the hospital had made the decision that he was going; sudden death was therefore acceptable.

Because most of the carers had been providing care intensely for a long period of time, not only did they have to be prepared for the loss of their partner/parent but also for a loss of their own role.

> *"for people whose whole life revolves around the person you're caring for and then suddenly you've lost your raison d'etre if you like, much as it's an awful grind" Angela (PD) Care Home*

One might think this would mean that they were more likely to have been offered bereavement support, but this did not appear to be the case.

Most carers in the VOICES survey had not talked to any HCPs after their relative's deaths (Figure 43). Carers whose relatives had died in hospices were significantly more likely to have talked to an HCP about their bereavement compared to all other locations [Hospice vs Hospital OR 7.385 (3.002 – 18.166) p<0.001; Hospice vs Care Home OR 13.486 (5.483 – 33.171) p<0.001; Hospice vs Home OR 4.926 (1.939 – 12.516) p=0.001]. There was no significant difference between PD, PSP and MSA. There was little difference when comparing POD by COD, though PD carers were statistically less likely than cancer carers to have received bereavement support if their relative died in hospital (see Appendix J xxxix).

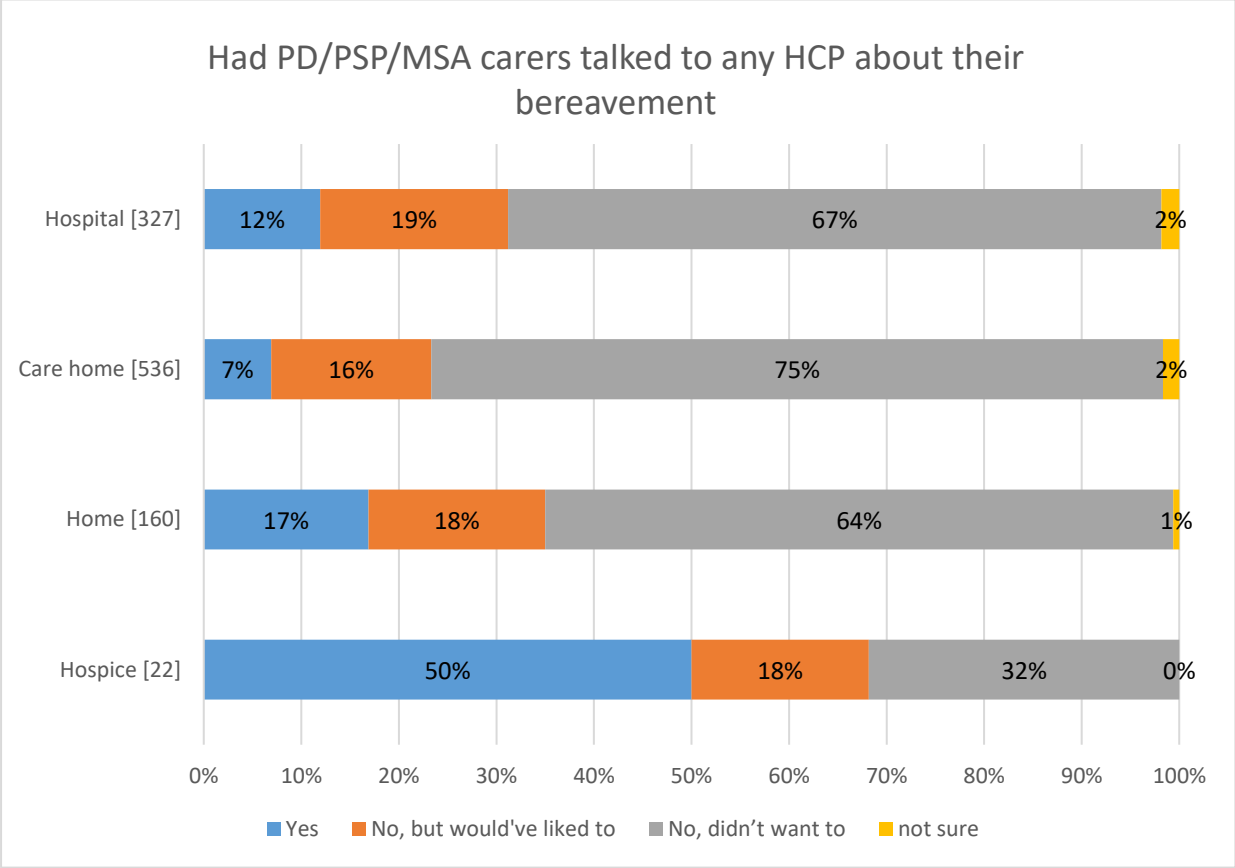

Figure 43 Bereavement support, by POD, England 2012-15

It appeared that many carers in the VOICES survey had not spoken to anyone because they hadn't wanted to; this was true of all carers except those whose relatives died in hospices (Figure 43).

There were several carers who felt the same way in the interview sample, stating that that they didn't feel bereavement counselling was for them.

"CM: If it <bereavement support> had been offered do you think that it is something you would have been interested in?
Charles: most certainly not, that's not my character" Charles (MSA) [Hospital]

There was some suggestion that people shouldn't need professional help; that they should be getting on with things themselves.

"I think unfortunately whatever somebody's condition is, whether it's PSP related or any other condition, to a very large degree you have got to pick yourself up and dust yourself down and get on with it" Constance (PSP) Care Home

And one gentleman, Colin, could not see what good it would bring to have bereavement support, suggesting perhaps what it could offer should be clarified.

"well what do you think bereavement support is? What does it mean? I mean people talk to me or whatever, or people do practical things? I mean I actually, I have to say, I mean bereavement counselling after a death I find it a difficult notion. I mean the person's gone, I spent my life with them and all that; what are they going to do to help me except to tell me to do other things and done the best you can and all these other sorts of things. I'm not a believer in bereavement counselling that sort of way, that's me I'm afraid" Colin (PSP) Care Home

There was a suggestion then by several carers that needing bereavement support was almost a negative character trait, with people talking about being 'sufficiently strong' to manage on their own. This likely reflects a societal viewpoint regarding coping with adversity which may well differ if this study was conducted in another country where counselling may be less of a taboo.

Other carers were not against the idea of professional bereavement support as such but felt that they had adequate support from other people in their lives.

CM: And do you think it would have been useful at any point since he's died to have talked to somebody about it?
Susan:"no coz I've talked to my family instead of just keeping everything all bottled in, I talked to them and they were just sitting and listening to us and that's all I needed" Susan (PD) Hospital

CM: did you get any offer of bereavement support?

> *"yes, I did, but I didn't really feel I needed it. I had terrific bereavement support, if that's what it is, from having a personal pastor, someone who actually does come and see me and talk to me and pray with me" Sebastian (MSA) Home*

In the VOICES survey, carers whose relatives died in care homes were less likely to have spoken to HCPs in their bereavement, but they were also less likely to have wanted to talk to anyone. It is not entirely clear why this is the case, but it may be because carers had already grieved to some extent and detached themselves a little, especially in cases of disease related dementia, which was more common in care homes.

> *"his personality did change, he wasn't the same person, I feel personally that, I know I'm saying that Derek died <9 months prior> but for me personally I lost him a long time before that, it was gradual and I think <12 months ago> when he went into hospital with the chest infection I think it would've been a shock if he'd gone then but it would've been kinder, because the deterioration after that was so awful that I think if he'd gone then it would've been better for everybody" Gail (PD) Care Home*

Importantly, a few of the carers who'd had counselling had needed it much later, certainly more than a year after their relatives had died. If the VOICES survey had been sent to them 4-11 months after their relatives had died, they would likely have answered no to wanting help, it was only later that the need arose. Julie (MSA) mentioned that she had initially not wanted bereavement counselling when her dad died, but she needed it two years later when everything caught up with her. Hope (PSP) also recalled that she'd had her counselling too early; now that she runs a support group she advises people to wait, if they have the option, because they will know when they need it.

> *"I was offered bereavement counselling by the hospice and I took it, I didn't feel I needed it but I thought it was polite <laughs>…what I realised was that I took it too soon, I really needed it when all the business that follows a death, the probate and everything, all that had finished and that's when the foreverness kicks in and you realise that everything has now changed forever" Hope (PSP) Hospital*

Hope took up bereavement support because it was offered to her, even though she had not felt she needed it. If an offer had been made to carers in the interview sample it usually came from hospices and this probably accounts for the significantly higher proportion of surveyed carers who answered that they had spoken to someone after their relative died in a hospice, as opposed to the other locations.

Some carers mentioned they knew there was support available from somewhere if they needed it and others had contacted charities, such as Cruse, and gone on their courses, or attended bereavement retreats. Only a few carers had been in contact with their movement disorder teams, but when they had they found it beneficial. A lot of carers mentioned letters they had received from HCPs, which were appreciated.

> *"Six weeks later I received a call from his neurologist (and promptly burst into tears) but he was a very kind man, and I also received a really lovely letter from his dentist. At my next visit to my GP I told her that my husband had died, but there was no support offered" Sandra (PD) Home*

Unfortunately, often letters were the only communication that carers received in their bereavement. There were several carers in the interview sample who had wanted more help but didn't get it.

> *"I do wish that 'end of life' support for the remaining spouse/family members were in place. If one has a faith then the hospital chaplain attends but for just one session. There are so many questions one wants to ask. Not just the nursing team but to ask the consultants too. I know that would be near impossible due to time and cost to NHS. Perhaps if someone (a PD nurse?) could visit a short while after a death in order to answer questions; that could be a possibility" Barbara (PD) Hospital*

Others had contacted Cruse or similar charities to find that they did not cover their area or had not known who to ask; these people equate to the carers in the VOICES sample who would've liked to talk to someone but had not.

Interestingly, despite hospices being most likely to have offered bereavement help, Figure 43 shows that they are no less likely to leave people wanting additional help. Helen (MSA) had been to speak to someone at a hospice and initially found it helpful

but when she later told them that she had considered suicide they informed her they were not a bereavement service and that they would need to report her suicidal intent. She answered 'no' when asked if she had received bereavement help, as did Angela below, so it may be the quality of the interaction which reflects whether people feel they have talked with someone about their bereavement or not.

> *"no I haven't had any bereavement support at all...my doctor did suggest seeing the counsellor that comes occasionally to the surgery and I did see her eventually, this was more than a year after Graham's death, but she just talked about anxiety and how to cope with anxiety and she didn't talk at all about the bereavement and so it wasn't any use really" Angela (PD) Care Home*

Angela explained that she had not talked the whole experience of her husband's death through with anyone outside of her family until her interview, which indicates that bereavement support means different things to different people and might explain the proportion of surveyed carers who were 'not sure' whether they had talked to anyone or not.

Most of the interview sample were unsure if bereavement help would be useful; because it had not been offered, they couldn't say whether they would have wanted it or not.

> *"I didn't have any offer of any sort of support whatsoever from anybody, whether it would've been well received I don't know because I never got it so I can't give you an answer" Vincent (MSA) Hospital*

As there was no option in the VOICES survey for people who were unsure whether contact with professionals would've helped them after their loved one died, these people are not represented in the VOICES survey. It is these carers, along with those who would have liked additional help, who may benefit most from bereavement support.

6.4.5 *Summary*

This section has discussed the interactions between the carers themselves and HCPs around the time of their relative's deaths. It has discussed what support meant to

carers and whether bereavement support was wanted/needed. Once again one of the most important points for carers was that their loved one was valued by the healthcare system and that their loss was therefore realised. Because carers had been caring intensely for a long time, they were often exhausted and felt bewildered when the end came and several of them were then left with unanswered questions. Despite an apparent need for bereavement support few people had been offered it and though many people felt they did not need it at first, some had found the counselling they had received useful.

Hospices seemed best at supporting carers. There was little difference found between the other locations though care homes were felt to show more sensitivity and support at the time of death than hospitals. Although home might be the PPOD ideologically, there are gaps in support systems that make a home death difficult for carers and a greater proportion of carers disagreed or strongly disagreed they had been supported when their relative died at home.

6.5 Overall Summary

In conclusion, most people who died from PD/PSP/MSA had not expressed a preference for POD; when they had expressed a preference, home was the most likely choice. Experiences at home were very dependent on the level of support available. Care at home was largely provided by the carer themselves, with additional support from paid carers or family. When the level of support was not great enough, and carers had become exhausted, it was unlikely that a person would die at home. Similarly, unless it was clear that a person was dying and they had expressed a wish to remain at home, often admission to hospital occurred and for a variety of reasons it was then difficult to get people home again. Interestingly, private homes were not significantly better than hospitals, the place that carers felt their loved ones would least like to die, across most domains. Care homes however did provide a greater support for the emotional needs and physical symptoms of those dying, and for the carers themselves, than hospitals did. There were several carers who mentioned that they had not wanted their loved one to die in a care

home, referencing negative media reports. Given that care homes provide a level of support at the end of life, which is second only to hospices across most domains, there is perhaps a suggestion that the rhetoric surrounding care homes should change. That being said, respect and dignity appeared to be shown less often in care homes than home environments and both hospitals and care homes appeared to treat people with PD/PSP/MSA with less respect and dignity than people dying from other causes. Chapter 5.1.3 (Table 8) showed that people with PD, MSA and especially PSP were felt to be less able to make their own decisions at the end of life than people dying from other causes and this may well be linked to the respect and dignity they were perceived to have been shown. Indeed, the other area of difference when comparing COD was regarding awareness of dying; with people dying from PD being less aware than people dying from other causes. Certainly they were less likely to have been informed that they were dying and again cognition, and the ability to communicate, may well play a role. Hospices appeared to be rated most highly across the VOICES survey and so access to hospice provision is an important point of discussion. However, the qualitative data showed that there are positive and negative points across all locations and though some aspects of care provision are difficult to change, such as the business of hospitals, there are simple changes that could be made to at least improve experience.

This chapter shows that maintaining identity by seeing a person as an individual and supporting their choices is the key to providing good care regardless of location. This improves not only the experience of the person dying but also improves the experience of their carer as they are more likely to have faith in a location that obviously recognises their relative's worth. Figure 44 outlines the themes of the chapter, it shows identity as the central focus with emotional and practical elements of support and preparation impacting on experience. Identity, in this chapter, encompasses personal identity regarding being seen as an individual, relational identity in regard to having family present and material identity being represented by the importance of an environment filled with photos/music that matter to the individual.

Figure 44 The principle themes of the project as they are represented in this chapter

Emotional support at the end of life comes from recognising a person's individual characteristics and sense of self and trying to maintain the things that give them joy, while practical support centres more on symptom control. This chapter shows that all locations are good at symptom control but that emotional support can sometimes be lacking. It also shows how important preparation is if dying in a particular place is of importance and that making carers aware that the end is imminently approaching is of benefit. Emotionally, people who are dying must be able to think/talk about it to prepare but, practically, they also have to be told. The same is true of carers. It may seem obvious to HCPs that the end is approaching but without clear unambiguous communication relatives can be left with unanswered questions that then impact on their bereavement.

In conclusion, it is hard to predict when the end of life is close for people with PD/PSP/MSA but it certainly appeared that prior planning, and being cared for by staff that knew the individual person and about their disease, improved the experience; not only for those dying, but their carers as well. Much of the support had to be set up far in advance of the last three months of life and has been previously discussed in Chapter 5.

Chapter 7 Identity, preparation and support

This chapter will outline a model that explains the main themes of the thesis. It will then explore the themes in greater depth and situate them within sociological and health policy literature.

7.1 A model

The two results chapters show that there are many emotional and practical elements that affect a person's end of life experience, but that they are principally related to preparation, support and identity. There are emotional and practical elements to preparation for the end of life, including awareness & acceptance of dying and ACP, which in turn require emotional and practical support, with co-ordinated care being delivered empathetically. The level of support a person needs and the level of preparation for the end that they undergo is shaped by their identity, encompassing personal, relational, collective and material elements. In addition, disease identity (here represented by HCP's knowledge of the disease) appears to be important as it also affects the way that an individual, and their family, interact with the healthcare system.

In the last few days of life identity, preparation and support continue to shape experience. Here preparation relates to the awareness of dying and the knowledge that death is approaching imminently; not only for the person who is dying but also for their carer/relatives. Support here relates to the relief of symptoms such as pain, support with eating and the ability to have family present. Support also relates to attempting to get someone to their PPOD, and to be able to do this awareness that death is imminent is needed. An understanding of an individual's identity is required to allow emotional support to be delivered and to ascertain the degree to which awareness of dying is desired, so the three themes remain closely related when death is imminent.

Figure 45 outlines the components that affect the end of life care experience for people with these diseases and their carers

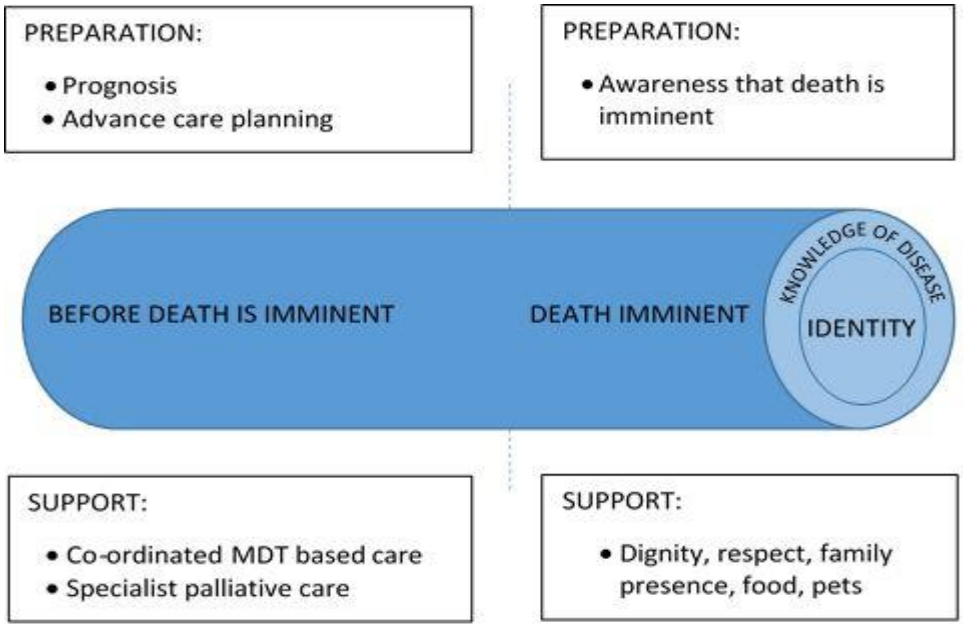

Figure 45 A model of the components affecting palliative and end of life care for people with PD, PSP and MSA

The model shows that there are factors which have more of an impact before death is imminent, those that are more in line with chapter 5 and those that have more of an effect when death is imminent, more closely aligned to chapter 6. However, at any point in time, from the diagnosis of a life limiting condition to the time that a person dies (and after the death for carers) there is preparation that can be undertaken for the death and support that can be offered. These factors may not necessarily be different than those dying from other conditions but there are some potential inequities in care born out from the rarity of PSP/MSA and the fact that PD is not always considered to be life limiting. In addition, these identifying labels, and HCPs understanding of them, shape the experience that people with these conditions have regarding the other factors. The individual nature of each person with the disease, the biological make up of symptoms, their psychological adjustment to the disease and what that means for their social situation will shape the preparation that they do and the support that they need; for this reason identity is central to the other factors. Identity is not split into differing time periods because the importance of self, worth (the way that a person was perceived by others), the relationships they had with family/friends/groups and knowledge of the disease were relevant across all places and times.

The following sections will talk through the three themes of identity, support and preparation, comparing them to the existing sociological literature and UK health policy. As this study was situated in the UK, most references are made to western societal values and the way they are represented in health policy. As the main differences compared to other COD appeared to be regarding identity and awareness of dying, these areas are focussed on more strongly within the discussion.

7.2 Identity

Identity in this project was comprised of the nature of the individual who died, the relationships they had with their families and friends, the way that their disease affected their sense of self and the way their family believed HCPs perceived them as an individual. Disease identity also played a role.

There are a multitude of ways to consider identity and it has been studied through many disciplines. Schwartz et al (137) in their handbook of identity theory summarised the different ways identity can be considered as:

- Personal identity: how an individual views them self as a person e.g. kind, brave
- Relational identity: their interpersonal role regarding others e.g. dad, husband
- Collective identity: their identification with groups or social categories e.g. British
- Material identity: what their clothes, house, car, finances say about them as a person

Schwartz et al (137) called for an integrated definition of identity suggesting that studies usually focus on one of the components rather than recognising that all will actually play a part in a person's identity as a whole. This study showed that being diagnosed with a

neurodegenerative disease has the potential to affect all these aspects (see Figure 46).

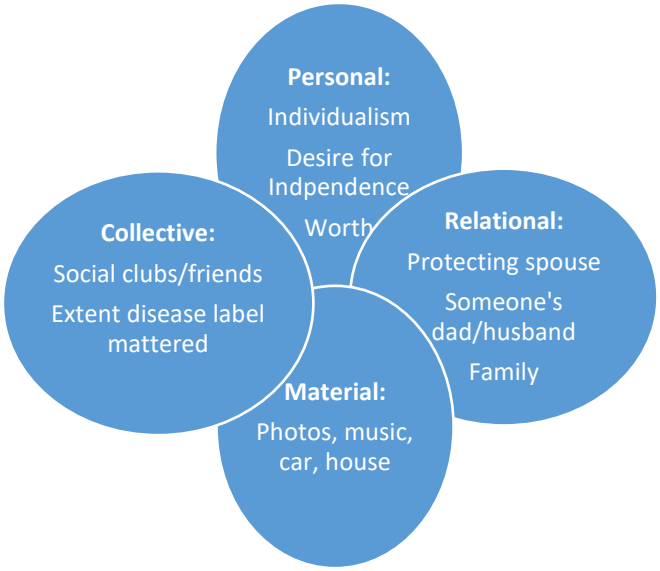

Figure 46 Aspects of Identity in this project

In the interviews it was clear that the personal identity of people with PD/PSP/MSA is threatened not only through the symptoms that occur due to the diseases but also through the way people with the diseases were treated by family, friends and HCPs. In the UK and other western cultures individualism is the dominant authority of society (138) and as such, personal identity and autonomy are felt to be of paramount importance. Anything which threatens individualism/independence is therefore problematic.

In 1982 Bury (139) described the 'biographical disruption' that can occur for people with chronic diseases, where a presumed future life is altered drastically by the problems the chronic disease brings. Charmaz (140) later outlined the loss of self that could occur through chronic disease. Although not previously discussed in regard to PD/PSP/MSA, biographical disruption and loss of self has been described in MND (141) and loss of self/personhood has been described multiple times in dementia (142-144); though there is some debate about the extent to which personhood persists in dementia (145), likely dependent on the definition of personhood adopted (146). The effect of relational identity is referenced in the literature that explores changing roles and carer burden. While some people find their relationships become stronger, others find their relationships are more

strained (147, 148); both were related by carers in this study. Collective identity was decreased by the fact people could no longer get to groups or activities, especially if friends did not call. However, it was also increased in relation to being a person (and carer of someone) with these disease labels, as support groups and forums provided the camaraderie of people going through the same thing. Lastly the burden of the diseases affected finances, either through loss of jobs or cost of care, and several carers related that they had to move to a new house or change cars to adapt to the diseases; reflecting changes to material identity. Preservation of material identity at the end of life occurred by ensuring environments were filled with photos and by ensuring a person was dressed in their correct clothes, to maintain their dignity.

Although all forms of identity play a role, the focus of this chapter will largely be on personal identity because of the level of importance it plays in UK society and health policy, in relation to autonomy and ACP.

7.2.1 *Personal identity and loss of self*

Charmaz described the ways that chronic illness could lead to a loss of self by discussing four points: individuals living restricted lives, social isolation, discrediting definitions of self and becoming a burden (140). In this study carers explained that as PD/PSP/MSA progressed their relatives were more restricted and required increasing amounts of care. Several carers were upset by the social isolation that they encountered as friends and family dropped away. Charmaz (140) suggested that sometimes restrictions and social isolation can be voluntarily, but prematurely, caused by individuals due to the stigma they feel. This has certainly been described in PD previously, with reduced mobility (9, 10), tremor (10) and speech difficulties (7) all cited as reasons for social withdrawal. Some of these points were echoed by carers in the interviews, but for the most part it appeared that they fought to keep their loved ones from social isolation and found it disappointing when relatives or friends stated it was too emotionally difficult for them to visit. Adequate access to support and timely rehabilitation interventions may reduce the degree of restriction.

In terms of interactions with HCPs, carers related multiple instances where discrediting definitions of self occurred. Sometimes this was through negative views, such as exclaiming

a person was not trying when it was their physical illness that precluded them from doing what had been asked. Predominantly however, discrediting occurred through tacit means by not acknowledging the person with PD/PSP/MSA as a 'bona fide participant' (140, p184) because communication was difficult, or treating them as a problem rather than a person; a frequently shared experience in regard to medical admission units. Carers were aware of this and felt that they could not leave their relatives alone, at home or in hospitals, because no-one would make the effort to talk to them.

The idea of tacit discrediting mirrors that of social death somewhat, where it appears, at least to some parties, that a person is gone and they are just looking after a body (149, 150). Bramley and Eatough (151) in their IPA study regarding an individual with PD reported that their subject experienced an inner self (mind) and outer self (body) at odds with one another. Her body was deteriorating, yet her mind remained intact; she felt ok around her family, as they knew the inner self, but was not ok around others as they only saw her body (151). Similarly, most carers in this study did not perceive a loss of personhood, whereas when they encountered HCPs they found that some of them perhaps had; there were multiple examples of communication where the individual with the disease was ignored and carers were spoken to instead. Timmermans(152) explored the idea of social death in regard to resuscitation and found that the way staff perceived the social worth of a person directly influenced the resuscitation attempts that were made (despite previous authors stating that the protocolised nature of CPR would prevent this from occurring). A similar phenomenon appeared in this study regarding discussions about admittance to ICU and whether a person should be for resuscitation; quality of life appeared to be frequently cited as a reason to avoid aggressive treatment, without first ascertaining the subjective quality of life that individual was experiencing. The anger relatives who experienced this felt was not just due to the judgement they had witnessed regarding their relative's worth, but also the fact that these pronouncements were often made in front of their loved ones, as if they were not there; further discrediting sense of self. One could argue that a more subtle form of discreditation occurred when health and safety concerns, even in hospices, overruled individual's desires for independent mobility. Health and safety was directly mentioned as

dehumanising by Constance (PSP), who was prevented from helping her husband to the toilet, meaning he had to wait, anxious that he might be incontinent.

Charmaz points out that 'supportive intimates usually bolster the ill person's self'(140 p183) and the sense of identity that the carers of those with PSP/MSA related was strong. This may be related to their knowledge of the disease and how it could affect their relative. They were so expert in the disease process they were able to separate its burden from their loved one's self and understand that it did not define them; though this of course could be due to post processing and the methods of recruitment used for this study. Those who are alone, without people who have prior knowledge of their identity are at greater risk of discrediting by medical personal because they do not have others to reaffirm their importance; something which echoes the fears that carers mentioned in their interviews in regard to people who did not have relatives to speak out on their behalf.

The last point in Charmaz's article regarding loss of self is in regard to becoming a burden, where physical dependency results in reduced independence and a person can feel useless, especially when they see the strain that care takes on their caregiver (140). Carers in this study frequently mentioned their exhaustion and certainly the length of time that care is provided, and the intensity of that care, is likely higher than for other diseases. An interesting point Charmaz makes is that part of becoming a burden is the ill person recognising that their illness has become their major source of social identity (140); it would therefore be interesting to know whether people with PSP/MSA desire an increase in knowledge regarding their diseases as much as their caregivers do.

Loss of personal identity/self is particularly pertinent in western societies, because much of our values are based on independence, autonomy and the role we have in society (153). Interestingly loss of the ability to communicate is rarely discussed in regard to personhood or the self and yet it is what sets these diseases apart from many other chronic illnesses and makes the threat for loss of personhood even greater (154). It is perhaps therefore not surprising that a proportion of the group had expressed that they did not want their life prolonged and in some cases that they wanted to hasten death. Monforte-Royo et al (155) in their systematic review regarding 'what lies behind a wish to hasten death' found that loss of self was one of the leading factors. Indeed, some of the issues related above such as

becoming a burden, feeling physicians have given up and a fear of losing autonomy are the principle reasons that people with parkinsonism requested assisted suicide at DIGNITAS (156)

7.2.2 *Will to die (WTD)/wish to hasten death (WTHD)*

Studies have shown that 20-30% of people with PD express death intent/WTD and around 11% express suicidal intent/WTHD; with depression being a consistent predictor of both (157-160). There are no published studies that discuss WTD/WTHD for people with PSP/MSA despite the fact that health related quality of life is shown to be worse, and depression greater, than for people with PD (161). The MND population have a higher request rate for assisted dying than any other disease group (162) and as the progression of symptoms for those with PSP/MSA is closer to MND than PD it is not necessarily surprising that some people with PSP/MSA expressed a WTHD to their carers. The reasons given for why people with MND have a WTHD are varied; some studies have shown a link with depression (163), others have not (164-167); being a burden (163, 166), feeling hopeless (164, 167) and maintaining control (164, 165) are all related, reflecting the loss of 'self' mentioned above (and the desire to maintain it).

Other studies concerned with the broader WTD, rather than a WTHD, have shown multiple related factors including increased disability (168, 169), speech impairment (169), incontinence (170) and depression (171). This study found that a WTD had been expressed by people with PD/PSP/MSA to their relatives and this may not be surprising given that Saleem et al (172) showed that 51% of people with PD/PSP/MSA had severe mobility problems, 28% had severe communication problems, 13% had severe trouble controlling urine and 16% felt depressed most of the time. Ohnsorge et al (173) have criticised the literature surrounding the WTD because when WTD is studied in surveys there is little effort made to distinguish between the differing intentions behind the WTD. Following multiple repeated interviews with 30 people diagnosed with terminal cancer and their caregivers (both relatives and HCPs n=116), they compiled a typology of intentions (173) that could account for a person expressing a WTD; many of these intentions appear to have been expressed by those dying of PD/PSP/MSA to their carers in this study (see Table 13).

Onsorge et al's intentions	Examples for this study
Wish to live	"CM: she'd never expressed that she wanted things to end? Charles: quite the opposite, it was the attitude was well we'll keep this ship going as long as we possibly can" Charles (MSA)
Acceptance	"My mother was calm, comfortable and at peace. She said things like 'I just want to sleep... forever', 'Is this what dying is like?' in the weeks before she died" Jennifer (PD)
Wish to die:	
Not considering hastening death	
Looking forward to dying	"he did say on several occasions, not just to me, but he said that you know, he would be happy to go, because it wasn't living" Constance (PSP)
Hoping that dying happens more quickly	"she would ask our pastor occasionally and perhaps the week before 'is it alright to ask Jesus to take me now?" Sebastian (MSA)
Desiring to die (but hastening death is not considered)	"He had previously told his carer he did not want to live anymore and that his quality of life was poor" Sandra (PD)
Considering hastening death	
Hypothetically considering hastening death (in future, if certain things happen)	"we had discussed it and he said that there's no way he said that he would stockpile pills or something he would do something you know before things got too bad" Aileen (MSA)
Actually considering hastening death, but at the moment (for moral or other reasons) it is not an option	"and he said 'oh, just let me take a tablet', I said 'do you know something dad, if I had one, I would' and he said 'I know you would, I know' " Julie (MSA)
Actually considering hastening death, hastening death is a (moral) option	"she said 'I wouldn't want to go abroad to that clinic' and by then she wouldn't have been mobile enough it would've been a major task anyway, she said 'if my doctor offered me an injection tomorrow I'd take it, but I don't want to go to a Swiss clinic' "Philip (MSA)
Will to die	
Explicit request	"I went in one day and they said to me 'we have to tell you this, because last night when the night team were going round he asked them to give him something' and I knew what they meant, he didn't want to wake up" Hope (PSP)
Refusing life-sustaining support (such as food or treatments) with the intention of hastening death	"My daughter tried to give Elizabeth a dose of antibiotics and although she couldn't speak Elizabeth clamped her mouth shut, her intentions were clear" Cecil (MSA)
Acting towards dying (such as suicide or assisted dying)	*No examples of this in the study*

Table 13 Quotes that reflect Ohnsorge et al's intentions to die (173 p1023)

In a different paper, reporting results from the same cohort, Ohnsorge et al presented the reasons, meanings and functions of WTD requests (174). The reasons related to the full range of bio-psycho-social and spiritual causes, including pain, anxiety, loneliness and being locked in a disabled body (174). The meanings related more closely to relationships with others and their culture, such as a desire to let nature take its course and avoid being a burden. The functions related to more practical concerns, such as an appeal for help with symptoms, a gateway into discussing dying or a way to preserve agency (174). Ohnsorge et al cautioned caregivers not to assume that expressions of a WTD equated to depression (174) and although people with MND who have depression are more likely to express a WTD than those who are not depressed, many people expressing a will to die do not have depression (175). Most carers in this study did not feel that depression was the cause of their loved one's WTD. They equated it far more often with the existential suffering that loss of independence, speech and swallowing could bring and a readiness to die to escape from that suffering. Often, they saw the WTD as a marker of acceptance and saw that their loved ones continued to live, enjoying time with grandchildren for example, at the same time as expressing a WTD. Ohnsorge et al described that the wish to die coexisted with the will to live and both fluctuated over the course of a person's deterioration in a non-linear fashion (173, 174). Within their study 8 people had a fixed WTD, 5 only ever had a will to live and the remaining 17 fluctuated, illustrating the dynamic characteristic of a WTD (174). Within the narratives related by carers in this study some were fixed in their desire for death to come, because their lives had become unbearable. Others only ever wanted to live and continue as long as possible. Others who had mentioned that they would end their lives when things got worse, didn't seem to reach the point at which life became unbearable and some seemed more at peace as the disease progressed.

The fluctuation of a will to die likely reflects the response to loss of self that is described in the literature. Charmaz pointed out in later work that loss of self is not fixed in most cases, but fluctuates, and people find varying ways of dealing with their illnesses from fighting the diagnosis, to surrendering to the diagnosis (contentedly) or to resigning oneself to the diagnosis in depression (176). As people are faced with the threat to identity that chronic illnesses bring, and the change it makes to previously imagined futures, they can deal with

that disruption in differing ways. The different ways of coping, especially those that allow people to construct new meaning in their lives, has been termed biographical repair.

7.2.3 *Biographical repair*

Biographical disruption was first described by Bury, who postulated that being diagnosed with a chronic illness forced a person to review their previous life goals and led to a requirement for social change, due to the stigma associated with chronic illness (139). Locock et al revisited this work when they explored biographical disruption in MND, showing that the idea of biographical disruption and subsequent repair was possible even within a terminal disease, where improvement from a symptom point of view was not possible (141). They explained an abruption, a feeling that life was already over when people were first given the diagnosis of MND, disruption much like Charmaz's loss of self, and varying examples of repair, including (141 p1047)

- balancing avoidance and acceptance of the future
- keeping hold of normality, which sometimes meant employing paid carers to allow informal carers to return to a role of relative instead
- creating new normality by starting new hobbies or socialising online
- living life to the full
- and finding new meaning; becoming closer in personal relationships

All these factors were mentioned by carers in this study (see Table 14). Locock et al explained that each time a new hurdle occurs, life can become disrupted again and so, as with the WTD, the process of disruption and repair is in flux (141). As repair happens, people can deal with more than they thought possible and this has important implications for the timing of discussions regarding future wishes. Repair also means that people may value life and that no-one should make a judgement about its quality and importance except the person with the disease.

Indicators of biographical repair	Examples from forums and interviews
balancing avoidance and acceptance of the future	"Talking about it when it is less critical early on in diagnosis was what my Mum had wanted to do - then it was put aside. She - when very unwell - would say 'I think it is time for my Advance now.' So I think it gave her reassurance" Jennifer (PD)
keeping hold of normality, which sometimes meant employing paid carers to allow informal carers to return to a role of relative instead	"I think the reason we did it was I didn't want to be her carer anymore I wanted to be her daughter and just go and chat to her because she couldn't talk, move or do anything by that stage and it was just nice going in, taking the kids in to see her and taking the dog in and all those sorts of things rather than worrying about whether she had food or medication, all that sort of thing" Kate (PSP)
creating new normality by starting new hobbies or socialising online	"he was a voluntary educator for Parkinson's, which mean you, they give you, they they train you and you have um disks and you know DVDs to show and you go to care homes and speak to the staff… so he enjoyed doing that" Brenda (PD)
living life to the full	"one of her preoccupations was spending time with the grandchildren and doing all the usual granny things with them… she was very determined to keep going and as she declined we became more and more expert at keeping her mobile to the extent that in the month before she died, and she was getting pretty bad at that point, uh we managed to fit in a trip to Ireland, fit in a trip to Lourdes and fit in a trip up the shard in London" Charles (MSA)
finding new meaning; becoming closer in personal relationships	"you do start to appreciate each other, all over again you know because life kind of takes you on a whirl you know you're both working, and that forced us to be together so although it was a horrible time I actually look back and think well weren't we lucky" Helen (MSA)

Table 14 Quotations from the qualitative sample that indicated biographical repair, as defined by Locock et al (141, p1047)

Some of these instances of repair relate closely to personal identity, whereas many of them are more to do with relational, collective and material identity. As the attributes that people value in themselves are affected and bodily function decreases, it is likely that people will look more strongly towards other aspects of their identity to help them to continue to live with the presence of the disease. Fegg et al showed this in their study regarding meaning of life for people with PSP (177); those affected with PSP attributed less meaning to health and work than healthy German counterparts, whereas family, home,

animals and spirituality retained their importance. Fegg et al had previously shown similar results with an MND population (178).

Western literature, regarding identity, is predominantly related to personal self and almost all UK policy, with regard to patient care, references person-centred care equating to personal self and autonomy. Roger et al in Canada are critical of the importance placed on autonomy and noted that the people they interviewed with PD, and their relatives, very much lived an intertwining identity as a cooperative unit (25). The same appeared to be apparent in this study, relational identity and the collective identity of the immediate family seemed at least as important as autonomy. This may be because carers were interviewed rather than individuals actually living with/dying from the diseases, but it mirrors what I see in practice.

Boersma et al found that as people with PD felt threatened by a loss of personal identity, identifying with the larger PD community gave meaningful friendship and support (10). Hudson et al noted that PD groups provided psychosocial support, practical support and continued connection, especially for carers, whereas some people with PD (and occasionally carers) found the groups depressing (7). As with Hudson et al's findings, carers in this study appeared to gain benefit from the charity support groups, but there appeared to have been more ambivalence reported from those with the diseases; especially MSA/PSP. Locock and Brown (179) explored the attitudes of people with MND and their carers towards peer support groups and showed a similar level of ambivalence. Some people with MND found the social comparison useful to give them hope or make them feel better about their current situation, perhaps aiding repair, whereas others were shocked by what lay ahead (179). Some people rejected being seen as a person with MND and labelled because of their diagnosis (179). Whereas others liked being a part of a group that was in the situation together and revelled in the collective identity; these people also felt they could be more like themselves and talk about things other than MND because the group already understood MND, so it restored their 'normalised identity'(179, p1502).

This last point may explain to some extent why knowledge of disease is such an important issue, especially for people with rare diseases such as PSP/MSA/MND; when other people/HCPs understand a disease process they can perhaps more readily separate the

individual person from their diagnosis. This point, along with other factors that make knowledge of disease important, will be explored in the following section.

7.2.4 *Knowledge of disease*

The desire for HCPs to know more about particular diseases and the way they can affect a person is common in the palliative care literature: the CQC have identified a lack of understanding and training as an issue in caring for people with dementia (180, 181) and authors in the UK have cited a lack of knowledge as an issue for people with MND, especially with regard to paid home care workers (107, 182). Hudson et al identified the same concerns in Australia regarding PD; carers were particularly anxious that HCPs knew enough about PD to meet the needs of their relative and anxiety over hospital admissions was reduced when carers perceived that expertise was available (7). In this study one carer mentioned that if people thought more about the non-motor side of PD they may be more forthcoming with empathy, but the desire for increased knowledge was predominantly related to practical concerns, such as medication, mobilisation and support for eating and drinking.

The emphasis on knowledge of disease from the carers of people with PSP/MSA was greater. The practical concerns were still there, but there appeared to be a stronger emotional element attached to the disease label that was related to identity. In terms of self-identity, having to explain a diagnosis repeatedly to HCPs means the focus of care, at least initially, is on the diagnosis and learning about it, so a proportion of time is spent explaining the disease rather than addressing the concerns of the actual person; the focus automatically becomes biological to some extent. If continuity of care is not present, and the diagnosis needs to be explained repeatedly, this could lead to a person feeling defined by the disease, rather than feeling they are an individual who happens to have the disease (reflecting the burden of chronic disease suggested by Charmaz (140)). In addition, having to repeatedly explain the disease and how it affects you, sets a person apart from others and increases isolation, a phenomenon reported in the report from Rare Disease UK regarding mental health (183). Relational identity might be affected through increasing dependence, as spouses or children become carers, and it is not hard to see how someone

in the position of a carer may also start to incorporate the disease into the way they view their loved one, especially if they must repeatedly explain the diagnosis to other people.

However, if repetition and explanation was the principle problem, then it should not matter if HCPs were not interested in knowing about the disease, provided they were able to deliver adequate care. Although one carer, Charles (MSA), did express this view, most were adamant that a lack of knowledge affected care. Other carers said that it was not the lack of knowledge that bothered them per se, they recognised that the rarity of the disease precluded widespread knowledge; it was when HCPs did not want to learn more about it that they were most frustrated. This was related to empathy. If HCPs knew more about the disease they could understand better what a person was going through. Perhaps HCPs need to think more about the concepts of biographical disruption (and repair) so that they understand that dismissing the importance of knowing more about a disease is belittling the huge hurdle that the individual, and their family, have surmounted. Getting the diagnosis on the death certificate is an extension of this and appeared to help carers maintain the identity of their loved one as a person who fought bravely until the end, rather than someone who weakly succumbed to a 'simple' chest infection.

There is very little literature regarding the way rare diseases impact on identity, possibly because 80% are genetic and affect children, whose personal identity was not necessarily established before the disease took hold; so degenerative diseases like PSP/MSA are rarer in their experiences still. Interestingly MND is a rare disease in terms of numbers[25] and yet due to increased publicity it was not perceived to be as rare by carers in this study; they felt more HCPs and members of the general public knew what it was. A literature search suggests the same is true within medical circles as there are 20179 studies for MND on 'Medline' but only 2239 for PSP and 2575 for MSA; even less when it comes to end of life care. Joachim and Acorn (184) in their Canadian study regarding life with a rare chronic disease found that the ignorance people encountered affected their sense of self; they suggested that HCPs need to consider the rarity of a disease as well as the symptoms it

[25] A rare disease is classified as such when it affects less than 5 in 100000 people (EURORDIS)

causes to provide useful care. The EURORDIS survey, a cross Europe survey of people with rare diseases suggested the same was true of relationships with friends and family, with around 50% of respondents feeling that the rarity of their disease caused, or amplified, their isolation due to a lack of understanding, (185), though interestingly 45% felt it had strengthened their immediate family unit.

The rare disease surveys show that there is a lack of information and understanding about rare diseases and highlights that patients themselves have to become the experts. This in itself can change the dynamic between people with the diseases and HCPs (186) and certainly affected the degree that carers in this study felt they could trust the professionals they met. There were increased concerns regarding the practical delivery of care such as getting the right equipment at the right time, as that relied on understanding the disease and its progression, and several carers noted a delay in adequate services because they were not yet experts themselves. Carers also explained the difficulties they had encountered with gaining CHC funding and benefits, partly because the diseases were unheard of and partly because unless they went to the support groups no-one had informed them about their rights. This again reflects the EURORDIS survey, where 70% of people surveyed with rare diseases felt ill informed about their social rights (185).

Better knowledge about diseases certainly improves care on a practical level. Though papers written about rare diseases state that medical education should provide increased knowledge of that disease, across healthcare disciplines, this is not a particularly practical suggestion. Far better is the provision of continuity of care, so that constant focus on the disease itself and re-explanation about what it means is unnecessary. Arguably patients should be looked after in specialist centres with expertise and MDT working, and yet many people with rare diseases do not know if there is a specialist centre for their disease (187). Most of the carers for people with PSP/MSA in this study stated that they went to specialist hospitals for their care, with some of them travelling for hours to attend, yet the services suggested did not then automatically follow. Carers were forced to organise them themselves, spending hours trying to co-ordinate care; issues that were common in the rare disease UK report (187).

7.2.5 *Summary: Identity*

This section has explained the theme of identity, something that has not been discussed in detail regarding PD/PSP/MSA before. Although Charmaz's theory of loss of self and the idea of biographical disruption was described for chronic diseases in general, the fact that PD, PSP and MSA often cause a loss of speech, mobility and cognition makes the threat to personal identity even higher than for many non-neurological chronic diseases. For PSP/MSA, the rarity of the diseases further affects identity and adds an additional component to the complexities of managing care. When it comes to planning, decisions will undoubtedly be affected by an individual's identity, not just the way they have always felt about planning, but also how much loss of self they have undergone and similarly where they are in terms of any biographical repair. Towards the end of life, carers related that support hinged on human factors and allowing things that matter to an individual to be provided, again showing the importance of identity and how it increases right at the end of life.

7.3 Support

Support in this project comprised of the help provided by HCPs, family, friends and external agencies, such as transport providers. 'Support' was also split into time frames: before death was imminent, at time of death and after death (for carers). It overlapped with the other two themes as good support improved preparation (and vice versa) and excellent support was felt to be akin to care which bolstered identity.

Both results chapters discussed the importance of co-ordinated care and indicated the high care needs that people with PD/PSP/MSA have as the conditions progress. Within the interviews carers clearly voiced the difficulties they had with providing 24-hour care, seven days a week, for months/years prior to death being imminent. One of the main issues described was a lack of timely access to services, including the automaticity of referrals to SPC. A lack of support can lead to an individual feeling more like a burden and, as discussed above, this has been linked with a loss of self and the will to die.

7.3.1 *Access to medical and social services*

A lack of co-ordinated care has been described multiple times for those with PD (5, 9, 148); it is also the focus of the majority of reports aiming to improve palliative care provision (82, 180, 188, 189). The lack of knowledge about rare diseases makes co-ordinated care even more pertinent and the rare disease strategy set out guidance for improving the provision of services for rare diseases by 2020 with one of its main aims being an improvement in co-ordination of care (190). Unfortunately, a recent report showed that people with rare diseases still felt co-ordination was a problem, with 35% feeling care was less coordinated in 2015 than in 2010 (187). In addition, although centralised specialist clinics were meant to liaise and educate local services to improve knowledge, and continuity, this only happened in 30% of cases (187). This reflected the findings from the interviews in this project; co-ordinated care was a rarity and when specialist nurses were able to help co-ordinate they were lauded. People with rare diseases are meant to have a co-ordinator to drive care and yet only 12% of people surveyed in the rare disease report did; most often this was a specialist nurse (191). Parkinson's UK's most recent audit, in 2017, showed that 96% have access to a PD nurse (improved from previous audits) and that most services were improving access to people specifically trained in PD (192). Ideally Parkinson's UK would prefer clinics run on an MDT basis, so that physiotherapy, occupational therapy, doctors, nurses and other allied health professionals were all available in a one stop shop and availability of this type of clinic had increased in the latest audit, but not everywhere. In this project, some carers lived in an area where a neurological navigator was present and they reported a better access to services; Calvert (193) showed the same was true for people with PSP/MSA in their research. Care coordinators/navigators have been put forward as a way to improve coordination across services in the government's commitment to end of life care (189), with the national council of palliative care set to look into implementation.

In terms of social services support and help finding paid carers, CHC funding was reported to be a big problem in this project (see Chapter 5.2.3). This has been reported across other disease groups and widespread geographical variation has been shown (194). As of October 2018 new rules came into force regarding CHC provision that aimed to lessen the postcode lottery and put the individual with the disease and their carer at the heart of the

assessment(195, 196). The new assessment is based on need, rather than diagnosis, to provide a more equitable service and part of the assessment is to take place with the main HCP, which may lessen the effect that a lack of knowledge can bring (195).

7.3.2 *Access to SPC and the hospice*

During the interviews, carers pointed out that they had noticed that access to SPC services and support did not occur with the automaticity they perceived for people with cancer. Similarly, Hasson et al commented on the lack of automatic referrals to hospices and a difficulty in accessing them for those with PD (5). This is a common finding in the literature for non-cancer conditions (180, 197-200). Indeed, the NCPC report in 2015-16 pointed out that whilst only 31% of people who died had cancer, they made up 60% of hospice care, with older people being represented less often; people with neurological disease (not including MND or dementia) made up 10% and accounted for 4% of deaths (199). Non-cancer provision has risen but inequity is still there(199). A 2018 retrospective cohort study across UK hospices also showed that older people, and those with non-cancer conditions, were likely to be referred later to palliative care(200), reflecting the feeling carers had in regard to services coming too late (see Chapter 5.2.5). However, part of the question should be what are hospices and SPC providing people. Although the symptom burden of many diseases, in terms of number of symptoms, equals that of cancer, many of the symptoms in movement disorders relate to issues that SPC cannot necessarily help with, such as reduced mobility and fatigue. There is no denying that people with severe pain that has not been eased by their usual doctors should be seen by SPC but a lot of the things that carers loved about the hospice, such as the way that they helped co-ordinate care and provided respite periods could be provided by existing medical/social services. Field and Addington hall (201) discussed whether it was right to roll out SPC to all and argued that although people needed better holistic care this should not have to be provided by SPC. They also argued that most SPC physicians were skilled in cancer, but not other diseases (201), although the balance of this has probably been redressed now as more SPC physicians take on specialist interests outside of cancer.

Arguably this study indicates the hospice is not necessarily needed for practical support, aside from the coordinating role it performs, but may be needed to a greater extent for emotional support. Given the existential crisis that people with these diseases undergo in terms of identity, especially PSP/MSA due to the speed of decline and rarity compared to PD, they may need earlier access to the hospice for help managing this. Studies have suggested short term SPC access for people with neurological conditions (74), which certainly may work for PD, whereas this thesis indicates the rarer diseases may need sustained access, partly because the diseases progress faster, but also because the hospice can already provide a continuity that other services lack.

7.3.3 *Support at the end of life*

At the very end of life, when death was imminent, support related to the control of physical symptoms and practical concerns, such as eating and drinking, as well as human factors that were more closely related to an individual's identity.

Several surveys, reviews and qualitative studies have been conducted worldwide to ascertain issues that are felt to be important at the end of life for people with terminal diseases (life expectancy though to be less than 6 months). For those dying, and their relatives, control of physical symptoms ranks highly (202-204) as does the need to have confidence in physicians (202, 204). Care that is respectful/compassionate (204) is felt to be important, as is honest/effective communication from doctors (202, 203). A recent review regarding hospital deaths highlighted that those that are dying also feel the environment they are in is important, in terms of larger de-medicalised rooms (205), yet interestingly in almost all of the surveys actual place of death is ranked as one of the least important concerns.

7.3.4 *Physical symptoms/support*

Dying in pain is one of the things that people with palliative conditions fear most (77) and it is one of the aspects that people dying from chronic diseases and current/bereaved family members feel is most important to control (202-205). Most people did not have pain or other symptoms in this study and if they did the symptoms were usually well controlled

(Chapter 6.2.2); this meant they were not raised as an issue of predominant focus in the interviews. However, when pain was present and intractable, as in the narrative from Aileen regarding her husband John, it became the focus of care and was hugely important. Fortunately, most people with PD/PSP/MSA do not suffer from uncontrollable pain; in the VOICES survey (2014/15) only 2.8% of carers disagreed that their relative had sufficient pain relief in the last 2 days, with 20% stating pain relief was not needed at all. This contrasts with Goy et al's (12) study where 27% of carers felt those with PDRD received no pain relief, despite moderate/severe pain being present. It is not clear why there is such a difference except that their study asked about the last month of life and the VOICES data implies that pain relief improves across all locations in the final 2 days.

The importance of eating and drinking seemed to be related to the amount of communication from HCPs. Where communication was good and reasons for preventing eating/drinking were explained, as in hospices, carers did not feel it was an important issue (see Chapter 6.2.3). Many carers felt they had to be present to advocate in hospital situations for pain relief, and food/drink, and this was also reported by Teno et al (206) in their study with bereaved relatives. In their study carers only felt relief from the burden of advocacy once hospice/SPC was involved(206).

7.3.5 *Emotional/spiritual support*

Although a review by Virdun et al (205) mentioned that it was important HCPs took a personal interest in a dying person and treated them with dignity, several of the studies informing the review had 'being seen as an individual' ranked lower than many other attributes (202, 204). This finding contrasts with this thesis as HCPs recognising the person as an individual was hugely important. This difference may be because people with reduced communication were excluded from the surveys that informed the review and these are the people most at risk from being ignored, and whose relatives are most concerned about efforts being made to see them as a person. Dignity in this study related to maintenance of identity and having worth recognised by HCPs and this is in keeping with the Royal College of Nursing's definition of dignity (207). In the VOICES surveys, although there was no difference in the support offered for physical symptoms when comparing those dying from

PD/PSP/MSA to those dying from cancer, this was not the true for dignity and respect. Although the ranking of services was the same, the percentages of people always treated with respect were higher for people with cancer across all services, apart from GPs. The difference may well reflect the fact that a higher proportion of people with cancer will retain communication and cognition; only 7% of people dying from cancer were felt unable to make decisions in the last 3 months compared with 23% MSA, 52% PSP and 30% PD. The fact that respect and dignity is significantly lower in care homes highlights an area to focus improvements. The VOICES survey does not show the length of time a person was in a care home before they died, and this would be an interesting area of exploration as carers in the interviews suggested care was better when staff knew the person and their family well. There is some work suggesting that transfer to a care home, especially if from a hospice setting is met with dissatisfaction (208). A couple of carers had experienced this transition, one found it fine, the other felt care decreased mainly because it was a specialist neurological home and she felt there was not enough focus on the individual, something which had not occurred in the hospice.

That trust/confidence in physicians ranks highly, is important regarding the rarer conditions as it was clear less trust/confidence was present if staff did not know about PSP/MSA and more confidence was present if they did. Compassion was also related to knowledge of the diseases.

7.3.6 *Summary: support*

Regardless of place, the main determinants of positive care in this study were time, continuity and communication. The environments that provided these factors were felt to be more supportive.

7.4 Preparation

Preparation in this study related to knowledge about prognosis, ACP and awareness that death was approaching for those dying and their carers. The preparation that could be undertaken was related to whether a person had the information to prepare practically and whether emotionally they were willing to think about the future or not.

Preparation, both practical and emotional is linked to the awareness and acceptance of dying. There is debate in the sociological literature about the extent to which a denial of dying is present in society (91) but many policy documents in the UK decree that denial of dying is a national issue which is affecting planning for good end of life care provision (77, 82, 83). Part of this denial, it is postulated, comes from the removal of dying from communities into institutions, meaning that most people have not readily experienced dying.

Historically, along with medicalisation removing people from communities and into hospitals, there was also a switch in power with regard to who controlled an individual's death(91). Research in the USA, in the 60s, illustrated that patients had little say in what was happening to them, especially with regard to awareness of dying (95, 209). Glaser and Strauss' study in 1966 led to the development of awareness contexts, with the states of awareness being

- Closed awareness: doctors (and often relatives) know an individual is dying but the dying individual is not told and remains unaware
- Suspicion aware: the dying individual suspects something is wrong and tries to get the healthcare staff to tell them
- Mutual pretense: the dying individual is pretty sure they are dying, the doctors/relatives feel the same, but no-one openly talks about it and the dying individual is not told that they are dying
- Open awareness: the dying individual is told that they are dying

Glaser and Strauss suggested that HCPs were deliberately preventing awareness in dying individuals because acknowledgement of dying opened up additional emotions and made providing care more difficult (95). Their study, alongside other pieces of work such as Elizabeth Kubler Ross's 'on death and dying' (94), led to calls for more open awareness and there followed an assumption that open awareness was preferable for patients, as well as HCPs, at least in the UK/USA (110). There has been criticism of Glaser and Strauss' model because it paid little attention to the part that the emotions of a dying person play in their awareness (210, 211) and arguably, as open awareness increased, the way that an individual dealt with the knowledge that they were dying required more exploration. Timmermans added to Glaser and Strauss' construct by pointing out that once a person had been told they were dying they dealt with that knowledge in differing ways (211). He expanded their

awareness constructs to focus on the dying individual themselves, so that open awareness split into three parts: suspended, uncertain, and active. Suspended open awareness referred to those who block out the bad news they have received, uncertain open awareness referred to a maintenance of hope (that relied on the uncertainty of prognosis) and active open awareness referred to people fully accepting and able to discuss aspects of future care. Most of the people with PSP/MSA were in some form of open awareness in this study, but it was clear their ability to think about it in depth affected how open. Timmermans (211) pointed out the role that HCPs have to play in awareness but arguably, with the advent of support groups and online information, the ability to be better informed exists and so closed awareness should be more unlikely still.

The next section outlines issues akin to awareness of dying: the sharing of prognosis and information regarding dying once the conditions worsened.

7.4.1 *Prognosis/planning/awareness of dying*

The 'information tension'(212) that has been noted previously for people with PD was evident in the stories carers recounted in this project. There are several reasons that have been recounted in the literature that could account for this; a lack of acknowledgement that people die from PD (7, 9), a reluctance to discuss dying on the side of patients and their families (4, 9, 10) and the difficulty doctors have emotionally discussing the life limiting nature of disease(213). The latter two reasons are likely to be the same for those with PSP/MSA, though prior to this study there was little/no literature regarding the sharing of prognosis/ACP in these diseases to support this assertion.

7.4.2 *Is PD terminal?*

In 2006 Hudson et al discussed that one of the major barriers to people with PD receiving palliative care was that it was not considered to be a terminal disease (7). Most of the carers in this study had been told that 'you do not die from Parkinson's disease' and in a recent Irish study most people were told that PD was not terminal (9). One might argue that this is akin to closed awareness, but Glaser and Strauss (95) suggested that doctors willingly deceived patients, whereas the heterogeneity of PD does make an accurate prognosis

difficult; it may well be that HCPs had not discussed the end of life because they had not believed it would be caused by PD. Awareness is not as reliant on doctors now as it was in the 60s, especially with the widespread use of the internet; multiple studies have shown that life expectancy is reduced by PD (57, 214, 215) yet the idea that you can die from PD, or rather the complications directly related to it, is not readily acknowledged on PD websites (216, 217) and this should perhaps be rectified. This study adds to the evidence that PD can lead to death, with data from the VOICES survey suggesting that up to 50% of deaths are thought to be directly attributable to PD (chapter 4.1.1). These figures may well be an overestimate regarding the total number of people with PD, as the VOICES data can only investigate those people that had PD recorded on their death certificate. Hobson and Meara (57) found 34% of their cohort had PD recorded as an underlying COD and these figures are likely lower than the VOICES survey because they include data from an entire PD service, including those who did not have PD recorded anywhere on their death certificates (47% of their cohort).

However, does knowing a disease might be life-limiting change anything in terms of quality of life? The CQC in their report addressing inequalities in healthcare felt that people with dementia were not having conversations about their future wishes early enough because many doctors had not considered their disease to be terminal (180) and they felt this negatively impacted on experience. Hasson et al, in Northern Ireland, found that many of the carers they spoke to were unprepared for the end, in some cases because they were unaware PD was incurable (5). There were certainly carers in this study who felt they, and their loved ones, would have acted differently in life if they had been aware of the incurable nature of the disease. However, even if prognosis was certain, it does not necessarily mean that those with PD/PSP/MSA want to talk about it and for many people the way they can cope with a disease is to maintain some degree of hope through denial (111), reflecting the uncertain awareness that Timmermans discussed (211).

7.4.3 *Do people want to confront the future?*

There is a huge variability in the amount of information that people want, especially at diagnosis. Fox et al in Ireland (9) and Boersma et al in Canada (10) both showed that people

diagnosed with PD wanted differing amounts of information about the future; some wanted to know everything, others wanted to live day to day. Giles and Mijasaki (4) in Canada discussed the idea of 'wanting but not wanting' information. This matches the findings of this study and was described by the PSP/MSA carers as well. This concept is not unique to these diseases. Pollock et al showed the same was true across a range of chronic illness in the UK (105) and multiple studies regarding heart failure have shown the same (218-220); the desire for knowledge about the future is very individual.

However, there should be a willingness amongst doctors to discuss the future with individuals if they would like that to happen, which does not appear to necessarily be present, even when people have entered the advanced stages of the diseases.

7.4.4 *Are doctors able to tell people about the future?*

As with other studies in PD (5, 221) carers related that clinics predominantly focused on medication, even though, in some cases, the medication had failed to work for some time. In those with cancer, studies have shown that the very fact that it is possible to try more medication allows the possibility of delaying a difficult discussion, even in those who are rapidly deteriorating (213, 222). To some extent the same is true in PD, drugs can always be altered to try and improve symptoms and so the availability of trying one more thing may delay, or prevent, doctors having confronting conversations. Some carers in this study noted that doctors in movement disorder clinics were reluctant to talk about the end of life and the 2017 Parkinson's UK audit showed that although 21% of those with PD had signs of advanced disease only 37% of them had end of life discussions recorded (192).

However, even though prognosis was disclosed to those with PSP/MSA and medication is far less effective, there still appeared to be a reluctance on behalf of HCPs, certainly in movement disorder clinics, to give further information about how the disease might progress. This is again not unique to PD/PSP/MSA; it seems doctors are often reluctant to inform people about future deterioration (213, 219).

7.4.5 *Future care discussions*

In order to plan for the future, there has to be some degree of open awareness and Timmerman's additional contexts reflect the ways that people manage their diagnosis and prognosis (211). People in active open awareness are more likely to make plans, as they are actively thinking about what dying means. It may be incumbent on doctors to help those in other awareness contexts by drawing attention to signs of deterioration and allowing a person to plan for themselves. Or to find a way to allow plans to be made despite a lack of active open awareness. Although people who are dying often use denial as a way of managing to cope, they also fluctuate between denial and a desire to know more (111). So there may be opportunities for discussion that are missed if not actively sought.

There is some argument, both in the UK and abroad, that we should all be more open about the future and the inevitability of death, as it is denial about death that prevents us, in part, from having the end we desire. UK policy now reflects this, with suggestion that we should all talk about death more with our families, and HCPs, and have the chance to record our wishes in writing. Theoretically this is a sound idea, especially if done in the way it was intended, so that people can truly have their voices heard and their considerations for total care (biological, psychological, social and spiritual) followed. However, the danger is that if ACP is done en masse, without properly trained staff, it will become a repeat of the Liverpool Care Pathway; when done well it will be good for patients, families and the patient-HCP relationship, when done badly it could break down relationships, encourage nihilism and lead to more harm than good. Chapter 6.1.1 suggested some negative experiences had occurred, especially when DNAR was considered prior to the time death was imminent and was discussed quickly by staff that did not know the individual.

In addition, there is a policy/research disconnect to some extent. Policy suggests ACP should be done, research explains the barriers against undertaking planning for all (105). The main issues in the literature, and this study, relate to the **timing** of ACP, the **content** of the discussions (including how they are recorded) and **who is involved** in the discussions.

7.4.6 *Timing*

Pollock and Wilson (105) in their study regarding communication between HCPs and patients showed that current policy regarding ACP had not translated into practice due to a multitude of barriers. In addition to difficulty in prognosticating, and the variability of patients' desire for open awareness, another barrier related to the fact that individuals were unsure if their views, or indeed their future options, would change if they planned too early (105). Other studies have shown a reluctance to plan too early because views may change (223), and some have shown that views can fluctuate over time (173, 224). So, for many people, waiting until the end of life is closer may make sense; especially considering the adaptation to having a chronic/terminal illness that might occur (see section 7.2.3). However, delaying may just reflect Timmerman's suspended open awareness context and this thesis shows that when decisions are delayed, they often become reactive rather than proactive, or may not happen at all; something which echoes Pollock and Wilson's findings (105).

Pollock and Wilson (105) also pointed out that guidelines for ACP (which suggest discussion should occur when a person is likely to die in the next twelve months) incorrectly assume prognostication is accurate, most likely because they are based on cancer care. This finding was echoed in the 2016 CQC report on inequalities in healthcare, which showed that the difficulties in identifying the last 12 months mean conversations don't always happen early enough, especially for those with dementia (180)[26]. The CQC suggested a shift from the last year of life to talking about preferences at an earlier stage, though prognosis may not be clear. In 2018 NHS England, in collaboration with the Alzheimer's society, suggested that all patients with dementia should be able to discuss ACP early in their disease process (225); as ACP is fundamental for those with dementia in order that they keep their autonomy. Interestingly however, when de Boer et al (226) in the Netherlands asked people with early dementia what they thought about planning for the future most preferred to live day to day

[26] This report is of relevance to people with movement disorders as 40% of people with PD will develop dementia. Cognitive impairment is a recognised feature of PSP and is increasingly recognised to exist in MSA as well.

and didn't want to discuss it. This is not an uncommon finding within research about ACP initiation, in dementia (227) and other diseases (105, 128, 219). Yet in de Boer et al's study despite initial reticence to discuss the future, individuals with dementia became more interested in the idea of ACP as interviews progressed (226). The authors concluded that dynamic discussions with relatives over time may be better than fixed plans, such as ADRTs, which would be defunct if views changed (226).

The findings in chapter 5.1 show that this dichotomy is just as present for those with PD/PSP/MSA; there is a balance between not wanting to plan too early and risking the ability to make their wishes known if they wait. There are limited studies regarding ACP in PD/PSP/MSA. Tuck et al (8) in Oregon showed people with PD preferred to discuss plans regarding the end of life only when they worsened and Fox et al (9) in Ireland found that as medication worked less well people were more receptive to the idea of ACP, suggesting that waiting until the complex stage may be preferable. If this were taken as a suggestion, then the implication would be to discuss the future for those with PSP/MSA from the start but this did not appear to have happened with the people in this study. The only study regarding ACP in MSA, a retrospective notes review of an American neurological clinic, concluded that planning was done too late; most of the people with MSA were too unwell to discuss goals of care, or already on ICU when discussions happened (13).

7.4.7 *The content of ACP*

ACP covers a large range of future decisions. If we take ACP to relate to recorded plans, as policy seems to suggest, then the range of options in the UK are to do with those that refuse certain medical interventions, such as ADRTS and those that allow decisions to be made by family members should a person lose the capacity to make them themselves (LPAs). These are the decisions that have an element of legal weight to them in England and Wales (Scottish law differs). Other forms of ACP such as advanced statements have been used in SPC for a long time to allow a person, who is usually in the last months of life, to express their preferences for care that they would/would not like. Advanced statements are an indication of preferences rather than a legally binding document. This study showed that most people had not recorded plans and that for people with PD plans that had been made

were related more closely to practical life planning, for example wills, rather than decisions that were healthcare related. Churm showed the same in her work on ACP in PD in the north east of England (228). Churm suggested we should focus less on the healthcare element because of this; however, it may well be that the reason the plans were not healthcare related was that no-one from a healthcare setting had raised ACP, as suggested by carers in this study.

In this study, those with PSP/MSA were more likely to have discussed plans that related to their healthcare needs, such as PEG insertion, but few of them had recorded their wishes, with the exception of DNAR orders. In the Canadian notes review in MSA, 8/22 had a DNAR (four put in place by a proxy), 6/22 had a discussion about PEG and 5 had refused to have one inserted (13). There was no mention that a preferred place of care had been discussed, though it was suggested in the framework the authors developed for palliative care discussions in MSA (13).

It is worth noting that although policy in the UK suggests that everyone should plan, to maintain their autonomy, UK law limits the plans that can be made. For example, in current UK law doctors have the final say regarding the futility of resuscitation, the provision of intensive care beds and assisted dying is illegal. Therefore, the most fundamental decisions that a person could make in terms of life prolongation, or shortening life, are not available.

Preferred place of death (PPOD)

As discussed in the introduction PPOD is frequently cited as being an important component of ACP (82, 96, 189). In this study only 30% of the VOICES sample had mentioned a PPOD. A larger proportion of the qualitative sample had discussed PPOD but it did not appear to be the issue of most importance. This is not necessarily a surprising finding, when Steinhauser surveyed patients with chronic illness, bereaved carers and HCPs about what they considered were important issues at the end of life, only 35% of patients felt dying at home was important, in fact it scored lower than any other component in the survey (204). In the UK Pollock et al (105) found that 9 of the 21 people they interviewed had recorded home as their PPOD but it was not a fixed view and patients were more concerned about reducing their family's burden and being comfortable than with the place that they died. This is

interesting because not achieving a PPOD was one of the things that carers felt the most guilt about; even when it had not been discussed carers felt terrible that they had not enabled their relative to die at home. Perhaps we should be mindful that carers can feel this way and bring place of death into a pragmatic discussion so that people with life limiting illness can say whether it matters to them or not. If it doesn't matter carers can be reassured; if it does matter then we can plan how to help people achieve their aim to die at home, with adequate support in place. In addition, policy makers should be mindful of this potential guilt before they decree that home is best; home is best for some people, but not all (22, 90). One of the main studies used to suggest home is best was based on a survey of the general population who, for the most part, did not have health problems (100). This survey (100) also suggested that as people age they are less likely to desire a home death and Gott et al showed the same, especially if a chronic disease was present (229); people felt safer knowing help was close. The idea that home is best has been described as a somewhat false sociological ideology, because actually many of the people who previously died at home, before medicalization occurred, may well have been in severe pain or distress (92). PPOD is still pushed forward in UK policy. This may be because there is a cost saving to be had by preventing hospital admissions (22, 230-232) and also because POD is perhaps an easier target to measure and improve on than other aspects of end of life care.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR or DNAR)

Some of the carers in this study related that they had not made formal plans or agreed to DNARs in the community, because they felt it might be detrimental to future care provision. This is not a concern unique to these conditions, 29% of adults who had been asked about ACP in Norfolk felt that if they wrote their plans down doctors would stop treatment too soon (233). These concerns are not unfounded. Fritz et al when discussing alternatives to DNACPR cite several studies that have shown care can be compromised, in terms of the efforts shown to sustain life, when DNARs are in place (234). Due to the assumptions that carers encountered within hospitals with regard to quality of life, where they perceived that HCPs were blind to their loved one's personhood, it is even more understandable that they would not suggest a decision that might lead to potential withholding of care. DNARs are not legally binding but there is now a legal requirement, following the case of 'Tracey vs

Cambridgeshire' (235) and 'Winspear versus CHS Sunderland' (236) that if a DNAR is put in place the person it relates to is informed (or their family in cases of absent capacity). Currently a doctor has the right to refuse to resuscitate if they feel it would be physiologically futile but if there is disagreement between an HCP and a patient (or their family) then decisions are often revoked to prevent breakdown of doctor-patient or doctor-carer relationships.

7.4.8 *Models of ACP*

Due to concerns that levels of care may reduce where a DNAR is in place and because plans for the future change over time, there has been some movement away from fixed refusals of treatment to more of an over-riding view of preferences (78, 237). This would work well for diseases like PD/PSP/MSA where the trajectories are variable and the diseases are heterogeneous. Churm found that most people with PD in the service she worked in had no idea what ACP was about, or what options were available(228). This is clearly of practical importance; if people do not know what choices they have, they won't know where to start even if they have a desire to plan. There is a such a variety of tools available that even HCPs are uncertain what can be offered. There are many models across the country, such as the ReSPECT document advocated by Fritz and 'Deciding Right' in the North East. The department for health and social care in their document 'our commitment to you for the end of life' are piloting "serious illness conversations"[27] with a view to rolling it out across the UK if it proves successful (189). It may make more sense for there to be a countywide consensus, at least so that charities could signpost better and less confusion over acronyms existed. Whichever document is used, the principle is to gain a better understanding of a person's goals, with some discussion regarding quantity versus quality of life, whilst maintaining the understanding that goals can change. What is not always made clear is that these documents should be reviewed regularly to be useful.

[27] a system for discussing future wishes with patients that was developed by Atul Gawande in the USA

However, one of the dangers with placing emphasis on discussion and recording of preferences rather than legal refusal is what doctors may feel they are legally required to do. Kate (PSP) explained that even though both she and her father were practically begging the doctors not to place a PEG tube, the doctors overruled them because no documentation was present (see quote in Chapter 5.1.6). Policy is now suggesting relatives have a greater say in healthcare decisions where a person cannot speak for themselves, yet the over-riding control is with the doctors in the UK; which is not the case in the USA. One wonders that with negligence now being a prosecutable offence that the very thing that ACP was set up to avoid, prolonging life without gaining quality, might become more of an issue. Even when legally binding ADRTs exist, there have been reports that treatment was instigated anyway (107) and this may become more of an issue in an increasingly litigious society, where the balance of law stands in providing life sustaining treatment if a lack of clarity exists.

One way to ensure that carers have more say and cannot be overruled by doctors is to have a LPA set up. Against this there has been much criticism that views are not always shared and that carers decisions do not align well with those of the dying person (81, 238-240). The crucial point of a LPA is that it only really works, and helps carers, if previous conversations have been had in regard to what it is that a person might want The carers in this study who had had open conversations felt better knowing what their loved one wanted, whereas the carers who had been unable to discuss plans (for whatever reason) often felt guilty with hindsight that care went on too long and was perhaps more invasive than they, and certainly their loved one, would have wished. Studies have shown one element of a dying person feeling like a burden is that they worry about their loved one having to be responsible for future decisions (241) and so encouraging dialogue between those dying and their relatives may reduce their sense of burden and in some way increase their sense of self. In addition, a review of power of attorney decisions found that being responsible for formally making decisions for a relative caused significant distress and guilt for about a third of carers, yet a clear knowledge of preferences, through discussions or recorded wishes, reduced the likelihood of such feelings (242).

7.4.9 *Who should take part in ACP with a dying person?*

In response to the societal denial of dying there have been an increasing number of publications that explain the differing options that people have regarding planning for the future. One of the problems however is whether people are signposted towards these or not. The MND association have an award-winning booklet that explains the differing options and outlines future considerations for people with MND (243); there is nothing similar available for PD/PSP/MSA.

Although policy states everyone should be involved in ACP it is likely to be more beneficial when it is undertaken in collaboration with an HCP who knows about the disease, as they can suggest potential healthcare issues that might need to be planned for. A potential problem with policy suggesting everyone undertakes ACP is that it will become rushed and won't actually allow a person to consider what they would want. One of the selling points of the serious illness conversations, suggested in the department of health and social care policy (189), is that the conversation can be done and recorded in 22 minutes. Pushing everyone to undertake planning does not take into account the views of the person the planning is for. As discussed above some people do not actually want to plan, and Pollock et al suggest that ACP would work better as structured interventions to specific groups, by specific people, rather than something for everyone. In addition, policy predominantly refers to planning for healthcare events and PPOD, whereas some of the best plans that carers in the study related were from care homes. In part the purpose of the planning should indicate the best team to carry it out. Useful ACP takes time and decisions should be considered as dynamic, which is why they are done so well in hospice day care settings, because continuity is assured and time can be taken. From the interviews in this study it did not appear that movement disorder services were undertaking ACP and the Parkinson's UK audit seemed to support this; although it showed that an increasing number of people with palliative stage PD had appointed an LPA, the end of life discussions did not appear to have occurred within the movement disorder services (192).

7.4.10 *Awareness of imminent death*

For patients

At the very end of life preparation equates to awareness that death is imminent. As Chapter 6.3.1 showed most people did not know they were dying with any certainty. Only 20% were felt to be certain and an even smaller proportion had been told that they were dying. This is a smaller proportion than Goy et al (12) felt were aware in their USA study (36%) but comparable with a UK study in the 90s in which 20.8% of those dying from non-cancer causes were felt to be certainly aware (110). In that study Seale et al (110) showed that those dying from cancer were more likely to be aware (50.8% vs 20.8%) which was a finding that was replicated in this thesis. Seale also showed that mental confusion made awareness less likely (110); though there was no comment in regard to whether the ability to communicate affected awareness.

Over time there has been a move away from the suggestion that every dying person should be made aware that their death is imminent. Field and Copp (244) suggested that HCPs should develop a conditional disclosure, in the first instance ascertaining what the person actually wants to know, and this view is incorporated into the most commonly used tools for 'breaking bad news'. However, as with Seale's study (110), those with PD/PSP/MSA who died at home were more likely to be aware than those dying in other locations and so if dying at home is important to a person then open disclosure about dying should occur. That being said, Seale, when discussing awareness contexts, explains that there will be some people for whom awareness is not possible, as neither HCPs nor the dying person are aware that death is imminent (110).

Sullivan et al (245) conducted interviews with physicians who had looked after patients that had recently died in two USA hospitals and found that 11% of them anticipated the patient would die weeks before death occurred, 57% days before and 18% hours before. Most (76.8%) had not discussed the imminence of death with the patient. Part of the reason that the disclosure of death to patients themselves was low was that by the time dying was diagnosed the patient was unconscious or delirious in two thirds of the cases (245). Interestingly the age of the patient also impacted on whether they were informed, with

older patients less likely to have been told that they were dying(245). This has implications for people with PD/PSP/MSA as they are conditions that are associated with ageing.

For carers

Although patients had rarely been told that they were likely to die in Sullivan et al's study, 88.6% of families had been informed (245). Whilst it may not always be possible to explain to a person that they are dying, explaining to their family, so that they can prepare has been shown to be beneficial, especially in regard to bereavement outcomes (246, 247). Although carer awareness of death being imminent is not measured in the VOICES survey, the qualitative forums/interviews suggested a greater proportion of carers had been told than those dying. Unfortunately, several carers explained that the way the news was communicated did not help them to prepare themselves because it was too ambiguous and several studies have related the need for clear, but sensitive, communication (248, 249). Cherlin et al discuss that the amount of information carers desire and can process regarding end of life issues varies (250). Certainly in this study some carers related that they had to account for their own emotional denial to understand that the end was near and others stated that they were so exhausted from caring they were not fully aware of what was happening. Breen et al (248) discussed that it was often exhaustion from caring that hampered emotional preparedness in carers and they explained that forewarning carers that death was close did not mean they were prepared. Carers in the interview sample suggested that the emotional side of preparation was more difficult to predict and control than the practical side. Hebert et al (249) specifically explored preparation for death in carers and found that previous life experiences, uncertainty and communication all impacted on preparedness. They discussed that preparedness was made up of cognitive (information need), affective (emotional readiness) and behavioural (tasks such as funeral planning) elements and found that clear communication from healthcare teams was the best predictor of preparation (249). As described in chapter 6.4 of this thesis, Hebert et al found that there was a tendency for HCPs to assume preparedness in long term carers without actually ascertaining its presence through empathetic communication (249).

There are several reasons for ensuring carers are prepared for their relative's deaths: they can advocate for their loved one's wishes to be met, including PPOD if important and they are more likely to be present at time of death. In addition, being prepared has been shown to reduce anxiety after death and lessens the need for bereavement support (246, 249).

7.5 Summary: Preparation

This section has related the theme of preparation to the literature. Although ACP is advocated for all by policy makers there are many practical and emotional reasons that prevent an uptake in planning. In addition, even if plans have been made, without awareness that death is imminent they will not necessarily be able to be enacted. Awareness of dying close to the end of life is difficult for the dying person, as often the diagnosis of dying becomes apparent when conscious levels reduce. The additional reduction in communication and cognition that many people with PD/PSP/MSA experience further complicates planning and awareness. Empathetic communication helps carers prepare. Helping informal carers to prepare for the end enables any plans that are in existence to be considered, and achieved, as well as improving outcomes for bereaved carers.

7.6 Overall Summary

This chapter has related the central themes of this thesis to the sociological literature and situated the results within current UK health policy. It highlights the factors that are important for quality care to be delivered, regardless of location, explaining that preparation, support and maintenance of identity all play a role (see Figure 45 at the start of this chapter). The emotional and practical issues are intertwined and without both being accounted for, care for a person at the end of their life falls flat. The practical side is perhaps achieved more often (and is easier to measure) but it is the emotional side, which hinges on understanding who the dying person is as an individual, that needs to be achieved to ensure excellent care. This is true of all end of life care, regardless of the disease process, but because these diseases cause slowing down, quiet/absent speech and mobility/visual problems that affect all forms of communication, a greater deal of time and skill is likely to

be needed to ensure the individual person and their wishes are truly considered. In an NHS under time pressure and in locations where little continuity can be offered, such as with rapidly changing staff, there is a greater risk that care may be less than excellent.

Chapter 8 Discussion

This first part of this chapter will briefly compare the findings of this thesis to the existing literature concerned with palliative care and the end of life in PD, PSP and MSA. The next section will discuss recommendations for clinical practice in line with current UK policy guidance. The final section will discuss the strengths and limitations of the project and suggestions for future research.

8.1 Comparison to existing literature regarding the palliative and end of life experience of people with PD, PSP, MSA and their carers

8.1.1 *Information and ACP*

In PD

The existing literature showed a lack of clear information being presented through Parkinson's services. Saleem et al's (11) study showed that 62% of people with PD/PSP/MSA felt they had full access to information, with 38% feeling they would have liked more. The 2017 Parkinson's UK audit (192) showed that only 61% of people with PD felt they had enough information presented at the point of diagnosis. Neither of them explored the content of the desired information but other studies in Canada (10), Australia (7), Ireland (9) and Northern Ireland (5) have suggested that, in the main, the missing information pertains to a discussion regarding prognosis. This study indicates that the same is true in the NHS in England. This study mirrored others in regard to variability in the amount of information people with PD, and their carers, actually want to know about the future (4, 9, 10) and the varying degrees that people want to engage with ACP (8). Tuck et al, in the USA, and Fox et al, in Ireland, suggested that a greater proportion of people with PD preferred to delay future planning until their disease worsened (8, 9). Likewise, carers in this study had not felt discussing the end of life was necessarily needed in the earlier stages. Parkinson's UK showed that an increasing number of people in the palliative stage of PD had discussed/set up an LPA, but they also showed that only 37% of people in the advanced stages of PD had an end of life discussion recorded. Other studies have shown that movement disorder specialists focus on medication rather than ACP even when people are in an advanced stage

(5, 10). Carers in this study noted the focus on medication and suggested a perceived reluctance for doctors to discuss the future or explain that the disease had reached a palliative stage; something that Higginson et al had discussed in regard to their London cohort (6).

In PSP/MSA

Calvert et al (193) showed that 47% of those with MSA and 65.4% of those with PSP were offered information about their condition on diagnosis. Dayal et al found ACP was often undertaken too late for people with MSA (13).

What this study adds

There are no qualitative studies in PSP/MSA that discuss the issues above. This is the first to have done so; most carers in this study related that they had to search online or get in contact with the disease charities to get the information they desired. The same issues of variability regarding the amount of desired information were present as with the PD literature. It appeared that those with PSP/MSA and their carers did more planning for the future than those with PD and that their plans were more closely related to healthcare needs, such as PEG and DNAR. It seemed that hospice staff, local GPs (for DNAR) and speech and language teams (for PEG) did more planning than the movement disorder services. Exploring the types of future plans that people with these diseases have in the UK in a quantitative manner and exploring their acceptance of ACP is an area of potential future study.

8.1.2 *Access to health and social care*

In PD

The difficulties with accessing co-ordinated health and social care that were raised in this study have been shown previously in qualitative studies in other healthcare settings (4, 5, 7, 10). Saleem et al (11) showed that 42% of the people they surveyed with late stage PD/PSP/MSA had practical needs that were unmet by services. The need for a multidisciplinary service, or one stop shop (10), has been advocated, yet the Parkinson's UK

audit (192) indicates that there has only been a slight improvement in the number of clinics that contained a multidisciplinary team. In the audit, most clinics reported that the people they saw had access to a PD nurse (96%), but interestingly in the patient reported experience measure only 87.6% felt they had access (192). This may be related to response bias (192) but it could also reflect the regional variation that was mentioned in this study, where people travelled across clinical boundaries to get to specialist clinics and nurses that were assigned to people left the service. This study indicated that a few people had noted a decrease in input from the PD team when their relative was unable to get to appointments readily, something that has also been suggested previously (9). Studies, including this one, have suggested that support needs are most extensive when a person is living at home (7) and that people who live on their own have a greater need because relatives provide a lot of care and organisation of services (9).

In PSP/MSA

Calvert et al (193) in their UK study regarding the quality of life and support needs of people with rare neurological diseases found that patients with rare conditions used less health and social care services than their needs required, agreeing with Saleem et al's conclusions (11). Interestingly, in Calvert's study, 52.9% (n=9) of those with MSA and 42.3% (n=11) of those with PSP had a co-ordinating health or social care worker and it seemed that they had higher access to services than the diseases without a co-ordinator (193). In this study carers indicated the need for someone who could officially co-ordinate care and it did not seem as if usefully co-ordinated care was as prevalent as Calvert et al's (193) study suggests; not until people received support from hospice services anyway. This may be because of recall bias in this study, or because the people involved in the projects were based in different locations around the UK; some areas have more access than others.

What this study adds

This study, due to its qualitative nature, adds an understanding of the way that health and social care providers' knowledge of a rare disease impacts on the quality of the support provided and shows that along with co-ordinated care it is most useful to have continuity of care.

8.1.3 *QOL, symptoms and SPC*

In PD

Fox et al suggested a need for greater psychological support for people with PD (9). The increased prevalence of depression and anxiety in people with PD, compared to the general population, is well known and thought to be directly related to changes in brain chemistry (251, 252). Alongside the increased likelihood of depression through biochemical changes, other studies have noted the psychosocial burden in PD that aligns with a loss of identity due to changing roles (10), social withdrawal due to symptoms (7, 9, 10) and isolation as friends/family visit less frequently (5, 7) which contribute to/are a part of depression and anxiety. Depression in PD has been shown to cause a decrease in cognition, worse motor symptoms and an increase in caregiver burden; it is also the main determinant of reduced QOL scores (253) and expressions of suicidal intent (157-159). Given the multifactorial nature of depression/anxiety it has been suggested that a combination of antidepressants and psychotherapy might be most beneficial in helping to alleviate depression in PD (254) and both types of treatment have shown some reduction in levels of depression (255, 256).

This huge psychosocial burden of PD, along with symptoms of pain (15), fatigue (6, 9) and immobility (6, 15), which are comparable to the symptom burden of cancer (7, 11) and MND (12), has led to the suggestion of increased SPC input. The carers in this study did not mention pain as often as the psychosocial aspects, but physical mobility and change in cognition were mentioned a lot. Most PD carers indicated that they had not accessed SPC services or had hospice suggested as an option; a few people attended the day centre services at local care homes and this provided some respite. The day to day care needs and the level of support available from paid carers was a bigger concern, especially regarding the regional variation encountered. This was perhaps more evident in this study than it may be in others because the recruitment was UK wide and even the carers recruited locally came from a wide geographical area which included rural locations.

In PSP/MSA

There have been several studies that have aimed to measure health related QOL in PSP (17) and MSA (16, 257) across all disease stages, with some directly comparing the two diseases

(161, 258). Overall these studies show that disease severity and depression are inversely related to QOL and the discussions explain that QOL is lower in these diseases than for people with PD at the same disease duration. This is predictable given the fact that PSP/MSA progress more quickly than PD and so people are likely to be in a more severe disease category at a given duration length. Higginson et al (6) showed the difference in QOL scores remained true in late stage disease, though those included with PSP/MSA still had higher Hoehn and Yahr scores than the majority of those with PD. The lower QOL scores and the higher levels of depression suggest that people with PSP/MSA may have an even greater need for psychological support than people with PD and may also explain why the carers of people with PSP/MSA in this study related a greater degree of suicidal/death ideation in their loved ones.

What this study adds

This study adds to the PD literature on identity and links the experience of people with these diseases to the sociological literature regarding biographical disruption and the loss of self, demonstrating why they are particularly at risk in regard to threats to their identity. This study also suggests that people with rare diseases might experience the rarity of their disease as an even greater threat to identity, something which is alluded to the Rare Disease UK report relating rarity to mental health (183). In addition, this study highlights the greater need that people with PSP/MSA have for SPC services and the positive difference that being involved with SPC and hospice services has for people with these diseases and their carers.

8.2 The very end of life (the last three months/2 Days), after death and bereavement

Very few studies have explored the last few months of life in PD with the exception of Goy et al's USA study (12) and Hasson et al's Northern Ireland study (5); both used the views of bereaved carers. Other than the three people included in Goy and Carter's study (2 with PSP, 1 with MSA), no study has explored the last few months/days of life for those with PSP/MSA. There are no studies that mention bereavement in PSP/MSA.

8.2.1 *The last few days of life and POD*

Goy et al showed that at the end of life 42% of people dying from Parkinson's Disease Related Disorders (PDRD) had moderate or severe pain and that 27% of them had no relief from their pain (12). This study also indicated that pain remained a feature for people with PD; with 81% having pain in the last 2 days in the VOICES survey. Though the VOICES survey did not indicate severity of pain, it gives an assessment of how well pain was relieved and only 4% of carers disagreed/strongly disagreed that their relative had enough pain relief. Goy et al also assessed awareness of dying in their survey and showed that 36% of those with PDRD were very aware death was imminent and 35% were somewhat aware (12); this study asked whether people with PD/PSP/MSA knew they were likely to die and 21% were certainly aware and 35% were probably aware, so awareness about the imminence of death appears to be slightly less common in the UK, though the surveys are not directly comparable. Goy et al (12) showed that 19% of those with PDRD were not mentally alert at any point in their last week of life and a lack of alertness was a commonly reported finding in this study. In terms of POD, in the USA study 40% died in care homes, 13% in hospital and 25% in their own home (12), so more people died in their own home than in hospital, which contrasts with this study. This may be explained by the people in Goy et al's study, as 88% had an LPA and 90% had an ADRT (12). It could also be explained by the comprehensive hospice at home services available in the USA and the cost of hospital admissions, to an individual themselves, in the USA compared to the UK. Interestingly, despite the prevalence of ACP documents, Goy et al's study indicated that only 42% of those who died from PDRD died where they desired (12). In this study, although only a small proportion of people had indicated a PPOD (29%), for those that had, 47% died in the place they desired.

What this study adds

This study is the first to consider whether POD and PPOD align for people with PD in the UK. No other study has explored the PPOD for people with PD and this study indicated that POD does not appear to be high on the priority list for people with PD. Only 28% of people who died from/with PD in the VOICES surveys 2012-15 had indicated a preference (23% home, 4% Care Home, 1% somewhere else; 2% of people had told their carer they did not mind

where they died). Dying at home was pushed in government policy in part because it reflected general population surveys but also because Gomes and Higginson indicated that by 2030 institutions (i.e hospitals and hospices) would be unable to cope with the growing numbers of people predicted to die in them (230). Nevertheless, there appears to have been a shift away from stating that home is best in current UK policy, which is welcome given the guilt that carers can feel when they are unable to continue to provide care at home (22, 90), something alluded to in this study and mentioned by Fox et al in theirs (9).

Most studies that look at POD for PD have shown that the majority die in hospital, followed by care homes, home and then hospices. Across the VOICES surveys, when looking at every person with PD, whether it was a contributing or underlying COD, 42.7% died in hospital (n=1704), 42.7% died in a care home (n=1704), 12.8% died at home (n=509) and 1.8% died in a hospice (n=73). Those dying with PD as a contributing cause were more likely to die in hospital and those dying with PD as an underlying cause were more likely to die in a care home.

43% of the people who died with/of PSP (n=49) had indicated a PPOD (31% home, 6% care home, 4% hospice, 2% somewhere else). In terms of POD of the 106 people with PSP as an underlying or contributory cause on their death certificate 34% died in hospital (n=36), 38% died in a care home (n=40), 24% died at home (n=25) and 5% died in a hospice (n=5).

38% of the people who died with/of MSA (n=26) had indicated a PPOD (35% home, 4% hospice). In terms of POD 45% (n=28) died hospital, 26% (n=16) died in a care home, 21% (n=13) died at home and 8% (n=5) died in a hospice.

In addition to indicating where people with PD/PSP/MSA might prefer to die and providing population wide data on where they died, this study is the first to explore the end of life experience according to the place that they actually died. One of NHS England's current end of life care workstreams is to improve the experience of end of life care across the locations of hospital, care homes, home and hospice (23). This thesis sheds light on matters of importance across differing healthcare locations. The recommendations for practice set out in this chapter indicate the ways that all locations could improve the end of life experience for people with PD/PSP/MSA.

8.2.2 *Carers after death and bereavement*

Hasson et al's study showed that many carers of people who died from PD were themselves unaware that death was imminent and felt underprepared (5). They also showed that carers struggled to cope after death because, along with missing their loved one, they had become isolated themselves through the caring process (5). In addition, because caring had become their new role, they lost some sense of purpose when the caring stopped and the support they had been getting through the PD services also disappeared, compounding their loneliness (5). Their findings were echoed in this study; many carers were aware that their loved one was deteriorating but felt completely unprepared for the end and for the way that they would adapt emotionally after the death. This study, along with Hasson et al's (5) showed how much people rely on their family and friends to help with their bereavement and both indicated a lack of available services. Hudson et al mentioned one of the carers they interviewed stated they continued to go to the support group after their husband died because 'it's like going home' (7) and certainly many carers in this study continued to frequent support groups once their relative had died, some through routine and friendships, and some to retain the sense of purpose they had when caring, by helping others through similar situations.

What this study adds

Although previous studies have indicated a need for bereavement support, this is the first to explore whether bereavement support would be welcomed by the carers of those with PD/PSP/MSA (see Chapter 6.4.4) and the first to suggest ways that bereavement support might best be offered.

8.2.3 *In summary*

This study reflects the existing PD literature regarding SPC need and adds strength to the call for better information regarding prognosis and future care needs, alongside better signposting towards future care planning. It adds new insight into considerations of PPOD, and POD, for people with PD and adds to the literature on bereavement.

Other than the symptom comparison from Saleem et al (11) and Higginson et al (6) there are no published studies that explore the SPC, or end of life needs of people with PSP or MSA. This study has addressed that gap. Part of the reason that studies for these people are sparse may be their disease rarity and in addition to explaining the experience for people with PSP/MSA this thesis also sheds light on the experience of navigating the healthcare system as an adult with a rare life limiting disease.

8.3 Recommendations for clinical practice

As the purpose of this mixed methods study was one of pragmatism this part of the discussion will outline the varying ways that service delivery could be improved. In current UK policy, guidance for palliative and end of life care is based on the ambitions for palliative and end of life care document (77) and so the recommendations for practice will be set out according to these ambitions. There are six ambitions laid out in the document, which are shown in Figure 47.

Figure 47 The ambitions for palliative and end of life care 2015-2020 (77, p11)

8.3.1 *Ambition 1: Each person is seen as an individual*

To achieve this ambition the document suggests that every person (the dying individual and those close to them) is offered the chance to talk about death, dying and bereavement at an early enough opportunity to allow them to make plans. It suggests the barriers affecting the discussion of death and dying are broken down and that local teams make people aware of what can be reasonably delivered by the service. It also suggests that every dying person has access to needs-based integrated health and social care, with a structured care plan and personal budget that is individual to them. Lastly it points out that good end of life care includes bereavement (77).

Honest conversations: about prognosis

This study demonstrates that people with PD/PSP/MSA had a variable degree of desire for information about prognosis and that there was a gap between their need for information and what was provided. Because of the complexity of the diseases regular care is largely removed from primary care services and into specialist movement disorder services; it is here that information about prognosis and help with ACP should improve. There has been an improvement in the number of people that are given details of charity support in PD (192) and most of the carers of people with PSP/MSA indicated they had been given the details of the relevant disease charities, which enabled them to access more information. Nevertheless, information regarding future choices can be more personalised if related by an HCP who knows about the disease and the way it is affecting the individual in front of them (7). The palliative care section of the 2017 NICE guidance for PD (259) makes it clearer that movement disorder teams are expected to proactively offer information about progression, as well as support with ACP.

As the ambitions document suggests discussions about death and dying should be the norm it would be sensible for movement disorder clinics to have leaflets available about planning ahead. The Compassion in Dying charity have produced a resource called 'starting the conversation' (260) which explains the types of conversations people should be having with their family, and doctors, about the future and this could be placed in the waiting rooms of movement disorder clinics (and GP practices). Although this document is not specific to the

diseases, it might encourage people to raise questions about the future with movement disorder teams. Parkinson's UK do have a booklet about the end of life and decisions such as wills, LPAs and advanced statements but it is not very disease specific in regard to what could happen in term of speech, cognition or swallowing (261). The charities could develop something similar to the MND association's (243) award winning end of life booklet, which details the sorts of problems that may need to be planned for, such as PEG tubes. This would also be a useful resource for movement disorder teams to give to patients and their families to aid in any discussion. As a minimum movement disorder services should have a list of resources: written information, charity helplines, internet sites, social media groups, local support groups etc that could be given to people in clinic so they have a range of options to choose from when seeking more information.

Within the actual clinic appointment doctors and specialist nurses should ask people whether they want to talk about future deterioration or not, rather than assuming they would find it harmful to do so. NICE guidance suggests that there should be a balance of honest information and promoting a feeling of optimism when communicating with people with PD and their carers (259) and this may make doctors reluctant to discuss future deterioration and dying. However, maintaining optimism whilst planning for a future death are not mutually exclusive. Several carers in this study related that they found it easier to discuss the end of life when it was more hypothetical. Some felt that planning for the future strengthened their relationships. There are tools becoming available for professionals to help to guide conversations, such as the serious illness conversations (189), that suggest phrases that could be used to start a conversation. In addition, there are a multitude of training courses available regarding palliative care and ACP. These could be incorporated into training and continued professional development, something jointly suggested by the European association of palliative care and the European academy of neurology (262).

As discussed in the previous chapter the variable prognosis of PD, and PSP/MSA to some extent, may make it hard to know when to discuss the future. One option, for PD especially, could be to wait until the indicators that identity the end of life phase in neurological conditions are present (see Table 15) (263, 264).

Indicators of end of life care phase in neurological disease
Swallowing problems
Recurring infections
Marked decline in physical status
First episode of aspiration pneumonia
Cognitive difficulties
Weight loss
Significant complex symptoms

Table 15 Indicators that a person with a neurological disease may be approaching the end of their life (263, 264)

Doctors and specialist nurses working in movement disorder services should proactively ask people about these symptoms so that they can identity people who may be approaching the end of life or use their findings as a trigger for discussion, e.g. swallowing problems and PEG. The caveat to this is that waiting until this point in neurological conditions can mean communication and cognition are affected, making planning for the person concerned difficult. However, even if the indicators of the end of life phase are not useful for planning, identifying this palliative stage will allow better communication with carers that time may be limited. This may help prepare them better and allow them to help facilitate a PPOD, if a location was of importance to the dying individual or themselves. Continuity of care, from one movement disorder physician, once a person is in a complex phase would help, in part to identify deterioration and so that trust has been built and discussion about the future with a person and their family seems less abrupt.

In terms of the completion of ACP this does not necessarily need to be done in movement disorder clinics or by one person, in fact it may work better across services because neurology/movement disorder centres may not be located in the same geographical area as many of the people with these diseases; especially true of those with PSP/MSA. Ideally, as suggested in the ambitions document, services should be linked electronically so that if someone has already discussed their wishes that information is available for all and they do not need to continually revisit the end of life. Electronic records also allow for the updating of plans if it becomes obvious plans made at an earlier stage may need to/have changed.

This may be tricky across movement disorder services for PSP/MSA, given the differing CCGs that people will be referred from, but at the very least specialists could inform their patients about what might happen, and relate that discussion to GPs. This, in turn, would educate GPs regarding points they should be mindful of regarding progression and the UK rare disease strategy states that centres should have protocols in place to share their expertise with local teams. As related by carers in this study, hospices are excellent at ACP, because it is done in a holistic manner rather than as a tick box exercise. It may be that hospices are best placed to undertake ACP with people with these diseases but referral into SPC still requires honesty from movement disorder teams about what the future may hold. In addition, for some people, especially those who actively want information and to plan, hospice might not be necessary at the point these discussions should be taking place.

The recommendations related above are summarised in Figure 48.

- Movement disorder services
    - Place generic leaflets about thinking ahead in waiting rooms e.g. starting conversations
    - Actively ask people about thinking ahead using model such as serious illness conversations. Discuss what could happen. Have leaflets available regarding options people could choose. Suggest open to re-discussion anytime
    - Signpost regarding choices that may need to be made, even if link to local service such as GP to ensure they could be made, e.g. services in place
    - Ensure staff have been on ACP training so they become comfortable with raising discussions before it is too late
    - Once people reach complex stage try and ensure they are seen by the same doctor so that
        - Trust is built and initiation of end of life planning is more natural
        - Deterioration between appointments is more evident
    - Use local electronic systems so that any discussions amongst the team e.g. with Speech and Language services can be shared. If possible link to GPs/hospices as well

- Charities
    - Develop disease specific guidance about the sorts of plans people may need to make/consider e.g. PEG, NIV, PPOD
    - Include a section in the booklet where people can record their decisions

Figure 48 Summary of recommendations regarding ACP

Honest conversations: about the imminence of death

As discussed in the previous chapters, awareness regarding the imminence of death allows people to prepare for the end.

Improving communication about the imminence of dying can come from many sectors. In part it comes from education, on the part of movement disorder teams and the charities, for carers and other HCPs regarding what the end of life looks like. HCPs in general should be more open about the possibility of death. Rather than an active cure versus a palliative approach there should be more crossover so that people are actively treated for infection with a clear plan of what to do if that fails. Shared decision making should occur so that people with the diseases and their carers can discuss the aggressiveness of treatment.

Importantly any discussion about quality of life should come from the person with the disease or their carers; rather than a judgement from HCPs. There are various documents becoming available, such as ReSPECT (265), that will enable hospital staff to be clearer about where a person's priorities lie and they should lead to more proactive planning in the acute stage. HCPs should ask about the existence of prior plans and discuss them openly, including how prior plans could be achieved or explaining clearly if there are insurmountable reasons why they cannot; this may lessen the guilt of carers if prior wishes cannot be achieved.

Although there is much uncertainty about how imminent death might be, this uncertainty can be communicated to relatives so that they feel less in the dark and less isolated. HCPs, in all locations, should be mindful of the fact that people with life-limiting diseases and their carers can be unaware that the end has come. HCPs should be mindful that a person who has lost verbal communication can still be part of the decision-making process and they should remain the centre of discussions unless they indicate they would prefer not to be. Some degree of protective denial may well be in place and sensitive conversations rely on people being mindful of this fact; even if people who are dying seem reluctant to discuss it, this does not mean permission to speak with their relatives about their care cannot be sought. It may be that GPs/care homes feel they know less about the diseases than carers but they are likely to have more objectivity and should check whether a relative is aware that the end is imminent, or not, rather than assuming awareness. When discussing how close death is, language should be unambiguous and explicitly mention dying so that confusion is lessened and carers are aware that they should stay if it is important to them that they are there for the end.

These recommendations are summarised in Figure 49.

- Place of Death
    - Staff in all sectors should be clear about the goals of care of the people they are looking after
    - HCP should not assume that people with PD/PSP/MSA and their carers are aware that death is imminent and should check understanding; this is particularly pertinent in home/care home environments
    - If it is clear someone is approaching death then prior plans should be discussed with the dying person unless they indicate they would prefer not to; a lack of verbal communication does not preclude decision making, carers can often interpret better than staff
    - If a dying person is too unwell to discuss that death is approaching imminently, their relatives should still be informed to enable them to plan and be present if they choose
    - When discussing death clear unambiguous language should be used, especially with carers, even if the uncertainty of timing is present

Figure 49 Summary of recommendations regarding communication in the last 2 days of life

Bereavement support:

Not every person wants bereavement support from HCPs and only a small percentage of people (around 10%) are left with prolonged/complicated grief that requires counselling (266). However, carers of people with PD/PSP/MSA are at particular risk of situational factors that might lead to complicated grief as increased burden pre-loss, changes in role and lack of preparedness all increase the risk (267, 268), as does sudden death (269). For some of these risks pre-bereavement counselling may be useful as it may help prepare for the end; the national bereavement alliance, in their bereavement toolkit for commissioners, suggested that pre-bereavement counselling should be widely available (266). Aoun et al (270) showed that a barrier to finding counselling after death useful was that bereaved people felt a stranger was involved who did not know them, or the person who had died; pre-bereavement counselling would address these concerns. However, one of the problems with arranging pre-bereavement counselling for this group of carers is how to manage the time when they are providing care 24/7. Several of the interviewed carers had pointed out they were unable to make their charity support groups because they had no free time.

Logistically the best/only time would be to offer sessions alongside day care sessions either in hospices or care homes, but it would need to be piloted with regard to uptake as this is often the only 'free' time that carers have available to be themselves and not 'a carer'.

Formal bereavement support works best when people opt in to taking part (268), but in order for people to do that they need to be aware of their options. Hospitals have bereavement support teams, who could suggest options, and hospices have their own bereavement teams, but for people who die at home, or in care homes, carers do not necessarily know where to look, unless GPs are proactive in offering information about services. Carers in this study said they felt better just knowing that options for ongoing support were there.

Several carers implied a debrief would have been useful and this may be something that movement disorder teams could think about offering. Letters of condolences were appreciated by relatives; it made carers feel less abandoned by the services they had been involved with for years and made it clear that their relative had mattered. Phone calls were also appreciated and in some cases PD nurse specialists had offered to call in to visit bereaved carers they had built a relationship with over time. If a phone call or offer of a visit could be arranged as standard this might help reduce some of the 'cut off' feeling carers had. It might also help answer some of the questions people were left with and help signpost them to further support, or to hospital teams who could better answer questions regarding acute admissions. In addition, such a visit or phone call could also be used to screen for people who are more at risk of complicated grief and a GP could be informed, or a referral could be made to bereavement services if the carer was willing.

Lastly, it may be beneficial for the charity groups to consider setting up bereavement support buddies, either face to face, by telephone or online. A lot of bereavement services are run with volunteers who act as a befriending service but given the rarity/complexity of these diseases it may help people to be able to speak with someone who had been through a similar situation. Parkinson's UK offers peer to peer support through their website (271) and this could be extended to include bereavement. Some carers stated they preferred to speak with other people who had been long-term carers of people with PD/PSP/MSA because they understood better what it had been like. Several friendships sprang from

bereaved people in support groups meeting each other and other carers formed lasting friendships with bereaved carers they met on Facebook groups.

Many bereaved carers want to feel useful and continue to take on volunteering roles, including helping at support groups, but Locock and Brown's study (179) regarding support groups in MND perhaps cautions against too many bereaved carers being present in groups; some people with the disease felt it changed the focus of the meetings. Another option for those who want to help may be taking on a bereavement support role or chairing groups for newly bereaved people. There are limited studies regarding disease specific/situation specific bereavement groups. Cruse in Wales are in the process of developing a dementia specific support, including dementia specific bereavement training (272), and something like this could potentially be adapted to suit carers of those who died from other neurodegenerative conditions. In addition, the MND association is currently running focus groups with bereaved carers to review the bereavement support they offer (273); the findings could be used as a model for the other charities or they could perhaps join together to forms groups for bereavement in neurodegenerative diseases. A joint group would help reduce the issue of travelling for bereaved carers as MND, PSP and MSA are all rare and so the likely number of bereaved relatives for each individual disease in a given location will be small.

These recommendations are summarised in Figure 50.

- Pre-bereavement counselling
    - If a person with the disease is already attending day hospice/day care in a care home, suggesting that considerable carer burden may already be present, this could be offered

- Place of death
    - Once death has occurred the bereaved carer should be given information on the range of services available locally, on the telephone and online. Hospitals, care homes, GPs and hospices should all have a range of support available;, in fact the list could be provided through the CCGs

- Movement disorder teams/GPs/hospice
    - A letter of condolence at the very least should be sent once the team learns about the death
    - Ideally a phone call should be made +/- a follow up visit for those who want it to allow a carer to discuss any concerns or questions
    - This phone call or visit could signpost the bereaved carer to other services and allow a check for risk factors for complicated grief

- Charities
    - Consider extending existing peer to peer support to include bereavement (Parkinson's UK) and consider setting up peer to peer bereavement support for PSP/MSA
    - Consider training existing volunteers who are themselves bereaved in bereavement support and trial local bereavement support groups for bereaved PD carers
    - Parkinson's UK, the PSPA, MSA trust and MND association, or combinations, could consider working together to set up a joint group for bereavement for carers who have been bereaved through neurodegenerative disease, perhaps modelled on the dementia training from Cruse in Wales

- Wherever the offers of bereavement support come from it should be made clear that people can self- refer at a later date as bereavement often lasts more than a year and prolonged/complicated grief is only diagnosed if persistent for more than 6 months

Figure 50 Summary of the recommendations for bereavement support

In summary, ambition one is about treating people as individuals and as such many of the points interlink with ambition 3, maximising wellbeing. It is the very fact that people are all individual and approach life, death and their bereavement in different ways that means that

services need to offer a range of options to people across the healthcare, social care and voluntary sectors rather than a prescriptive one size fits all model in one modality.

8.3.2 Ambition 2 and 4: Fair access to care & care is co-ordinated

The steps suggested to achieve ambition 2 are predominantly related to audit and data analysis, suggesting that local services check they are providing equitable provision of care. The steps to achieve ambition 4 suggest finding a way to share records across IT systems to help co-ordinate care. Instigating a system wide response to co-ordinate care is suggested, with clear indications of the roles of people involved in care. Ambition 4 also states that 'everyone matters' and that services should find a way to encompass the needs of every person, including those living with loss, rather than focussing on those living with more 'predictable illness' (77, p28).

Each person gets fair access to care/everyone matters

In terms of fair access to care one of the problems highlighted in this study was the problem with continuing care assessments and how they varied across regions; this has been noted several times and highlighted in the national audit office report in 2017 (194). Following this report a new national framework for CHC assessments was implemented in October 2018 to reduce some of the inequity and improve provision of CHC funding (195). The framework suggests that "It is important that those contributing to this process have the relevant skills and knowledge"(195, p39) and so it is important that people with PD/PSP/MSA are assessed by someone with expertise in movement disorders.

Equitable access to SPC was also raised as an issue in the interviews; in part this seemed to stem from a lack of referral from movement disorder teams/GPs, but in a few cases it appeared people were told they were not eligible until the last year of life. In terms of PD not everyone will need SPC but trying to assess who might is important. Richfield adapted the Palliative care needs assessment tool (PC-NAT) to be used in PD to indicate palliative care need and triggers for referral to SPC (274); the POS-PD and EQ-5D used frequently in QOL research could also be used. Ultimately an agreement between services about what could be provided, and for how long, should be agreed. A couple of studies have evaluated

short term SPC interventions for people with neurodegenerative diseases to see if they would be beneficial and they have indicated an improvement in QOL, in terms of physical symptom burden, for those involved in the intervention arm (74, 275). A multicentre RCT, 'OPTCARE neuro', evaluating the effectiveness of short term SPC intervention for progressive long term neurological diseases is ongoing in the UK (75). Professionals involved in 'OPTCARE neuro' were surveyed regarding their views on integrating SPC into neurology services and some of the barriers that might occur (75). SPC doctors felt that discharging people following short term intervention would be difficult, or inappropriate, and neurologists and palliative care physicians both felt that an increase in referrals might become a problem in regard to an unmet need for increased resources (75). It is important to ascertain what SPC will deliver above that which could be arranged through the movement disorder services. Short term intervention may well work for PD, the condition progresses more slowly so there is possibly more time after end of life triggers become evident to refer; it would also work for physical symptom need. This study suggests that at present it would not be enough for people with PSP/MSA because the rarity of the diseases means the continuity found in SPC is highly valued. Their rarity also adds to the degree of existential/identity burden on top of their ongoing needs and continual losses. In addition, the rarity of the diseases should allow continued hospice care as the numbers of people engaging with services is unlikely to overburden them.

Importantly movement disorder teams need to ensure that care is provided right up until the end of life, rather than waning when it becomes difficult for people to reach clinics. Some may feel that GPs could take over once a person was in a nursing home/homebound and unable to come to clinic but this is the very time that more expert input is likely to be needed. In addition, because these people are told that their condition should be managed by movement disorder teams, GPs are disenfranchised and are unlikely to be equipped to deal with these disorders in the complex/palliative phases. Movement disorder teams that do not have provision for home visits need to adapt the way that they work, and the links

that they have, to ensure that the people with these conditions who most likely have the highest degree of need are not abandoned.

Care is co-ordinated

One of the reasons hospices were lauded in this study was that they had a single point of continuous contact and helped with co-ordination of care. This should not have to be the remit of SPC and could be organised outside of the care SPC services provide. The need for co-ordinated care is not unique to these diseases, but the uniqueness of the diseases makes efficient co-coordination of care, for those without disease specific knowledge, difficult. Healthcare navigators have been suggested as a way to improve co-ordination of care (189) and, where they are in place, better co-ordination and satisfaction with services has been shown (180, 193). Health Education England have produced a competency framework about care navigation and a figure illustrating the current roles of navigators (see Figure 51); this figure shows that navigation covers many of the points carers found were lacking.

Figure 51 Elements of care navigation according to job descriptions in the UK (276)[p17]

The rare diseases strategy suggests people with rare diseases should have a co-ordinator for their care but a survey of people with rare diseases in the UK shows that only 19% do (191); which appeared to be reflected by the carers' views in this study. NHS England is developing a set of criteria that will hold providers of care for people with rare disease to account, to ensure that "there is a person responsible for coordinating the care of every person with a rare disease"(187)[p39]. In light of this Clinical Commissioning Groups (CCGs) should ensure a set person is available to coordinate care.

Many CCGs already have existing navigators, all with differing roles, and perhaps there could be some provision made for neurological training so that the needs of people with these diseases are better able to be met. Ideally a navigator who was specifically trained to understand the needs of people with neurodegenerative conditions would be best and this

may be something that could be added as a role into movement disorder teams. Even if navigators were available the ability to share records across services would aid in co-ordination and continuity of care. The care of people with PSP/MSA often crosses CCGs as neurology services are mainly found in larger teaching hospitals; something the neurologists in the OPTCARE neuro raised as a potential barrier to the short term SPC initiative (75).

These recommendations are summarised in Figure 52.

- CCG/movement disorder service
  - Ensure share records within service and ideally across different services to allow continuity of care
  - Consider training of a neurological navigator to act as point of access and co-ordinator of services
- Movement disorder services
  - Consider palliative needs of the person in the service using an assessment tool such as NAT-PD. Use the tool to help decide whether people would benefit from SPC or not and refer appropriately
- Hospice/SPC
  - Receive people based on need rather than diagnosis or prognosis
  - Work with local care homes to replicate day centre set up for those with PD, with perhaps a monthly visit by a specialist

Figure 52 Summary of recommendations for co-ordinated and fair care provision

8.3.3 *Ambition 3: Maximising comfort and wellbeing*

The steps to achieve this ambition are for staff in every setting to recognise and address all forms of distress whether caused by physical, emotional, social or spiritual suffering. A part of this aim is to ensure excellent assessment and management of physical symptoms, such as pain, and agree with the person dying the extent to which they are managed, for instance balancing pain against conscious level (77).

Wish to die statements

Maximising wellbeing is important all the way through a disease process and is one of the reasons that SPC intervention is advocated before the last year of life. What is interesting is that a large proportion of people with chronic diseases, and certainly those with

neurological disease, express death and suicidal ideation, which the ambitions document does not mention. HCPs are often uncertain of what they should say to people who express a wish to die and rather than explore it they tend to avoid the subject (174, 277). However, those that have studied expressions of a wish to die have shown that exploring it can help people address physical symptoms, social and psychological concerns (173, 174, 277). Hudson et al suggested a two phased approach in response to desire to die statements; first asses the nature of the statement and then asses factors that might be contributing, discussing ways these could be addressed (277). It has been suggested, given the prevalence of death and suicidal ideation, physicians should actively be asking about it in their reviews to enable them to provide better care (174). Even if reversible issues were not found patients could be guided to ACP documents that would at least allow them a choice regarding the aggressiveness of future care and may help them feel more in control.

At the very end of life

It was clear from the interviews that if physical symptoms, such as pain, were present in the last few days the control of these symptoms took over all other concerns. It can be difficult to ascertain pain when people have cognitive or communication difficulties but there are pain scales available that have been designed for use in elderly people with limited communication which may be helpful (278).

Control of physical symptoms is important but once this is addressed it is the emotional factors that relate to identity that matter the most at the end of life. When people with advanced chronic illness were asked the most important factors at the end of life freedom from pain, being at peace with god and the presence of family all ranked highest (204). In addition, 95% or more felt that being kept clean, having a nurse they felt comfortable with, being listened to and maintaining dignity were very important (204). In this study human factors were important, including recognition of the dying person as an individual and the presence of family, as were environmental factors such as good food, music, pets and space. Places that provided food, drink and space clearly provided a better end of life experience for all, especially the carers; as did places with continuity of care. This is one of the points where hospitals, outside of ICU, fared badly compared to care homes and hospices. There

are simple things hospitals could do to improve matters such as minimising changes in staff (by assigning someone who is going to be present for the week), providing free parking to the carers of people who are dying, food/drink vouchers for cafes or at least tea/coffee/sandwiches on the ward and potentially allowing pets to come in, especially if the dying person is in a side room. Another factor is ascertaining whether POD is a matter of importance and, if it is, all effort should be made to ensure it is achievable, with unnecessary delays minimised. Ultimately having a discussion with people about what they want is important and certainly ACP in some nursing homes seem to allow these important aspects to be planned for in advance.

These recommendations are summarised in Figure 53.

- Movement disorder team/hospice/GP
    - Explore physical, psychological, social and spiritual health when reviewing
    - Specifically explore what people are finding hard and if appropriate ask whether people have ever thought that life is not worth living?
    - Given that in PD there is an association between death ideation and depression a formal depression assessment should be done for people who share they have death ideation with an explanation that brain chemistry in this disease makes depression more likely
    - If people outwardly say they wish it was over then explore why they feel that way to ascertain if increased social help, symptom control or future planning may help alleviate the feeling

- Place of dying
    - Ensure physical symptoms such as pain, breathlessness and nausea are asked about and treated according to the desires of patients
        - If problems with cognition/communication are present then discuss with carers and use appropriate pain scales
    - Ask if any ACP has been completed to ascertain issues of importance for the end of life, including whether a PPOD exists
    - Try to minimise changes in staff so that the dying person and their carers have some degree of continuity
    - Allocate a space for relatives if possible, aim for care in a side room, provide food/drink and cover parking costs

Figure 53 Summary of recommendations for maximising wellbeing

8.3.4 *Ambition 5: All staff are prepared to care*

The steps to achieve this aim are that everyone in the health and social care sectors should be trained in end of life care to ensure they understand the holistic nature of caring for a dying person and staff should be supported with comprehensive supervision. HCPs can only provide good care when trained and so education and improving knowledge, including awareness of legislation, is key; palliative and end of life care should be supported at board level as an issue of governance in all organisations. Lastly HCPs should become used to working with technology that might improve their own knowledge and access to those they care for (77).

Knowledge based judgement

Although movement disorder teams can, and do, provide education within hospitals and local care homes regarding PD, the bulk of education comes from the disease charities. In this study some care homes, GP practices and care agencies invited expert speakers to teach them about MSA/PSP when they were caring for someone with the diseases and this should be encouraged as a point of good practice. Parkinson's UK have a comprehensive booklet for care home staff and have recently made a 20minute video for care homes to inform them about PD. They have a podcast on keeping people safe in hospital and are launching an interactive course for ward staff, which hospitals could add to available training; they also have an online 'palliative care in PD' module with the open university. The MSA trust and PSPA are much smaller charities, both have booklets about caring for people with the conditions; which carers in this study frequently handed out. However, one of the limiting factors for staff, especially in acute hospitals, is time and a quick video made by the charities may provide information in a more easily accessible format. All three charities run study days which increase the profile of the diseases and provide education. Part of NHS England's rare disease insert includes a clause suggesting that each provider should give their patients an 'alert card' containing information about the condition, treatments and contact details for individual experts (187). Given that these alert cards are set to become a requirement, movement disorder teams might consider these for patients; alternatively,

some charities such as the MND association and Muscular dystrophy UK make alert cards already and this may be something else the MSA trust/PSPA could consider.

One of the problems that Rare Disease UK identified in their report on the way that having a rare disease impacted on mental health was that HCPs do not understand the additional emotional burden that a rare disease brings (183). Individual rare diseases are often not included on medical school curriculums, because they are rare, but curriculums could be adapted to teach about the experience of living with a rare disease. In addition, staff could be taught techniques to help them when encountering a person with a rare disease; even looking it up beforehand would help show interest and allow the focus of discussion to then be on the individual rather than the disease.

Using new technology

The suggestions above have indicated the ways that technology could be used to facilitate care and especially education. In addition, technology could be used to better facilitate episodes of care in movement disorder services. A lack of information is something that people with the diseases and their carers are concerned about and there are a lot of online sites which contain information and peer to peer support that movement disorder teams could signpost people towards. This was a recommendation in the rare disease report into mental health and along with a mention of charity support groups it referenced 'Facebook' groups and 'Rareconnect' as online sites for people to gain peer support. An additional use of technology in clinics would be to use telemedicine to maintain a connection with people who were unable to come to clinics, something that has been shown to be effective in frail elderly populations in Scotland and Wales (279) and is mentioned in the rare disease strategy (280). Charity support groups could also look at using technology such as teleconferencing to enable people with the diseases and carers to remotely access their meetings once travelling became too difficult. Parkinson's UK is developing an app and device library and this might be useful for people with PSP/MSA as a resource as well.

These recommendations are summarised in Figure 54.

- Movement disorder teams
    - Continue to provide training to hospital staff, medical schools and care homes about movement disorders
    - Consider using telemedicine via apps such as skype to allow continuity of care with people unable to attend clinic appointments
    - Explore and signpost people to the range of support services available, including online sources

- Care providers
    - Provide training to staff regarding the needs of people with rarer conditions

- Universities
    - Consider training medical students, nursing students and allied health professionals about the experience of people with rare diseases and how to make that experience better

- Charities – MSA trust/PSPA
    - Develop short videos that could impart key information about the disease to healthcare and social care providers
    - Consider designing 'alert cards' that people could carry with them to share information and contact details of experts
    - Consider using teleconferencing apps to allow better access to support groups

Figure 54 Summary of recommendations regarding staff preparation to care

8.3.5 *Ambition 6: Each community is prepared to help*

The steps to achieving this ambition relate to public health initiatives and a call for all organisations to raise public awareness regarding the difficulties people face, alongside help they can receive. It suggests local health and voluntary organisations should work with each other to provide support and information/training and highlights the fact that more volunteers should be recruited to help deliver support in differing ways (77).

Public Awareness

Increasing awareness about PSP/MSA and the non-motor side of PD, and how that can affect people, were all suggested as areas that need improvement by carers in this study. Public awareness about SPC would help as one of the reasons people with

neurodegenerative disease may not want to engage with SPC is because of its link with death (75); movement disorder services can help to dispel this myth. The charity websites already point out SPC is not just for the dying and carers in this study pointed out that local support groups help raise awareness about this as well.

Another important point of public opinion to work on is the negative attitude towards care homes. This study should help to reassure people that care homes can, and do, deliver good care, especially at the end of life. People should be encouraged to think of care homes as positive choices rather than second best. Day care with possible hospice involvement in care homes would allow people to access care homes at an earlier stage and build up a relationship with staff so that the idea of living in a home was not so negative. Respite stays in care homes rather than hospices could also be considered, if training for staff had taken place. Although having additional carers coming into a person's private home or moving into a care home are huge changes, it is not uncommon that people find they regain their roles as husbands, wives, sons and daughters when caring duties are relieved, and this should be relayed as a positive more often.

Practical support

Several suggestions for increased practical support have already been outlined above, such as using teleconferencing for support groups or providing disease specific ACP guidance. Other options that the PSPA/MSA trust could consider would be peer to peer support. Data privacy laws may make this difficult, but if carers gave permission the charities would be able to link local carers together for mutual support.

Volunteers

All three charities have volunteers and there are various ways that former carers can help. Increasing their involvement in bereavement support may be helpful. Another suggestion would be for hospices/care homes to actively recruit former carers of people with movement disorders to help raise awareness among staff. Teaching hospitals could build links with the charities to increase undergraduate experiences and people with the diseases or former carers could come to grand rounds/morbidity meetings to talk about their

experiences within the hospital; not only would this raise awareness of the diseases, but it may also change practices for the better.

These recommendations are summarised in Figure 55.

- Movement disorder teams/specialist nurses
  - Explain that hospices/SPC teams provide care to many people who are years from dying
  - Talk of the positive aspects of care homes

- Charities
  - Make peer to peer support available locally
  - Encourage volunteers to help in hospices and care homes to increase knowledge of the diseases and to support others
  - Encourage active links with hospitals/medical schools to raise awareness

Figure 55 Summary of recommendations regarding the community

8.3.6 *Summary*

This section has outlined recommendations for clinical practice based on the findings of this thesis and linked to current UK policy.

8.4 Strengths and Limitations

8.4.1 *Bereaved carers as proxy*

As discussed in the methods chapter there has been debate in the past over whether bereaved carers' views represent a reasonable proxy view of patient experiences (79, 80). Reliability studies showed that views match well for service provision and less well for symptoms and psychological matters (80). Taking this into account the aspects of this study that reflect on service provision, such as co-ordinated care, communication and planning are likely to be closer to the views of the people that had died than views on pain, mood and identity. Given the variability, lack of communication and cognition that can occur in the latter stages of these diseases however, it is arguable that carers have to be used to represent the experiences of people dying in the palliative phases. In addition, as some people don't want to think about the end of life, and often within clinics they have not been told they are approaching the end of life, recruiting people within the palliative phase in an

ethical manner could be very difficult. If recruitment did occur it would also be more likely to represent those who were in full open awareness and willing to talk about death, which may over predict the willingness for ACP. Often studies that did interview people in the latter stages of these conditions excluded people who were unable to speak or had significant cognitive impairment (11, 74) whereas this study was able to capture their experiences to some extent by interviewing bereaved carers. In addition, as the aim of palliative care is to treat the person who is dying and their family as a unit of care, the fact that views may not align entirely is perhaps less important when evaluating palliative/end of life care delivery. A leading matter of importance to those dying is that their family is cared for around, and after, the time of their death and in terms of health policy, most of the changes that have occurred in the last five years have done so because of the voices of the bereaved (83). That being said there are some limitations in this study in regard to the selection of bereaved carers, with the main issue of potential validity related to the time of bereavement.

Time since bereavement

Some carers responded quickly and may have been subject to more negative views due to grief; though that did not appear to be the case. Other carers were interviewed a long time after their relative's deaths and so their recollections may have been more at risk of recall bias (80) and not accurately reflect what was said at the time. However, as processing likely occurred, recollections/feelings that were still vividly present after time were likely to be important.

In addition, because improvements have been made in certain areas and the charities have grown some of the issues that were shared in the interviews of carers bereaved years ago were less relevant to current healthcare policy; although this was taken into account when the analysis took place. A strength of interviewing people who had undergone a longer period of bereavement was that it demonstrated the ways that people managed their bereavement over time in a way that a study with shorter bereavement period could not.

8.4.2 *Recruitment*

One of the challenges of this project was that the local information governance team did not allow next of kin details to be used to contact bereaved relatives. This resulted in a project redesign that affected the timescales of the project. However, the fact that the recruitment methods had to change became one of the strengths of the project. In most projects that look at the palliative needs of people with PD/PSP/MSA participants are recruited through movement disorder services and an element of gatekeeping can take place; this was lessened by the opt-in nature of the project. In addition, most studies are centred on one region or service and, as these services are often leading the field regarding the disease groups they are studying, they may not represent the experiences of the rest of the population. In contrast this study recruited people from across England and Wales and so shows the range of experiences that people can have in different locations, rather than reflecting one service.

Whilst the opt in nature limits the bias of healthcare teams, it can lead to bias in another way as it is possible that it is mainly the people with the strongest views, both negative and positive that respond. There is no way to avoid this, but it led to a greater need for consideration when undertaking analysis to ensure that all views are represented. I was mindful of this fact during the analysis phase and as such ensured that the voice of every participant is represented in this thesis, even if their view on a subject was not as vehemently expressed as another's might have been.

Sampling

Another limitation of this project was that aside from the carers of people with PD who were interviewed locally there was no way of checking the diagnosis of the people who had died. In addition, because the numbers recruited were small and people who contacted me through the charities were keen to participate the sample was recruited as a convenience sample rather than purposefully; despite this all places of death were represented across the three diseases. Where purposeful sampling was able to be used, in the local PD carers, people who died with PD and dementia were actively recruited, because they are underrepresented in nearly all studies regarding palliative and end of life care in PD.

8.4.3 *Forums*

The forums did not work as well as was hoped. The levels of recruitment were dependent on where/how they were advertised and resulted in limited recruitment. In addition, they did not act as a forum; there was little interaction between participants and people tended to join, post a comment and then leave, which made it difficult to ask follow up questions. The forums did not feel as comfortable as the interviews because it was more difficult to check emotional responses to questions than in an interview. It was also difficult to check the demographics of the people taking part because they only interacted with the forum once.

However, a strength of using the forums was that information posted came in a pre-considered response and so every part was relevant to the initial questions about place of death and the matters of greatest importance were clearly presented. The forums also allowed people to post responses when they felt they were ready because of their opt-in nature and showed that some people are willing to share their experiences long before the usual bereavement period of 3-4 months that many studies fix upon.

8.4.4 *Reflexivity*

One of the strengths of this study was that, as a trainee in Geriatric medicine, I was involved in working in a movement disorder team at the start of the project and had a reasonable knowledge of PD, PSP and MSA before the project began. This helped me to build rapport, especially in the interviews with the PSP/MSA carers, where it seemed they appreciated that I knew about the diseases because it meant that they did not have to explain them. In addition, because I had recent experience of working in acute hospitals, with previous experience working in hospices and into care homes, I was also aware of the treatments and interventions that people with the diseases may have encountered, meaning that the flow of the interviews did not need to be halted because of a lack of understanding. Conversely, however, it is possible that because of this understanding of hospitals I may have made assumptions about certain scenarios that were presented without exploring them in depth from the point of view of the participants. For example, when people related to me the chaotic nature of medical admission units I did not explore this more deeply as it is a

situation I encountered regularly. Being a doctor may have affected the degree to which people felt they were able to share their feelings about negative aspects of the healthcare service and there did appear to be more reticence to discuss negative views in the locally recruited carers.

Another difficulty was the adjustment to becoming an interviewer rather than an educator, which became easier with time. Once or twice the roles coincided and that may have influenced the nature of the interviews. For example, in an early interview after Vincent had explained how hard he found it to process the fact that his wife died without warning I said 'well you probably know that sudden death is fairly common for people with MSA' only to be told he was unaware. This then led to a discussion about sudden death which, although he said it helped him, undoubtedly changed the remainder of the interview.

Several qualitative researchers speak of the need to protect themselves when undertaking bereavement research because of its emotional nature and I was concerned part way through the process that I was not emotionally affected as much as I felt I should have been. This is likely due to my usual role as a geriatrician; I see people die and speak to their families about death regularly and so death has become less of a taboo. This did not mean that I was unable to show empathy, but my objectivity is likely to have affected the analysis of the interviews and forum samples. In addition, because the aim of this project was to try and improve services it is possible that the analysis is swayed towards matters that could be improved and are negative, rather than reflecting many of the positive aspects of care that were relayed, as I was looking for things to fix.

8.4.5 *VOICES*

Strengths

The strengths of using the VOICES survey is that it includes opinions from across England and Wales, rather than a single geographical area and allows the viewpoints of multiple carers to be considered and compared. As it was collected by the ONS it is not subject to the bias it might be if it was sent by local teams. Because the sample was large (n=1074) places of death could be compared and statistical conclusions could be drawn; Hunt et al

showed in their VOICES redesign for the national survey that a NET sample size of 651 was enough to make statistical comparisons with a margin of error of 0.025 (125).

Limitations

The main limitation of the VOICES survey when used to compare POD is that the recorded POD on a death certificate and the perceived POD from a carers point of view can differ. Table 16 shows the degree of disagreement.

POD according to Death Certificate [total number of dc]	POD according to carer [total number]				
	Hospital [324]	Care Home [531]	Home [162]	Hospice [27]	Elsewhere [8]
Hospital [331]	320	2	1	4	4
Care Home [538]	4	524	4	3	3
Home [162]	0	5	157	0	0
Hospice [21]	0	0	0	20	1

Table 16 A comparison of POD according to the death certificate and bereaved carers, England 2012-15

In addition, in the 2012-13 surveys carers were asked 'where their relative had spent their last 2 days' and again there was an indication that the views carers shared about the last two days may not match the recorded POD (see Table 17).

POD according to Death Certificate [total number of dc]	Where did he/she spend the last two days of their life according to carer [total number of responses]				
	Hospital all time [138]	Care Home all time [246]	Home all time [76]	Hospice all time [8]	Other [13]
Hospital [153]	137	7	2	0	7
Care Home [242]	1	235	0	1	5
Home [79]	0	4	74	0	1
Hospice [7]	0	0	0	7	0

Table 17 Comparison of POD according to the ONS and carer's views of where their relatives spent their last 2 days, England 2012-13

Most of the viewpoints did match, but it does mean that questions regarding the last 2 days of life may not be entirely representative of the place recorded on the death certificate in all cases.

The final limitation of using the ONS data is that the surveys were not completed with any researcher guidance, which may make it difficult to compare issues such as respect and dignity because it is possible they will mean different things to different people and different things according to location. For example dignity may mean being kept clean in a hospital or care home but might mean respectful communication from a GP.

8.4.6 *Overall*

The main strength of this study is that it is mixed methods, and this helps to overcome some of the limitations in terms of adequately representing place in the qualitative component and in terms of interpreting survey responses in the quantitative sample.

8.5 Suggestions for future research

This study has answered some questions regarding POD for people dying due to the diseases and it might be interesting to compare those dying from PD as an underlying or contributory cause to see if there are differences.

In addition, carers of people with these diseases felt that care was not as good as it might be for cancer. It would also be interesting to compare these diseases to cancer over time to see if any differences in service provision are lessening; we might expect this to be the case as SPC for neurological conditions is likely to have increased over time. The ONS plan on making the free text responses to the VOICES survey available for analysis and comparing them to the views of this study would be of interest.

Lastly, although this study has described the experiences of people with PSP/MSA according to their carers there is still a huge gap in the qualitative literature in terms of understanding the way that people with these diseases experience care. Certainly, some of the issues suggested by this study in regard to potential loss of self and adjustment to disease, as well as views on engaging with ACP, would be useful areas of study to help improve services and

support. Given that there is little in the qualitative literature about the experiences of rare diseases, findings from such studies would add to the rare disease literature as well.

8.6 Thesis Conclusion

This study aimed to explore two areas of research with little available literature:

1. The palliative and end of life care needs of people with PD, PSP and MSA
2. Whether the quality of the end of life care experience varies by location for people with PD, PSP and MSA

These areas were explored through qualitative interviews, internet forums and analysis of the National bereavement surveys.

The main findings were that the rapidity of decline, combined with the rareness of PSP and MSA, shaped experience, meaning it differed to some extent from people with PD.

All locations had positive aspects of care reported but those that provided good communication, time, an effort to understand the dying person, and continuity, provided the best care. It is the reduction in verbal communication (and to some extent cognition) which makes these factors even more important to people with PD, PSP and MSA but at the same time potentially harder to achieve.

Appendix A: Information Sheets and Consent Forms

i. Invitation letter for the MSA Trust/PSP association

Dear_____

The MSA Trust has kindly agreed to send this letter to you as they know that you cared for someone who has died from MSA. I know that this may still be a very difficult time for you but I would like to invite you to take part in a piece of research aiming to improve the services and care provided at the end of life for people with Multiple System Atrophy.

Taking part in the study would involve being interviewed over the telephone about the time surrounding the end of your loved one's life. This interview would be carried out by Claire Morris, a research doctor currently working with the Northumbria Parkinson's disease team. The interview would last around 60 minutes and is very valuable as it would allow us to hear from you what you felt were the most important factors for you and your loved one nearing the end of their life. Ideally we want to try and determine what, in your opinion, influences good and bad experiences when a person with Multiple System Atrophy is approaching the end of their life. We would not want this to be overly upsetting for you and so if any questions were too distressing or difficult to answer Claire would move past them. Also the interview could be stopped at any time. We would want you to be as honest with your feelings as you were able to be when answering, as we want to get an accurate opinion so that we can try and improve services for the better. The interview would be audio-recorded and once it was completed it would be kept in a secure location and transcribed; at this point it would be made anonymous. Once the whole project is completed, which is likely to take around eighteen months, Claire would send you a summary of the results.

If you do decide you might like to take part please contact Claire on the details provided at the bottom of this letter and she will arrange to send you a research pack containing more

information. Whether you take part or not after reading the pack, your personal details will not be released to anyone else and it will not affect your future care in any way.

Thank you very much for your time,

Professor Richard Walker

Consultant Physician Northumbria Healthcare NHS Foundation Trust

Details for Claire Morris:

Call 07745302325 or e-mail: c.e.morris3@newcastle.ac.uk

ii. Project information for participants

Factors that influence the quality of the end of life experience for people with Parkinson's disease (PD), Progressive Supranuclear Palsy (PSP) and Multi-system Atrophy (MSA)

Introduction

Thank you for agreeing to receive more information about this project. Please take time to read the following information carefully. You can ask the researcher questions and please talk the study over with others if you wish.

What is the study about?

This study is about understanding what factors affect the experience of a person with PD, PSP or MSA in the last months of their life. We specifically want to focus on people with PD, PSP and MSA as the nature of the diseases means their experiences at the end of life may be very different from the general population. The aim is to use this information to try and improve care and services for people with these diseases coming to the end of their lives

To enable us to do this we are interviewing the carers of the people who have died and also setting up internet forums.

The interview is to understand what you, as a carer, feel are actually the most important issues for us to focus on when looking after a person with Parkinson's disease coming towards the end of their life.

What difference will the research make?

We hope that this research will lead to improvements in the way that we provide services and care for people coming to the end of their lives with PD, PSP and MSA. It will help develop guidance for HCPs, care homes and hospitals about what matters most in the last few months/days and what areas we need to improve upon.

It will also help us to see which symptoms we should focus on controlling better and whether Parkinson's medication is beneficial for people with PD right up to the end of their life.

Why have I been invited?

We are interested in what contributes to good and bad experiences at the end of a person's life. You have been sent this leaflet because we know that you cared for someone with Parkinson's disease and you previously indicated you would be willing to be contacted with regards to research.

Do I have to take part?

It is up to you to decide whether you wish to participate in the study. Your decision will not affect the care you receive. Even if you agree to have an interview, you can change your mind at any time and do not have to give a reason. Deciding you do not want to be interviewed, even at the last minute, will not affect the standard of care you receive in anyway.

If you are willing to take part in this research study please read and complete the consent form in this pack and return it to us. If you do not want to take part please just let us know and we will not contact you again.

What will happen if I decide to take part?

If you decide to take part, Claire, the main researcher will explain the interview over the phone, check that you are still happy to take part and that you understand the research. Please feel free to ask her any questions. She will then agree a time and a place which is most convenient for you for the interview to take place. We would anticipate this to be within three weeks from the phone call, providing that this would fit into your plans

What will the interview entail?

During the interview she will ask you to talk her through, in your own words, the last few months and days of your loved one's life. She will ask you your thoughts and feelings about:

- Whether where the environment your loved one died made a difference, e.g. at home or in hospital

- Whether you think the place they died was the right place or not
- She will also ask whether you received enough information and, if not, what you feel would have helped more

She may also explore with you:

- What you think constitutes 'a good death' for people with Parkinson's disease?
- What you feel were the positive and negative experiences at the end of your loved one's life?
- What you think could have improved this time for your loved one and yourself/your family?

This allows you to tell us what you think made a difference in your own words, rather than us interpreting what represents quality from questionnaires/guidelines.

The interview will last about 1 hour, but it can be stopped at any time if you wish. The interview will be audio-recorded. **You do not need to answer any question you do not feel comfortable with**. Except in extreme circumstances, i.e. you disclose something illegal that she has to report, everything you say will be confidential, even from the Parkinson's disease team. The interviews will then be transcribed and made anonymous. Once they have been transcribed, the original audio recording will be destroyed.

What are the possible benefits of taking part?

Some people find it helpful to talk through their experiences and feelings after caring for a loved one who has died. In some cases it can also help with the bereavement process.

What happens to the information I give?

At the end of the study, the findings will be reported to GPs, consultants and other professionals who care for people with PD, PSP and MSA. They will also form part of an educational project for Claire and they may be published in medical journals. We will also send a written copy of the key results to you. Your name will not appear in any reports or publications arising from the study. No comment or reflection you make about your loved one's care/experience will affect the standard of care you receive in the future. All transcripts of the interviews, which will be made anonymous, will be stored on a secure

computer network; the original recordings will be destroyed once they have been transcribed.

The study has been reviewed and approved by the Research Ethics Committee (REC Reference number: 15/NE/0066).

Who is organising and paying for the study?

The study is funded by the Northumbria Healthcare NHS Foundation Trust and is part of a MD undertaken at Newcastle University by Dr Claire Morris. The research team is based at North Tyneside General Hospital and is led by Professor Richard Walker.

For further information about the study please contact:

Dr Claire Morris c.e.morris3@newcastle.ac.uk **07745302325**

What if I have a problem or wish to make a complaint?

If you have any concerns or complaints about the research, we will do our best to resolve them. Please contact:

Ms Caroline Potts

North Tyneside General Hospital

Rake Lane

North Shields

Newcastle upon Tyne

NE29 8NH

Telephone: *0344 811 8111*

Email: caroline.potts@nhct.nhs.uk

What if I would like any extra information or support?

For further information about the study or for extra support please contact your Parkinson's Disease Nurse Specialist or Dr Claire Morris.

You may find it helpful to speak to your family, a friend or your GP about bereavement. You can also get advice on the subject from:

Parkinson's UK	*0808 800 0303*
Cruse bereavement	**www.cruse.org.uk** **Telephone: 0844 477 9400** **e-mail: helpline@cruse.org.uk**

Thank you for taking the time to read this document.

iii. Consent form for the interviews

Factors that influence the quality of the end of life experience for people with PD, PSP or MSA

Name of participant:	Please initial
• I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily	
• I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected	
• I understand that the information collected during the study may be looked at by individuals at Northumbria NHS Trust, Newcastle University or regulatory authorities where it is relevant to my taking part in this research	
• I understand that my interview will be audio-recorded	
• I understand that all information I give will be stored in a locked, secure storage system and/or on a password protected computer network only accessible by the research team	
• I understand that any publications involving information collected will be made completely anonymous prior to publication	
• Should I for any reason lose capacity I consent to any information previously gained to be used in data analysis	
• I agree to take part in the above study	

…… ……. …… …….

Name of Research participant Date Signature

…… ……. …… …….

Name of Researcher Date Signature

iv. Forum introductory Information

A forum to discuss factors that influence the quality of the end of life experience for people with Parkinson's disease.

Firstly, thank you for taking the time to come through to this forum. We understand that this must have been/must still be a very difficult time for you and we are really grateful that you are considering sharing your thoughts about this topic.

What is the forum for?
This forum is part of a qualitative research project which is aiming to understand the issues that affect people the most when they are coming to the end of their lives with PD.

We specifically want to focus on people with PD as the nature of the disease means that their experiences at the end of life may be very different from the general population. The aim is to use this information to try and improve care and services for people with PD coming to the end of their lives by providing guidance for healthcare professionals, care homes and hospitals about what matters most and what we could improve upon.

Rather than using a survey, we want to know what you feel are actually the most important issues for us to focus on when looking after a person with PD at the end of their life. We would especially like to know if the place a person dies makes a difference i.e. care home, hospital, own home or hospice but anything you tell us would help us understand better what matters to actual people with PD and their carers.

Taking part
The decision about whether to take part in this forum or not is completely up to you. If you do decide to take part, you'll need to read the consent form and click to say you agree to your comments being used in the project. Even if you do agree to take part, you are free to leave the discussion forum at any point in time without explaining why.

How does the forum work?
The forum will be open for around six to nine months. Over the time period the main researcher will post questions to guide the discussion a little. You can choose whether you want to comment about these new questions or not. You can also post as little or as much as you want onto the forum. At the end of the period the forum will be shut down and comments that have been posted will be reviewed alongside data from local interviews.

What happens to the information I give?
Throughout the study the comments you make will be used to further the discussion forum, as they would in a normal online forum. Once the forum closes all of the comments will be reviewed and looked through, alongside interview data, to see if there are any issues that are commonly occurring. The main issues found will be reported to GPs, consultants and other professionals who care for people with PD. The findings will also form part of Claire, the main researcher's, MD thesis and may be published in medical journals. Your forum pseudonym will not appear in any reports or publications arising from the study. All efforts will be made to reduce direct quotation so that a quote searched for on the Internet, will not bring up a record of the forum.

For further information about the study please e-mail c.e.morris3@ncl.ac.uk

What if I would like extra information about bereavement?
You may find it helpful to speak to your family, a friend or your GP about bereavement. You can also get advise from Parkinson's UK on 0808 800 0303 or Cruse bereavement: Tel: 0844 477 9400 e-mail: helpline@cruse.org.uk

v. Terms and Conditions on the forum

• I confirm that I have read and understand the information for the above study. I have had the opportunity to consider the information, e-mail questions and have had these answered satisfactorily	
• I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason	
• I understand that the information collected during the study may be looked at by individuals at Northumbria NHS Trust, Newcastle University or regulatory authorities where it is relevant to my taking part in this research	
• I understand that the e-mail I use to sign up with will be seen by the main researcher but will not be shared with other third parties by the research team	
• I understand that all comments I make will be visible to other people on the forum	
• I understand that any comment I type will be read by the research team and analysed alongside other comments and interviews	
• I understand that as the forum is hosted on the internet it is impossible to ensure complete security	
• I understand that any publications involving information collected will be made anonymous prior to publication and my pseudonym will be changed	
• Should I for any reason lose capacity I consent to any comments previously made to be used in data analysis	
• I agree to take part in the above study	

Appendix B: The VOICES questionnaire

Office for National Statistics

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NHS England

VOICES

VIEWS OF INFORMAL CARERS - EVALUATION OF SERVICES

Dear

Invitation to help with the VOICES survey of experiences of care in the last months of life.

If you would like to receive this information in large print please call our Survey Enquiry Line on 0800 298 5313

We are writing to you because you registered the death of .
We appreciate that this may be a very difficult time for you, but we would like to invite you to take part in the VOICES survey. VOICES gathers information on your experiences of health care services in the last months of life and is used by NHS England and other health care charities to monitor and improve the services they provide. For more information please read the information leaflet enclosed.

If you **do** wish to take part please complete the questionnaire and return it to ONS in the pre-paid envelope by Friday 12th December 2014.

If you **do not** wish to participate please tick the box on page 15 of the questionnaire and return it to ONS in the pre-paid envelope provided. This will ensure that you do not receive reminder letters.

Your views are important and will help improve health care for patients in England. We apologise if this enquiry has caused you any distress and hope that you feel able to take part in this study.

Yours sincerely

Emma Gordon
Head of Life Events Analysis,
Office for National Statistics

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☑ **Answer the questions by putting a tick in the most appropriate box or boxes.**
If you wish to change your answer, cross through the answer you do not want.

- ☒ Excellent
- ☐ Good
- ☑ Fair

If he died suddenly, please go to question 38.
Otherwise, please continue with the questions below.

1 **How long had he been ill before he died?**

Tick one only

- ☐ He was not ill - he died suddenly - **go to question 38**
- ☐ Less than 24 hours
- ☐ One day or more but less than one week
- ☐ One week or more but less than one month
- ☐ One month or more but less than six months
- ☐ Six months or more but less than one year
- ☐ One year or more

2 **Did he spend any time at home during the last three months of life?**

Tick one only

- ☐ Yes - **go to question 3**
- ☐ No - he was in a care home for the whole 3 months - **go to question 12**
- ☐ No he was in hospital - **go to question 24**

Care at Home

These questions are about care at home - not in a care home

3 **When he was at home in the last three months of life, did he get any help at home from any of the services listed below?**

These may be provided by different organisations, such as voluntary organisations, a private agency or social services.

Tick all that apply

- ☐ A district or community nurse (a nurse in uniform who comes to the house)
- ☐ A Macmillan nurse, hospice home care nurse or specialist (a care nurse who visits or telephones to talk and advise on medications and other aspects of care. Not in uniform)
- ☐ A Marie Curie nurse (someone who comes to the house for a few hours or overnight to care for the patient)
- ☐ Any other nurse at home
- ☐ Home care worker, home care aide or home help
- ☐ Social worker / support worker
- ☐ Counsellor
- ☐ Religious leader
- ☐ Meals-on-wheels or other home delivered meals
- ☐ Hospice at home
- ☐ Occupational therapist (OT)
- ☐ Rapid response team (team of nurses and home care workers who provide care over the short term to allow someone to remain at home and prevent hospital admission)
- ☐ He did not receive any care
- ☐ Don't know
- ☐ Something else

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4 **When he was at home in the last three months of life, did all these services work well together?**

Tick one only

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No, they did not work well together
- ☐ He did not receive any care
- ☐ Don't know

5 **Overall, in the last three months of care, do you feel that you and your family got as much help and support from health and social services as you needed when caring for him?**

Tick one only

- ☐ Yes, we got as much support as we needed
- ☐ Yes, we got some support but not as much as we needed
- ☐ No, although we tried to get more help
- ☐ No, but we did not ask for more help
- ☐ We did not need help

6 **During the last three months of his life, while he was at home, how well was his pain relieved?**

Tick one only

- ☐ Does not apply - he did not have any pain
- ☐ Completely, all of the time
- ☐ Completely, some of the time
- ☐ Partially
- ☐ Not at all
- ☐ Don't know

Urgent Care Provided Out of Hours

7 **In the last three months of life, while he was at home, did he ever need to contact a health professional for something urgent in the evening or at the weekend?**

Tick one only

- ☐ Not at all in the last three months - **go to question 12**
- ☐ Once or twice - **go to question 8**
- ☐ Three or four times - **go to question 8**
- ☐ Five times or more - **go to question 8**
- ☐ Don't know - **go to question 12**

8 **The last time this happened, who did he contact, or who was contacted on his behalf?**

Tick all that apply

- ☐ His GP or the out-of-hours number
- ☐ NHS Direct
- ☐ District nurses
- ☐ Macmillan nurses
- ☐ He used his 'lifeline' pendant
- ☐ A hospice
- ☐ 999
- ☐ Someone else

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9 **What happened as a result? Was he ...**

Tick one only

- ☐ Visited by his GP at home
- ☐ Visited by another GP at home
- ☐ Visited by a nurse at home
- ☐ Visited by a hospice doctor at home
- ☐ Given medical advice over the phone
- ☐ Given another number to ring to get medical advice
- ☐ Advised to go to an out-or-hours GP surgery
- ☐ Advised to go the GP surgery when it opened
- ☐ Advised to go to an Accident and Emergency Department at a hospital
- ☐ Advised to call 999
- ☐ Something else

10 **Overall, on this last occasion, do you think that the health services responded in the right way?**

Tick one only

- ☐ Yes
- ☐ No
- ☐ Not sure

11 **Overall, do you feel that the care he got when he needed care urgently in the evenings or weekends in the last three months of his life was:**

Tick one only

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know

District & Community Nurses

If he had care in the last three months from district and community nurses - **go to question 12.**
If he did not - **go to question 15**

12 **How often, in the last three months of his life, did the district or community nurse visit (at the most frequent time)?**

Tick one only

- ☐ More than once a day
- ☐ Every day
- ☐ 2-6 times a week
- ☐ Once a week
- ☐ 2-3 times a month
- ☐ Less often
- ☐ Don't know

13 **How much of the time was he treated with respect and dignity by the district and community nurses in the last three months of his life?**

Tick one only

- ☐ Always
- ☐ Most of the time
- ☐ Some of the time
- ☐ Never
- ☐ Don't know

14 **Overall, do you feel that the care he got from the district and community nurses in the last three months of his life was:**

Tick one only

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know

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Care from the GP

15 **In the last three months, how often did he see the GP he preferred to see?**

Tick one only

- ☐ Always or almost always
- ☐ A lot of the time
- ☐ Some of the time
- ☐ Never or almost never
- ☐ He didn't try to see a particular GP
- ☐ He did not need to see a particular GP - **go to question 20**

16 **How much of the time was he treated with respect and dignity by the GPs in the last three months of his life?**

Tick one only

- ☐ Always
- ☐ Most of the time
- ☐ Some of the time
- ☐ Never
- ☐ Don't know

17 **Were you able to discuss any worries and fears you may have had about his condition, treatment or tests with the GPs in the last three months of his life?**

Tick one only

- ☐ I had no worries or fears to discuss
- ☐ Yes, I discussed them as much as I wanted
- ☐ Yes, I discussed them, but not as much as I wanted
- ☐ No, although I tried to discuss them
- ☐ No, but I did not try to discuss them

18 **Overall, if the GP visited him at home in the last three months, how easy or difficult was it to get him/her to visit?**

Tick one only

- ☐ Very easy
- ☐ Fairly easy
- ☐ Fairly difficult
- ☐ Very difficult
- ☐ He wanted the GPs to visit but they would not visit
- ☐ Does not apply - the GP did not need to visit
- ☐ Don't know

19 **Overall, do you feel that the care he got from the GP in the last three months of life was:**

Tick one only

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know

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Last Care Home

20 **Did he live or stay in a care home at any time during his last three months of life?**

Tick one only

- ☐ Yes he was in a care home
- ☐ No - **go to question 24**
- ☐ Don't know - **go to question 24**

21 **How much of the time was he treated with respect and dignity by the staff at the last care home they stayed in?**

Tick one only

- ☐ Always
- ☐ Most of the time
- ☐ Some of the time
- ☐ Never
- ☐ Don't know

22 **During the last three months of his life, while he was in the care home, how well was his pain relieved?**

Tick one only

- ☐ Does not apply - he did not have any pain
- ☐ Completely, all of the time
- ☐ Completely, some of the time
- ☐ Partially
- ☐ Not at all
- ☐ Don't know

23 **Overall, do you feel that the care he got from the care home in the last three months of his life was:**

Tick one only

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know

Last Hospital Stay

24 **Did he live or stay in hospital at any time during his last three months of life?**

Tick one only

- ☐ Yes
- ☐ No - **go to question 29**
- ☐ Don't know - **go to question 29**

25 **During his last hospital admission, how much of his time was he treated with respect and dignity by the hospital doctors and nurses?**

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

26 **During his last hospital admission, how well was his pain relieved?**

Tick one only

- ☐ Does not apply - he did not have any pain
- ☐ Completely, all of the time
- ☐ Completely, some of the time
- ☐ Partially
- ☐ Not at all
- ☐ Don't know

27 **Did the hospital services work well together with his GP and other services outside of the hospital?**

Tick one only

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No, they did not work well together
- ☐ Don't know

28 **Overall, do you feel that the care he got from the staff in the hospital on that admission was:**

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Excellent
☐	☐	Good
☐	☐	Fair
☐	☐	Poor
☐	☐	Don't know

Last Hospice Stay

29 **Did he live or stay in a hospice at any time during his last three months of life?**

Tick one only

- ☐ Yes
- ☐ No - **go to question 33**
- ☐ Don't know - **go to question 33**

30 **How much of the time was he treated with respect and dignity by the hospice doctors and nurses?**

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

31 **During the last three months of his life, while he was in the hospice, how well was his pain relieved?**

Tick one only

- ☐ Does not apply - he did not have any pain
- ☐ Completely, all of the time
- ☐ Completely, some of the time
- ☐ Partially
- ☐ Not at all
- ☐ Don't know

32 **Overall, do you feel that the care he got from the staff in the hospice in the last three months of his life was:**

Tick one only

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know

Experiences in the last two days of life

33 **How much of the time was he treated with respect and dignity in the last two days of his life?**

Please answer for both doctors and nurses

Doctors	Nurses	
☐	☐	Always
☐	☐	Most of the time
☐	☐	Some of the time
☐	☐	Never
☐	☐	Don't know

34 **Please look at the following statements and tick the answer box that corresponds most with your opinion about the help he received in the last two days of life**

Tick one box for each question (a-c)

		Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	Don't know
(a)	There was enough help available to meet his personal care needs (such as toileting needs)	☐	☐	☐	☐	☐	☐	☐
(b)	There was enough help with nursing care, such as giving medicine and helping him find a comfortable position in bed	☐	☐	☐	☐	☐	☐	☐
(c)	The bed area and surrounding environment had adequate privacy for him	☐	☐	☐	☐	☐	☐	☐

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35 **As far as you are able to say, how much do you agree with the following statements about the overall level of care given by health and social care professionals to him in the last two days of life?**

Tick only one response per statement

a) In the last two days of life he had sufficient pain relief

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Pain relief was not needed
- ☐ Not sure

b) In the last two days of life he had support to eat or receive nutrition if he wished

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Food/nutrition was not needed
- ☐ Not sure

c) In the last two days of life he had support to drink or receive fluid if he wished

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Drink/fluid was not needed
- ☐ Not sure

d) In the last two days of life care and attention were given to problems apart from pain, thirst and hunger

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Does not apply
- ☐ Not sure

e) In the last two days of life his emotional needs were considered and supported

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Does not apply
- ☐ Not sure

f) In the last two days of life his spiritual and/or religious needs were considered and supported

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Does not apply
- ☐ Not sure

This question continues overleaf

continued from question 35 overleaf

Tick only one response per statement

g) In the last two days of life efforts were made to make sure he was in the place he most wanted to be cared for

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Does not apply
- ☐ Not sure

36 **Overall, how much do you agree with following statements about communication between you and health care professionals in the last two days of his life?**

Tick one box for each question (a-c)

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know	Not applicable
a) I/we were kept informed on his condition and care	☐	☐	☐	☐	☐	☐	☐
b) I/we had enough time with staff to ask questions and discuss his condition and care	☐	☐	☐	☐	☐	☐	☐
c) I/we understood information provided to us	☐	☐	☐	☐	☐	☐	☐

37 **How much do you agree with the following statement?**

In the last two days of his life you had a supportive relationship with the health care professionals.

Tick one only

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Does not apply
- ☐ Not sure

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Circumstances Surrounding His Death

38 **Did he know he was likely to die?**

Tick one only

- ☐ Yes, certainly
- ☐ Yes, probably
- ☐ No, probably not
- ☐ No, definitely not
- ☐ Not sure

39 **In your opinion, did the person who told him he was likely to die break the news to him in a sensitive and caring way?**

Tick one only

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No, not at all
- ☐ Not sure
- ☐ Does not apply - they did not know he was dying
- ☐ Does not apply - they did not tell him he was dying

40 **Were you contacted soon enough to give you time to be with him before he died?**

Tick one only

- ☐ Yes
- ☐ No
- ☐ I was already there
- ☐ It was clear that he was going to die soon
- ☐ I couldn't have got there anyway

41 **Where did he die?**

Tick one only

- ☐ In his own home
- ☐ In the home of another family member or friend
- ☐ In a hospital ward
- ☐ In a hospital Accident and Emergency Department
- ☐ In a hospital Intensive Care Unit
- ☐ In a hospice
- ☐ In a care home
- ☐ In an ambulance on the way to hospital or hospice
- ☐ Somewhere else

42 **Did he ever say where he would like to die?**

Tick one only

- ☐ Yes - **go to question 43**
- ☐ No - **go** to **question 45**
- ☐ Not sure - **go to question 45**

43 **Where did he say that he would like to die?**

Tick one only

- ☐ At home
- ☐ In a hospice
- ☐ In a hospital
- ☐ In a care home
- ☐ He said he did not mind where he died
- ☐ He changed his mind about where he wanted to die
- ☐ Somewhere else

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44 **Did the health care staff have a record of this?**

Tick one only

- ☐ Yes
- ☐ No
- ☐ Not sure

45 **Do you think he had enough choice about where he died?**

Tick one only

- ☐ Yes
- ☐ No
- ☐ Not sure
- ☐ He died suddenly

46 **On balance, do you think that he died in the right place?**

Tick one only

- ☐ Yes
- ☐ No
- ☐ Not sure

47 **Were you or his family given enough help and support by the healthcare team at the actual time of his death?**

Tick one only

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No, not at all
- ☐ Not sure

48 **After he died, did staff deal with you or his family in a sensitive manner?**

Tick one only

- ☐ Yes
- ☐ No
- ☐ Not sure
- ☐ Does not apply, I didn't have any contact with the staff

49 **Looking back over the last three months of his life, was he involved in decisions about his care as much as he would have wanted?**

Tick one only

- ☐ He was involved as much as he wanted to be
- ☐ He would have liked to be more involved
- ☐ He would have liked to be less involved
- ☐ He was not able to be involved
- ☐ Not sure

50 **Looking back over the last three months of his life, were <u>you</u> involved in decisions about his care as much as you would have wanted?**

Tick one only

- ☐ I was involved as much as I wanted to be
- ☐ I would have liked to be more involved
- ☐ I would have liked to be less involved
- ☐ Not sure

51 **Looking back over the last three months of his life, were any decisions made about his care that he would not have wanted?**

Tick one only

- ☐ Yes
- ☐ No
- ☐ Not sure

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52 **Overall, and taking all services into account, how would you rate his care in the last three months of life?**

Tick one only

- ☐ Outstanding
- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Not sure

53 **Since he died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his illness and death?**

Tick one only

- ☐ Yes
- ☐ No, but I would have liked to
- ☐ No, but I did not want to anyway
- ☐ Not sure

Information About You Both

54 **What was your relationship to him? Were you his:**

Tick one only

- ☐ Wife / Partner
- ☐ Son / Daughter
- ☐ Brother / Sister
- ☐ Son-in-law / Daughter-in-law
- ☐ Parent
- ☐ Other relative
- ☐ Friend
- ☐ Neighbour
- ☐ Staff in care home
- ☐ Warden (sheltered accommodation)
- ☐ Other official
- ☐ Someone else

55 **What is your age?**

- ☐ 18 - 19
- ☐ 20 - 29
- ☐ 30 - 39
- ☐ 40 - 49
- ☐ 50 - 59
- ☐ 60 - 69
- ☐ 70 - 79
- ☐ 80 - 89
- ☐ 90 +

56 **Are you:**

- ☐ Male
- ☐ Female

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57 **Please could you indicate which ethnic group <u>you</u> belong to:**

Tick one only

White

- ☐ English / Welsh / Scottish / Northern Irish / British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other white background

Mixed / Multiple ethnic group

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other mixed background

Asian / Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background

Black African / Caribbean / Black British

- ☐ African
- ☐ Caribbean
- ☐ Any other Black / African / Caribbean background

Other ethnic group

- ☐ Arab
- ☐ Any other ethnic group

58 **Please could you indicate which ethnic group in your opinion he belonged to:**

Tick one only

White

- ☐ English / Welsh / Scottish / Northern Irish / British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other white background

Mixed / Multiple ethnic group

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other mixed background

Asian / Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background

Black African / Caribbean / Black British

- ☐ African
- ☐ Caribbean
- ☐ Any other Black / African / Caribbean background

Other ethnic group

- ☐ Arab
- ☐ Any other ethnic group

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59 **What was his age when he died?**

- ☐ 18 - 19
- ☐ 20 - 29
- ☐ 30 - 39
- ☐ 40 - 49
- ☐ 50 - 59
- ☐ 60 - 69
- ☐ 70 - 79
- ☐ 80 - 89
- ☐ 90 +

60 **What was his religion?**

- ☐ No religion
- ☐ Christian (all denominations)
- ☐ Buddhist
- ☐ Hindu
- ☐ Jewish
- ☐ Muslim
- ☐ Sikh
- ☐ Any other religion

We would be grateful if you could return your questionnaire to us in the pre-paid envelope provided
If you require a replacement envelope or if you have any other questions please phone the Survey Enquiry Line on 0800 298 5313

If you feel that you would like to talk about your feelings or discuss painful memories brought back by completing this questionnaire, please call:

Cruse Bereavement Care 0844 477 9400
or e-mail: helpline@cruse.org.uk

☐ DECLINE - Please tick this box if you decide not to complete this survey.

If you would like to tell us why, please write any comments below.

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Please use the space below if there is anything you would like to say about the care provided.
What, if anything was good about the care? What, if anything, was bad about the care?

To ensure the information you provide is confidential, please do not give names of people or places.

Thank you for completing the VOICES survey, we will not ask you for any further information.

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Appendix C: Death certificates and Contributory/Underlying Causes of death

i. Death certificates with Parkinson's disease as an underlying COD

CAUSE OF DEATH

I (a) Disease or condition directly leading to death..... Parkinson's disease

(b) Other disease or condition, if any, leading to I(a).....

(c) Other disease or condition, if any, leading to I(b).....

II Other significant conditions
CONTRIBUTING TO THE DEATH but .....
not related to the disease or condition causing it.....

CAUSE OF DEATH

I (a) Disease or condition directly leading to death..... Bronchopneumonia

(b) Other disease or condition, if any, leading to I(a)..... Parkinson's disease

(c) Other disease or condition, if any, leading to I(b).....

II Other significant conditions
CONTRIBUTING TO THE DEATH but .....
not related to the disease or condition causing it.....

ii. Death certificates with Parkinson's disease as a contributory COD

CAUSE OF DEATH

I (a) Disease or condition directly leading to death..... Pancreatic cancer

(b) Other disease or condition, if any, leading to I(a).....

(c) Other disease or condition, if any, leading to I(b).....

II Other significant conditions
CONTRIBUTING TO THE DEATH but ..... Parkinson's disease
not related to the disease or condition causing it.....

CAUSE OF DEATH

I (a) Disease or condition directly leading to death..... Bronchopneumonia

(b) Other disease or condition, if any, leading to I(a).....

(c) Other disease or condition, if any, leading to I(b).....

II Other significant conditions
CONTRIBUTING TO THE DEATH but ..... Parkinson's disease
not related to the disease or condition causing it.....

Appendix D: How responses were collapsed

i. Care from staff towards those who were dying

Question	Responses	Way collapsed for statistical inferences	Rationale
In the last three months, how often was he treated with respect and dignity by a) District nurses (Q13) b) GPs (Q16) c) Care Home staff (Q21) d) hospital doctors (Q25) e) hospital nurses (Q25) f) hospice doctors (Q30) g) hospice nurses (Q30)	Always	Always	Always being treated with respect should be the norm
	Mostly	Not Always	
	Sometimes		
	Never		
	Don't know		

Question	Responses	Way collapsed for statistical inferences	Rationale
Overall how would you rate the care given to him in the last three months by: a) Out of Hours (Q11) b) District nurses (Q14) c) GP (Q19) d) Care Homes (Q23) e) Hospital Doctors (Q28) f) Hospital nurses (Q28) g) Hospice staff (Q32)	Excellent	Excellent	Aim should be for excellent care
	Good	Not excellent	
	Fair		
	Poor		

ii. Needs

Question 35	Responses	Way collapsed for statistical inferences	Rationale
In the last two days of life he had sufficient support for a) pain, b) eating c) drinking d) other symptoms e) emotional needs f) spiritual needs	Strongly Agree	Agree	
	Agree		
	Neither agree nor disagree	Do not agree	
	Disagree		
	Strongly disagree		
	Not sure		
	Not applicable (pain relief/ food/drink not needed or does not apply)		

Question 35	Responses	Way collapsed for statistical inferences	Rationale
In the last two days of life he had sufficient support for a) pain b) eating c) drinking d) other symptoms e) emotional needs f) spiritual needs	Strongly Agree	Food and drink were needed/pain relief was not applicable	Appeared to be a large variation across the locations with regard to those who felt relief from symptoms/eating and drinking was/was not required
	Agree		
	Neither agree nor disagree		
	Disagree		
	Strongly disagree		
	Not sure		
	Not applicable (pain relief/ food/drink not needed or does not apply)	Food and drink were not needed/pain relief not applicable	

iii. Awareness of Dying and PPOD

Question 38	Responses	Way collapsed for statistical inferences	Rationale
Did he know he was likely to die?	Yes, certainly	Certainly	Previous analysis on awareness of dying compares those who certainly knew
	Yes, probably	Not certainly	
	No, probably not		
	No, definitely not		
	Not sure		

Question 39	Responses	Way collapsed for statistical inferences	Rationale
Did the person who told him he was dying do so in a sensitive manner	Yes, definitely	Told dying	So few people had been told they were dying that this question could not be used to compare places with regard to the empathy shown. It was useful to compare how likely people were to have been told however
	Yes, somewhat		
	No, not at all		
	Not sure		
	N/A they didn't know he was dying		
	N/A they didn't tell him he was dying	Not told dying	

Question 42	Responses	Way collapsed for statistical inferences	Rationale
Had he ever said where he wanted to die?	Yes	Yes	
	No	No/not sure	
	Not sure		

Question 46	Responses	Way collapsed for statistical inferences	Rationale

Do you think he died in the right place	Yes	Yes	
	No	No/not sure	
	Not sure		

iv. Staff communication with carers

Question 36	Responses	Way collapsed for statistical inferences	Rationale
I/we a) were kept informed on his condition and care b) had enough time with staff to ask questions c) had a supportive relationship with staff	Strongly Agree	Agree	
	Agree		
	Neither agree or disagree	Do not agree	
	Disagree		
	Strongly disagree		
	Does not apply		
	Not sure		

Question 40	Responses	Way collapsed for statistical inferences	Rationale
Were you contacted to give you enough time to be there before he died?	Yes	Able to be there	Comparing those who had been told in enough time wouldn't have worked because some groups had a large proportion of carers who were 'already there'
	I was already there		
	No	Not able to be there	
	It wasn't clear he was dying		
	I couldn't have got there anyway		

Question 47	Responses	Way collapsed for statistical inferences	Rationale
Were you given enough support at the actual time of his death?	Yes, definitely	Yes, definitely	Either a person has enough support or their support is inadequate
	Yes, somewhat	Somewhat, no, not sure	
	No, not at all		
	Not sure		

Question 48	Responses	Way collapsed for statistical inferences	Rationale
After he died, did staff deal with you in a sensitive manner?	Yes	Yes	
	No	No/not sure	
	Not Sure		
	N/A no contact with staff		

Question 53	Responses	Way collapsed for statistical inferences	Rationale
Since he had died, have you spoken to anyone in health or social services about your bereavement?	Yes	Yes	
	No, but would've liked to	No/not sure	
	No, but didn't want to		
	Not sure		

Question 53	Responses	Way collapsed for statistical inferences	Rationale
Since he had died, have you spoken to anyone in health or social services about your bereavement?	Yes	Wanted bereavement support	
	No, but would've liked to		
	No, but didn't want to	Didn't want support	
	Not sure		

Appendix E: Demographics of the VOICES sample

ONS demographic data before response was considered. For each demographic the below tables show firstly the data for every person with PD/PSP/MSA somewhere on their death certificate and then split the data according to whether PD/PSP/MSA were recorded as a contributory or underlying COD.

i. Age

Mentioned on death certificate	50-74	75-84	85+
PD [3990]	477 (11)	1932 (48)	1581 (40)
PSP [107]	41 (39)	51 (47)	15 (14)
MSA [63]	31 (50)	24 (38)	8 (13)

Contributory COD	50-74	75-84	85+
PD [1960]	251 (13)	944 (48)	765 (39)
PSP [14]	7 (50)	7 (50)	0
MSA [12]	4 (33)	7 (58)	1 (8)

As underlying cause on death certificate	50-74	75-84	85+
PD [2029]	225 (11)	988 (49)	816 (40)
PSP [93]	34 (37)	44 (47)	15 (16)
MSA [51]	25 (49)	19 (37)	7 (14)

ii. Gender

Mentioned on death certificate	Male	Female
PD [3990]	2458 (62)	1532 (38)
PSP [107]	53 (49)	54 (51)
MSA [63]	35 (56)	28 (44)

As contributory cause on death certificate	Male	Female
PD [1960]	1240 (63)	720 (37)
PSP [14]	7 (50)	7 (50)
MSA [12]	4 (33)	8 (67)

As underlying cause on death certificate	Male	Female
PD [2029]	1218 (60)	812 (40)
PSP [93]	46 (49)	47 (51)
MSA [51]	30 (59)	21 (41)

iii. Social deprivation

Mentioned on death certificate	Most deprived 20%	2nd most deprived 20%	Middle 20%	2nd least deprived 20%	Least deprived 20%
PD [3990]	558 (14)	711 (18)	857 (22)	944 (24)	920 (23)
MSA [63]	8 (13)	8 (13)	20 (32)	12 (19)	15 (24)

As underlying cause on death certificate	Most deprived	2nd most deprived	Middle	2nd least deprived	Least deprived
PD [2029]	254 (13)	368 (18)	440 (22)	486 (24)	482 (24)622
PSP [93]	13 (14)	16 (17)	28 (30)	21 (23)	15 (16)
MSA[51]	6 (12)	5 (10)	16 (31)	11 (22)	13 (25)

As contributory cause on death certificate	Most deprived	2nd most deprived	Middle	2nd least deprived	Least deprived
PD [1960]	304 (16)	343 (18)	417 (21)	458 (23)	438 (22)
PSP [14]					
MSA[12]	1 (8)	3 (25)	4 (33)	2 (17)	2 (17)

iv. Dementia mentioned on death certificate

Mentioned on death certificate	Dementia mentioned on death certificate	Dementia not mentioned on death certificate
PD [3990]	1084 (27)	2906 (73)
PSP [107]	10 (9)	97 (91)
MSA [63]	4 (6)	59 (94)

As underlying cause on death certificate	Dementia mentioned on death certificate	Dementia not mentioned on death certificate
PD [2029]	750 (37)	1280 (63)
PSP [93]	10 (11)	83 (89)
MSA [51]	3 (6)	48 (94)

As contributory cause on death certificate	Dementia mentioned on death certificate	Dementia not mentioned on death certificate
PD [1960]	334 (17)	1626 (83)
PSP [14]	0	14 (100)
MSA [12]	1 (8)	11 (92)

v. The underlying causes of death for the diseases

The underlying causes of death for those who had PD/PSP/MSA but were not thought to have died from them

Contributory cause on death certificate	Underlying COD			
	Cancer	CVD	Pneumonia	Other
PD [1960]	254 (13)	539 (28)	374 (19)	793 (40)
PSP [14]	2 (14)	1 (7)	7 (50)	4 (29)
MSA [12]	0 (0)	1 (8)	6 (50)	5 (42)

Commonest causes of death listed in part 1a for those with PD

Most common COD recorded in part 1a for those where PD was the underlying factor [2029]			Most common COD recorded in part 1a for those where PD was the contributory factor [1960]	
Cause	Frequency (%)		Cause	Frequency
PD	526 (26)		Pneumonia	652 (33)
Pneumonia	431 (21)		CVD	539 (28)
Aspiration pneumonia	267 (13)		Cancer	254 (13)
Frailty	233 (12)		Aspiration Pneumonia	125 (6)
Unspecified dementia	198 (10)		Sepsis	78 (4)

vi. Place of death

Disease mentioned on death certificate	Hospital	Care Home	Home	Hospice
PD [3990]	1704 (43)	1704 (43)	509 (13)	73 (2)
PSP [107]	36 (34)	41 (38)	25 (24)	5 (5)
MSA [63]	29 (46)	16 (25)	13 (21)	5 (8)

Underlying cause on death certificate	Hospital	Care Home	Home	Hospice
PD [2029]	687 (34)	1044 (52)	263 (13)	35 (2)
PSP [93]	26 (28)	38 (41)	24 (26)	5 (5)
MSA [51]	21 (41)	15 (29)	10 (20)	5 (10)

Contributory cause on death certificate	Hospital	Care Home	Home	Hospice
PD [1960]	1017 (52)	659 (34)	246 (13)	38 (2)
PSP [14]	10 (71)	3 (21)	1 (7)	0
MSA [12]	8 (67)	2 (17)	2 (17)	0

vii. Response rates

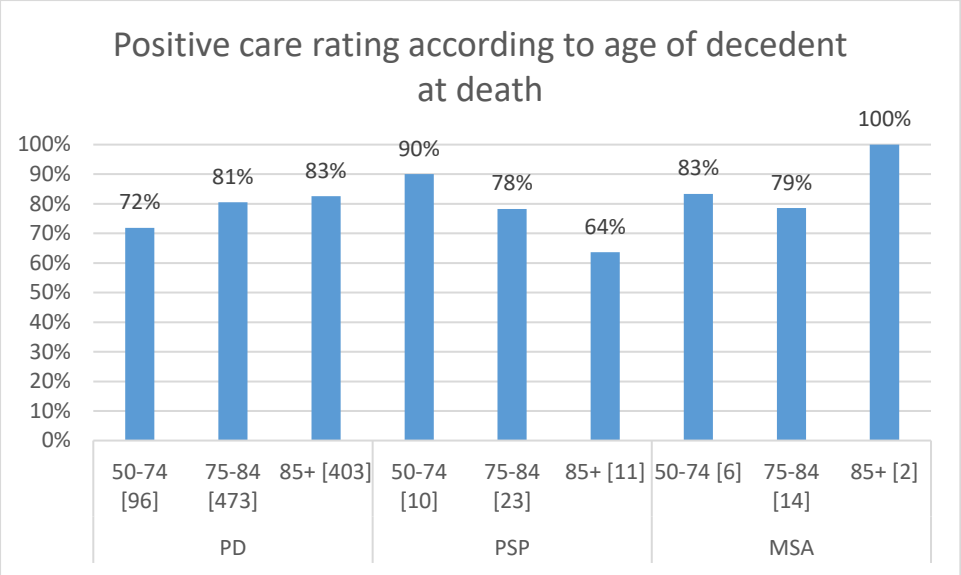
Disease mentioned on death certificate	Response	No response
PD [3990]	1933 (48)	2056 (52)
PSP [107]	49 (46)	58 (54)
MSA [63]	27 (43)	36 (57)

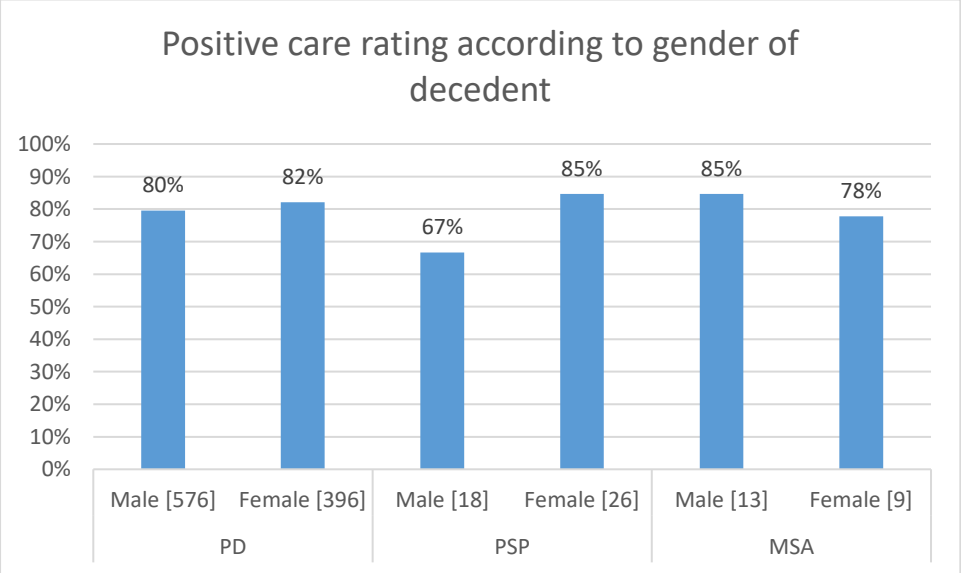
Underlying cause on death certificate	Response	No response
PD [2029]	1007 (50)	1022 (50)
PSP [93]	44 (47)	49 (53)
MSA [51]	23 (45)	28 (55)

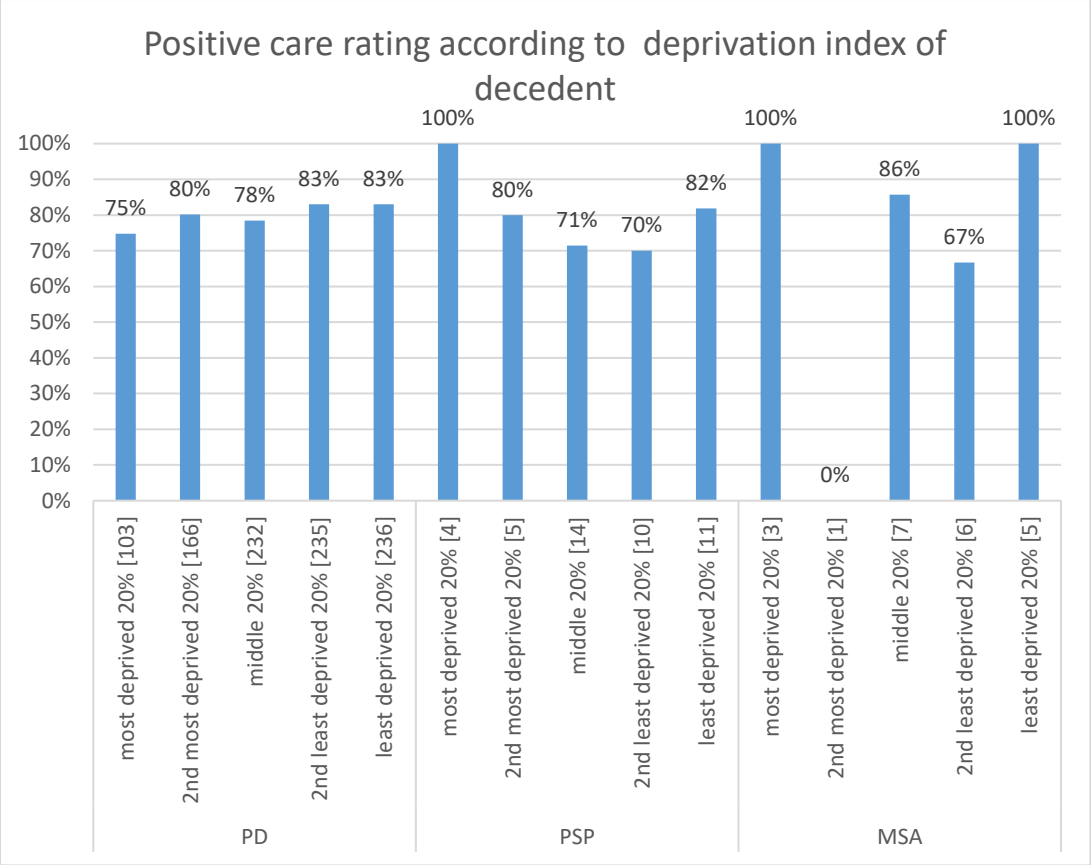
Contributory cause on death certificate	Response	No response
PD [1960]	926 (47)	1034 (53)
PSP [14]	5 (36)	9 (64)
MSA [12]	5 (42)	7 (58)

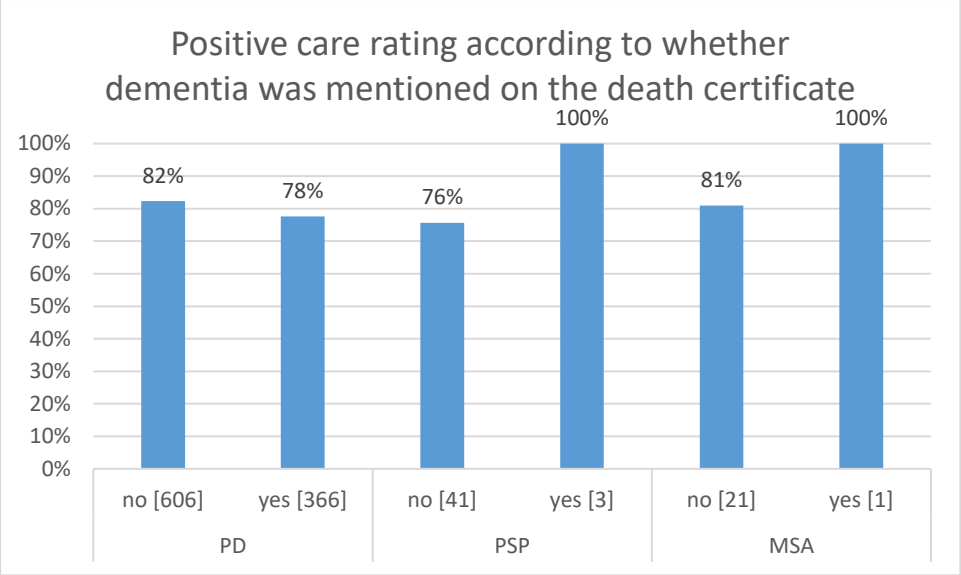
Appendix F: Differences in overall positive ratings between those with PD, PSP and MSA

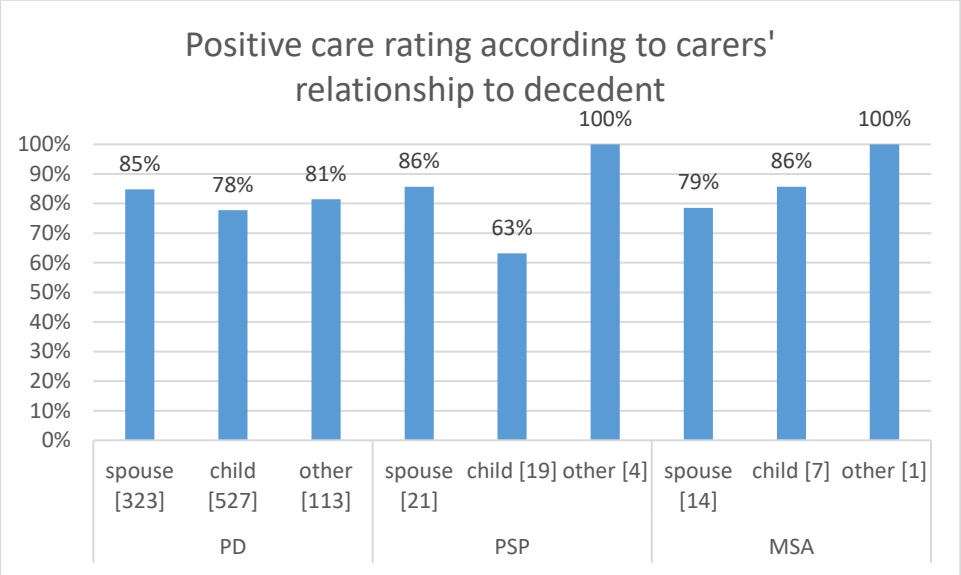
Percentage of carers for each underlying COD who rated the overall care given as outstanding, excellent or good according to…

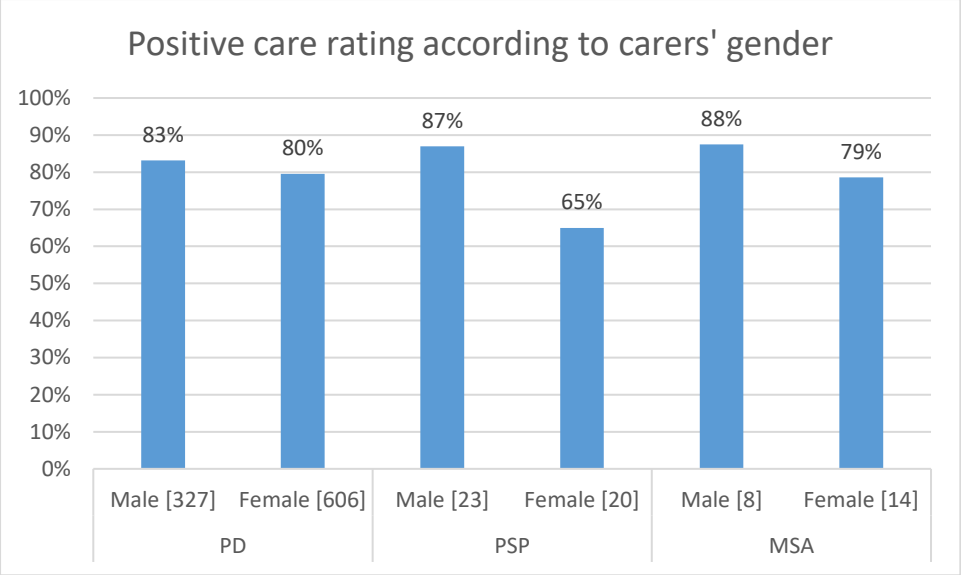


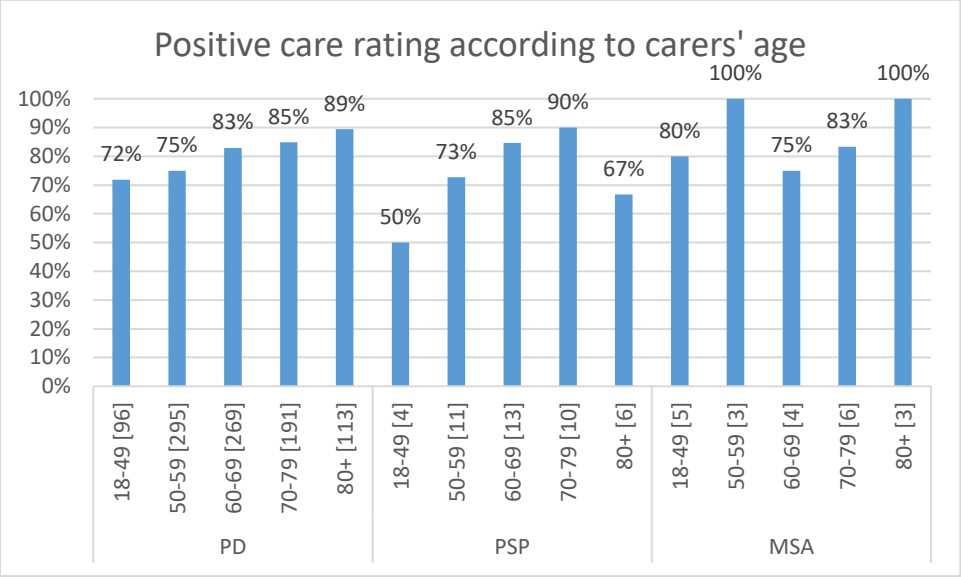


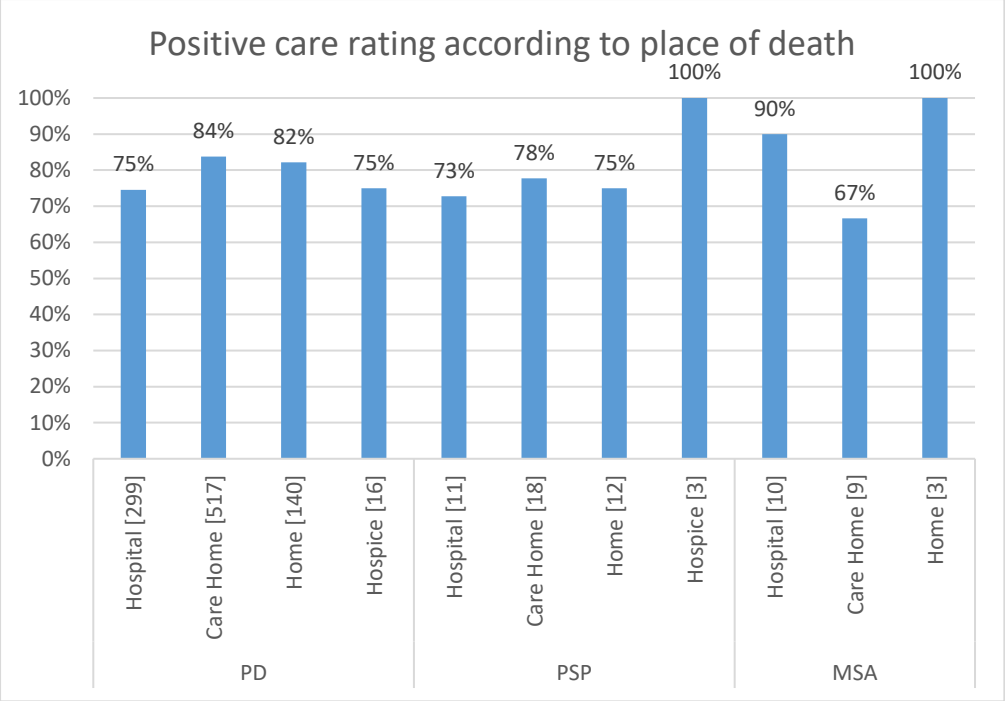

Positive care rating according to deprivation index of decedent
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
75%
80%
78%
83%
83%
100%
80%
71%
70%
82%
100%
0%
86%
67%
100%
most deprived 20% [103]
2nd most deprived 20% [166]
middle 20% [232]
2nd least deprived 20% [235]
least deprived 20% [236]
most deprived 20% [4]
2nd most deprived 20% [5]
middle 20% [14]
2nd least deprived 20% [10]
least deprived 20% [11]
most deprived 20% [3]
2nd most deprived 20% [1]
middle 20% [7]
2nd least deprived 20% [6]
least deprived 20% [5]
PD
PSP
MSA


Positive care rating according to whether dementia was mentioned on the death certificate
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
82%
78%
76%
100%
81%
100%
no [606]
yes [366]
no [41]
yes [3]
no [21]
yes [1]
PD
PSP
MSA


Positive care rating according to carers' relationship to decedent
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
85%
78%
81%
86%
63%
100%
79%
86%
100%
spouse [323]
child [527]
other [113]
spouse [21]
child [19]
other [4]
spouse [14]
child [7]
other [1]
PD
PSP
MSA


Positive care rating according to carers' gender
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
83%
80%
87%
65%
88%
79%
Male [327]
Female [606]
Male [23]
Female [20]
Male [8]
Female [14]
PD
PSP
MSA


Positive care rating according to carers' age
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
72%
75%
83%
85%
89%
50%
73%
85%
90%
67%
80%
100%
75%
83%
100%
18-49 [96]
50-59 [295]
60-69 [269]
70-79 [191]
80+ [113]
18-49 [4]
50-59 [11]
60-69 [13]
70-79 [10]
80+ [6]
18-49 [5]
50-59 [3]
60-69 [4]
70-79 [6]
80+ [3]
PD
PSP
MSA


Positive care rating according to place of death
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
75%
84%
82%
75%
73%
78%
75%
100%
90%
67%
100%
Hospital [299]
Care Home [517]
Home [140]
Hospice [16]
Hospital [11]
Care Home [18]
Home [12]
Hospice [3]
Hospital [10]
Care Home [9]
Home [3]
PD
PSP
MSA

Appendix G: Overall ratings: positive care vs negative care

i. COD

Underlying COD	Overall how would you rate the quality of care in the last three months?		
	Outstanding/Excellent/Good	Fair/Poor	Significance
PD [973]	870 (89)	103 (11)	1
PSP [44]	34 (77)	10 (23)	OR 0.40 (CI 0.19 to 0.84); p=0.015
MSA [22]	19 (86)	3 (14)	OR 0.75 (CI 0.22 to 2.58); p=0.65

ii. Age

Age of decedent	Overall how would you rate the quality of care in the last three months?		
	Outstanding/Excellent/Good	Fair/Poor	Significance
50-74 [112]	83 (74)	29 (26)	1
75-84 [510]	410 (80)	100 (20)	OR 1.43 (CI 0.89 to 2.31); p=0.14
85+ [416]	342 (82)	74 (18)	OR 1.62 (CI 0.99 to 2.64); p=0.056

iii. Gender

Gender of decedent	Overall how would you rate the quality of care in the last three months?		
	Outstanding/Excellent/Good	Fair/Poor	Significance
Male [607]	481 (79)	126 (21)	1
Female [431]	354 (82)	77 (18)	OR 1.20 (CI 0.88 to 1.65); p=0.25

iv. Dementia

Was dementia mentioned on the death certificate?	Overall how would you rate the quality of care in the last three months?		
	Outstanding/Excellent/Good	Fair/Poor	Significance
No [668]	547 (82)	121 (18)	1
Yes [370]	288 (78)	82 (22)	OR 0.78 (CI 0.57 to 1.06); p=0.12

v. Deprivation index

Deprivation index of decedent	Overall how would you rate the quality of care in the last three months?		
	Outstanding/Excellent/Good	Fair/Poor	Significance
Most deprived 20% [110]	84 (76)	26 (24)	1
2nd most deprived 20% [172]	137 (80)	35 (20)	OR 1.21 (CI 0.68 to 2.15); p0.51
Middle 20% [253]	198 (78)	55 (22)	OR 1.11 (0.66 to 1.90); p=0.69
2nd least deprived 20% [251]	206 (82)	45 (18)	OR 1.42 (CI 0.82 to 2.45); p=0.21
Least deprived 20% [252]	210 (83)	41 (17)	OR 1.59 (CI 0.91 to 2.76); p=0.10

vi. Religious belief

Religion of decedent	Overall how would you rate the quality of care in the last three months?		
	Outstanding/Excellent/Good	Fair/Poor	Significance
Christian [869]	704 (81)	165 (19)	1
None/other [153]	117 (76)	36 (24)	OR 0.76 (CI 0.51 to 1.15); p=0.19

vii. Carer decedent relationship

Carer's relationship to decedent	Overall how would you rate the quality of care in the last three months?		
	Outstanding/Excellent/Good	Fair/Poor	Significance
Spouse/partner [358]	303 (85)	55 (15)	1
Son/daughter [553]	428 (77)	125 (23)	OR 0.62 (CI 0.44 to 0.88); p=0.008
Other [118]	97 (82)	21 (18)	OR 0.84 (CI 0.48 to 1.4618); p=0.53

viii. Carer's Age

Carer's Age	Overall how would you rate the quality of care in the last three months?		
	Outstanding/Excellent/Good	Fair/Poor	Significance
18-49 [105]	75 (71)	30 (29)	1
50-59 [309]	232 (75)	77 (25)	OR 1.21 (CI 0.73 to 1.98) p=0.46
60-69 [286]	237 (83)	49 (17)	OR 1.94 (CI 1.15 to 3.27); p=0.013
70-79 [207]	176 (85)	31 (15)	OR 2.27 (CI 1.28 to 4.02); p0.005
80+ [122]	108 (89)	14 (11)	OR 3.09 (CI 1.53 to 6.21); p0.002

ix. Carer's Gender

Carer's Gender	Overall how would you rate the quality of care in the last three months?		
	Outstanding/Excellent/Good	Fair/Poor	Significance
Male [358]	299 (84)	59 (16)	1
Female [640]	506 (79)	134 (21)	OR 0.75 (CI 0.53 to 1.05); p=0.088

x. Time at home

Did he/she spend any time at home in the last 3 months	Overall how would you rate the quality of care in the last three months?		
	Outstanding/Excellent/Good	Fair/Poor	Significance
Yes [408]	321 (79)	87 (21)	1
No, Care Home whole time [513]	431 (84)	82 (16)	OR 1.43 (CI 1.02 to 1.99) p=0.038
No, Hospital whole time [62]	43 (69)	19 (31)	OR 0.61 (CI 0.34 to 1.11) p=0.10

xi. Place of Death

Place of death	Outstanding/excellent/good	Fair/poor	significance
Hospital [320]	240 (75)	80 (25)	1
Care Home [544]	453 (83)	91 (17)	OR 1.66 (CI 1.18 to 2.33) p=0.0030
Home [155]	127 (82)	28 (18)	OR 1.51 (CI 0.94 to 2.45) p=0.092
Hospice [19]	15 (79)	4 (21)	OR 1.25 (CI 0.40 to 3.88) p=0.70

Appendix H: Qualitative case summaries

i. Summaries of people who died from PD

Jennifer and Doris

Doris, died in a care home 2 years before her daughter Jennifer posted on the forum. Jennifer and her mum found having an advanced directive drawn up hugely helpful and she felt that their acceptance of the end of her mum's life may have helped. She also felt a lot of the important things for her mum were human touches, which had been included in her end of life care plan, which the care home had suggested she write. She felt that education of staff to make them more 'PD aware' would be helpful re: time needed for people with PD, medication etc.

Sandra and Edmond

Edmond died at home six and a half years before his wife Sandra posted on the forum. He had been declining in health with several infections; he then contracted pneumonia. Sandra had promised she would not make him go back into hospital (after a previously harrowing experience where they felt vulnerable). He therefore died at home. There was very little information imparted to the family. The community nurse told them to stop all of his fluid/food/medication, they were not involved in this decision. Sandra was uncertain about denying fluids at the time and now feels wracked with guilt she did not questions the decision, due to the more recent media coverage around the withdrawal of fluid at the end of life.

Moira and Samuel

Samuel, a gentleman in his 80s, died in hospital one month before his wife Moira posted. He had multiple comorbidities and deteriorated whilst an inpatient. Moira felt they had given up on him and she would have valued more support for herself throughout the last few days

as she had a lot of unanswered questions. She felt a debrief following the admission, even if PDNS or similar could visit at home, would have been beneficial.

Pippa and Cedric

Cedric died in hospital 15 months before his daughter Pippa posted. He'd had multiple admissions in the past where the family had been told he was dying and, on most, his medication had been stopped due to fears of aspiration. Pippa felt PD is a killer and we should be more open about the fact it can cause people to die. She also felt we should warn people about future symptoms such as hallucinations, which she and her mum found very difficult to manage. She felt that there is not enough support given to families when people are in the more complex stages of PD and suggested a co-ordinator of care would help.

Martha and Fred

Fred died at home 5 months before his wife Martha posted. He had been admitted to hospital with pneumonia and staff spoke to Martha and told her they thought he was dying. The couple had previously discussed the end of life and put POA in place and she was able to tell the staff that his wish was to die at home. The hospital facilitated a transfer back home and her GP then came and explained what the end might be like. She felt the staff she'd encountered were caring and communication was excellent throughout.

Brenda and Eddie

Eddie was diagnosed with Parkinson's at a fairly young age. Because there were no support services where he lived he was instrumental in setting up a support group. His wife, Brenda, helped develop the service as well and they successfully managed to get a post for a PD nurse, who improved local services dramatically. Eddie had complex PD but things had improved somewhat with a recent change to his treatment. He was admitted to hospital with what was thought to be a urine infection but he deteriorated quickly and was transferred to ICU. Unfortunately things did not improve and eventually he was diagnosed with an aggressive type of cancer and died shortly after. Aside from one individual

consultant, the staff on ICU looked after him well, communication was great and they listened to his wife Brenda when it came to aspects of his PD management, liaising with the PD nurse as well. Support around the time of his death was good and Brenda was going to return to the ICU for a follow up with the staff. Our interview took place three weeks after Eddie's death.

William and Pearl

Pearl was getting on ok with her Parkinson's though her mobility was affected quite badly. Her husband, William, was her main carer and had to help her with most things. Years before they had discussed resuscitation and put in place POAs. One day Pearl got up from the chair and fell causing herself significant chest trauma. She was admitted to hospital where she was treated; the staff were kind and caring but did not get the medication timings right. Sometimes the family felt they were not listened to and things happened without them being involved in the decisions, but William was fairly stoical about this.

Pearl seemed to be improving but then died suddenly and unexpectedly. William has had no formal bereavement support; he was fairly distressed during the interview but he doesn't feel bereavement support would help him a lot and he gets by with the support of his family.

Barbara and Derek

Derek had developed PD dementia and Barbara cared for him at home. This was becoming increasingly difficult and she was exhausted. He was admitted to hospital with an infection and was there for weeks, a planning meeting was held and the mutual decisions between staff and family was that Derek moved to a care home. He deteriorated there over the following weeks and was treated with antibiotics for a presumed chest infection. He did not improve and died in the care home. Barbara was glad he was able to have palliative care input in the care home, she had not wanted him to be transferred back to hospital and they chose the care home because it could deliver end of life care on site. She actually felt she had lost him long before he physically died due to the dementia.

Angela and Graham

Graham had symptoms of PD for several years before he was diagnosed, his PD then progressed rapidly. Because Graham and his wife Angela lived in a semi-rural location getting carers was difficult, so Angela was solely responsible for caring for Graham; night-time hallucinations and incontinence meant very little sleep. Graham had an acute episode of abdominal pain and was admitted to hospital, they couldn't find the cause but did diagnose him with pneumonia. He was in hospital for weeks and became much weaker, the staff suggested Graham needed nursing care and so he was discharged to a nursing home, where thankfully he knew the staff as he had gone once a week to the day centre. About two weeks after he moved there he vomited blood and the decision was made for him to stay in the home. There were semi-cryptic suggestions that he might be dying, but Angela was not told this was the case outright and so she felt she was somewhat unprepared for his death. She felt that bereavement support would have been useful as she was not formally offered any and some of the services, like cruse, were an hour's drive away.

Pam and Andrew

Andrew had been living with Parkinson's for more than 15 years and had reached the end stages of the disease. Pam, his wife, had tried to get continuing healthcare assistance to help her to provide care at home but had been unsuccessful, she felt this was due to her geographical location/her health board. Andrew had several hospitalisations with infections in the last year of life and was treated at home with multiple courses of antibiotics. When he failed to respond to one course his GP discussed hospital admission with him and he agreed. He deteriorated in the hospital and, because Pam had concerns about his care there, she was sure that was not where she wanted him to die. He had wanted to die at home but without additional care Pam knew she could not manage so, as Andrew had been attending the hospice, it was arranged that he go there for end of life care. His death was somewhat of a relief as Pam had found it very hard watching Andrew's deterioration and was exhausted through being a carer. She felt this exhaustion in some way prevented her grieving properly but she contacted cruse for bereavement support and attended a nun's bereavement retreat as well, both of which she found helped her a lot.

Susan and Paul

Paul had developed dementia a few years after being diagnosed with PD. His condition worsened fairly quickly and his wife Susan needed to help him with everything. Occasionally he was aggressive which was very unlike his previous personality. Susan found the PD team were very supportive but she felt she would really have benefitted from some additional help in the house, even for half an hour; Paul refused carers and nothing else was suggested. One day Paul had a fall and broke his arm. His mobility deteriorated hugely in hospital and the team there felt he needed a care home placement. Susan felt terrible about this and did not agree with the decision at the time as she had promised she would not let him go into a home. He died suddenly in hospital before his discharge. She felt this was the right thing for him and the end he would have wanted. She did not get any formal bereavement support but felt that her family were all she needed.

Simon and Gladys

Gladys had developed Parkinson's dementia about 7 years after diagnosis, her son Simon moved home to help care for her. She had a lot of problems with hallucinations but these improved when her medication was decreased. She became immobile, was unable to communicate verbally and had swallowing problems but Simon felt she was at peace and happy. Gladys had continuing healthcare and a great care package, although it had taken some fighting to get it. Gladys became unwell over a couple of days and was admitted to hospital; Simon was shocked to be told she had a severe pneumonia, as he had not spotted any signs. Although things initially seemed to improve, Gladys went downhill and Simon was informed she was likely to die. Simon felt the news of her pneumonia and the likely poor outcome were explained a little bluntly but the nursing staff were caring and he found the palliative care input on the ward supportive. They had discussed getting Gladys home to die, but this was not logistically possible. He has not had any formal bereavement support but he has information to contact people should he need it and feels this is helpful and all he needs for now.

Betty and Donald

Donald had quite a lot of medical problems and then developed PD. He steadily deteriorated and due to their remote location getting decent care provision was tricky. Luckily Betty knew of a local carer who they hired privately and she was a 'godsend'. Donald was admitted to hospital several times, though it was not clear what was wrong. Donald did not eat well and eventually Betty and the carer were unable to get him out of his chair at all and so he went into a care home. He collapsed when he moved there and they could not rouse him and so he was admitted to hospital. They felt he had seizures but Betty was never clear exactly what was going on as no-one really had time to explain. He got worse and she was told things were not going to improve and palliative care was suggested with a transfer back to the care home. He died before that happened. She was pleased about this as she felt moving Donald would have been too much. Betty had good friends and her daughter to support her after Donald died but she did not have any formal bereavement support and feels it may have been useful.

ii. Summaries of people who died from PSP

April and Janice

April and her mum Janice had discussed her Janice's wishes at an earlier stage but the end came quicker than expected. Janice contracted pneumonia and was admitted to hospital. She needed oxygen and morphine to help her symptoms and April felt, because her mum declined quickly, she could not have provided this at home. She felt her mum would have preferred to die elsewhere, as hospitals are busy and stressful, but she did not feel that communication or the kindness shown to her mum could have been better elsewhere. April's main concern in hospital was that she needed to 'nag' to ensure her mum had morphine in a timely fashion to help her pain, so she worried about others who did not have family members to act as advocates. She told her mum that the team were withdrawing care and chose not to alert the nurses when she felt her mum was imminently dying as she wanted them to be alone as they had wished. Fortuitously a doctor was present when she picked up the death certificate and that helped because she felt guilty she hadn't noticed symptoms of pneumonia but the doctor explained she felt that without PSP the pneumonia would not have ended her mum's life.

Samantha and Ronald

Samantha had experienced her mum dying from cancer not long before her dad died from PSP. She felt the support available for cancer, where people were 'crawling out of the woodwork' far outweighed that of PSP, principally because HCPs did not understand or know what PSP was. Her dad died in hospital and she felt she had to be there to be his advocate due to the staff's difficulty in communicating with him. She felt staff were mostly great but that a lack of knowledge affected their ability to make timely decisions about his care.

Peter and Yvonne

Yvonne was diagnosed with PSP in her 50s with double vision and mobility being her main troubles. She rapidly lost her mobility and became doubly incontinent, though her ability to

speak remained until the last few days. When at home her husband Peter felt he had to do a lot of organising and chasing to get her what she needed. He felt sometimes HCPs did not understand how Yvonne was limited by PSP and so labelled her as lazy and chastised her for not trying, whereas in reality she was unable to move. A GP dropped off some DNAR forms without any discussion and this upset Yvonne who hadn't wanted to discuss the future. After raising this with the GP surgery the couple were then referred to the hospice. There a nurse discussed the future over four sessions and this allowed Yvonne the time to think about what she wanted. The hospice offered Yvonne a day care place and was also able to get CHC funding and helped co-ordinate services. On her third neurology review the consultant told her she was advanced and she rapidly decline the following week refusing to eat or take her meds, the hospice brought her in for an emergency stay and she then went to a nursing home. They provided Yvonne with excellent care and she improved. She reached a family milestone and then died with her family present. Initially Peter felt guilty that she wasn't at home as she had wanted but others told him she was, because the care home had become her home and he agreed because they had essentially moved operations to be based there. He had bereavement support through the hospice and found it helpful. He does volunteer work for the hospice and the nursing homes now and that helps too. Overall the thing he felt made the most difference was people giving them time and getting to know them and treating them like friends, he wasn't overly enamoured with the medical professionals because they never had enough time

<u>Constance and Thomas</u>

Thomas started to notice he felt off balance and had trouble with double vision, after some difficulty with getting a diagnosis he was diagnosed with PSP. His wife Constance did a lot of research and contacted the PSP association and they went to local support groups. They found hydrotherapy session and the hospice day care to be very supportive and they also took part in research trials, which felt like a pleasant break from it all. Unfortunately, Thomas had a few falls and this seemed to increase his speed of decline and he was admitted to their local hospice. He was there for several months and eventually had a PEG fitted and stabilised and so left the hospice to go into a specialist neurological nursing home. Whereas the hospice had been adaptable and friendly, Constance found the care home to

be a little too regimented in its ways and the lack of flexibility and attention to health and safety sometimes meant Thomas was made to wait to go to the toilet as they wouldn't let her take him, which she felt was dehumanising. She noticed he was behaving strangely one day, as he sometimes did with a UTI and she told the care home staff. They called a doctor but there was some delay and he deteriorated a lot whilst waiting. The doctor and staff were sure he would improve with antibiotics but later that night he died. This was a shock to the care home, so much so Constance felt, that they started CPR on him, despite a DNAR order. He was a brain donor but this did not happen, as death certificates etc were not sorted in a timely manner. As it happened a post mortem was carried out and COD recorded as PSP and COPD. Constance has not had any offers of formal bereavement support and although she might have welcomed it she feels there is a large element of dust yourself off and get on.

Stephanie and Nigel

Nigel started to have falls, most of them backwards, and was quickly referred to a neurologist and diagnosed with PSP. Nigel's main problems were falls, impulsivity and visual sensitivity to light. Stephanie cared for him at home, he had several admissions to hospital due to falls and she found that these were helpful in providing future support for her at home as a review of their home circumstances was carried out. Nigel took part in a few pieces of research and this helped him feel 'useful'. They had to move house, due to Nigel's PSP and buy a new car, both things they lost money doing. Latterly Stephanie's sister pushed her towards asking for help from the hospice, something Stephanie had not thought would be available for people without cancer; she found the hospice day care was excellent. As they were getting a wet room fitted Nigel went into a care home for respite but he was admitted to hospital two days later with pneumonia. He initially improved with antibiotics and NG feeding but when he tried to eat again he got another pneumonia. He did not want PEG feeding and his chest was not improving with antibiotics and so in discussion with the hospital team they stopped treatment and withdrew food and fluids. He died a couple of days later with Stephanie and their son by his side. She initially felt some relief that her husband was free from the disease and that she could get back to herself again somewhat. She bereavement support two years later as her son moved away and this set off a

depression. Now she helps with a local PSPA support group, something that was absent in her area when Nigel was alive, and she finds this rewarding. She feels the profile of PSP should be raised as if more people knew about it, aside from the increased likelihood of a cure, there would be more empathy for those suffering with it and their carers.

Kate and Marion

Marion had a lot of falls and after a couple of years was eventually diagnosed with PSP by which time her eyes were badly affected. Her daughter, Kate, helped her father to care for Marion, who lost her ability to speak soon after diagnosis. Kate felt that a lot of the help they got had required them to fight, whereas when her dad was later diagnosed with cancer support flooded in. Her mother in law was also later diagnosed with PD and again there was a need to ask for help rather than the automatic response of support a cancer diagnosis had brought her father. After one hospital admission with pneumonia, where Marion had a PEG inserted against the wishes of her husband and daughter, they made the decision for her to live in a care home. Kate says part of the reason for this was that she wanted to be a daughter again rather than a carer. The care home staff were kind and also looked after her father, who stayed there all day and had his meals there. Marion went back into the hospital a few times when she was living in the home but was often discharged in less than 24 hours. After a few months of living in the care home she was admitted with another chest infection, which turned out to be more serious, and she died. Kate asked that the diagnosis of PSP would be put on the death certificate, she felt this was important because of the struggle her mum had had with the disease. During the time Kate looked after her mum she had found information from the PSP association helpful, especially their care advisors, and because there were no support groups in the area when her mum had PSP she has since set one up so that others do not feel the isolation her family did.

Margaret and Chris

Chris initially started having trouble with slurred speech but was reluctant to see anyone about it, when he did the pathway to diagnosis took 3.5 years. After diagnosis his wife, Margaret, contacted the PSPA and got a care pathway suggesting all of the help they would

need. Unfortunately it was a struggle to get the integration of services to provide the level of help they needed and when people did come they didn't know much about PSP so they didn't always get the right equipment at the right time. A lot of things came through chance mentions with Margaret chasing them up, and she felt people were asking her what was needed but she didn't know; she felt it was like being in a maze with a blindfold on and that everything came too late. Due to a meeting with another carer she found out about hospice and contacted them and they accepted Chris for respite, he had three stays in total. He had already completed an ADRT, the hospice consultant counselled against it saying things like pneumonia could be easily treated, but Chris felt there was no point as his existence wasn't living. One of Chris' main problems was thick saliva and they had hoped he would get Botox to help, however after waiting and hoping for months when he got his appointment they told him he was not eligible because his swallow was not safe. Margaret felt this disappointment combined with another episode of 'bungled' care after a fall led him to somewhat give up and he rapidly deteriorated over a 10 day period. Initially, because Chris had deteriorated in steps, Margaret felt it was just another step down which would plateaux and none of the visiting HCPs alerted her otherwise. After about a week she told them she thought he was dying, even though deep down she still wasn't prepared for it; he struggled and was present till the end and she found this very hard. After he died she wanted to end things but is gradually trying to get back to some of the things she enjoyed before Chris got ill. She would like to start a support group or volunteer in the hospice but they have advised her to wait a while; she has not had formal bereavement support and is unsure whether it would help her as she finds reliving the experience difficult.

<u>Hope and Dennis</u>

Dennis was diagnosed at a late stage of PSP. His mobility and speech had decreased but he had put it down to ageing. When he sought an opinion and saw a neurologist privately the diagnosis came quickly. He was relieved he did not have PD and didn't want to know too much about the new diagnosis. His wife, Hope, who had been caring for him sought out information and was appalled at what she found. Eventually, Hope became exhausted and when A GP was called to review Dennis's cough he admitted him to a community hospital in part to give Hope a break. Unfortunately something happened, Hope felt it was a stroke,

and Dennis declined. They felt he could not return home and so a CHC application was completed and a care home place found. Whilst in hospital Hope felt Dennis gave up and at one point he asked the nurses to give him something to end his life. He deteriorated further and she was called in to see him, he was unconscious. She sat with him and was trying to decide whether to stay or go home, the nurses said they would make a bed up for her and she felt Dennis had heard the exchange because he died minutes later. She was very glad she had stayed and was with him. He was due to start attending the day unit of a local hospice, but was admitted before this occurred, the hospice did offer Hope bereavement counselling however which she complete. She felt that actually she would have been better to wait a little longer, as it was later that year she found she really needed help, after all the sorting and probate etc was done. She is now a co-ordinator for a local PSPA group and this has given her a new sense of purpose and she finds supporting other carers and people with PSP very rewarding.

Colin and Grace

Grace had noticed she had problems lifting her feet when walking, she saw a neurologist and they diagnosed her. Over the years her swallow worsened but she refused to have a PEG. Colin found he had to organise everything; although he felt NHS individuals were very good the system itself was slow and unresponsive and not well co-ordinated. After a while Grace decided she would move into a care home as she was concerned about how exhausted Colin was getting. Most people suggested she try the neurological care home but she had found it a bit clinical environment wise and preferred to go to a local care home which was more homely and where staff had a more personal touch. She had previously discussed that she did not want to be treated if she acutely worsened and had recorded a DNAR with her GP. One day staff noticed she was worse and called a GP but no-on really communicated to Colin what they had noticed. As Grace did not seem that altered to Colin it was a great surprise to him when he was called at 5am the next day and told to hurry in as she was dying. She died before he got there and although he finds this sad for himself as he would have like to be with her, he felt it would have been a relief to Grace who had long since had enough. He got a lot of support from his family and does not feel talking to a bereavement counsellor would have helped him at all. He feels an increased awareness of

PSP/CBD is important so that people are diagnosed earlier and can get co-ordinated care at an earlier stage when it may be more beneficial.

iii. Summaries of people who died from MSA

Charlene and Evelyn

Evelyn remained independent even with the need for four times a day care. Her family had promised her she could stay at home, whatever happened, but she was rushed into hospital with pneumonia and told she was imminently likely to die. Charlene, her daughter, managed to get the family to her side and they were present when she died. She felt that her mum would have been in distress and pain if she had not been in hospital and praised the empathy shown by hospital staff. Evelyn died less than a month before Charlene posted.

James and Rachel

Rachel maintained a sense of macabre humour throughout her journey with MSA, she wanted to plan for the future, and did, without knowing exactly what the disease would bring. The biggest problems James and Rachel encountered was a lack of knowledge of MSA, meaning the system did not cater for her needs. The thing that hurt Rachel most was that some of her friends and family disappeared as her condition worsened. To counter the hopelessness she felt she had decided to donate her brain to research. Rachel had discussed euthanasia several times and asked James to help her at the end, this affected decisions in regard to further antibiotics for future infections. In the last month Rachel deteriorated and said she was ready to die, palliative care helped support her, and her family, at home. She died 3 years before James posted.

Nicole and Jake

Nicole cared for Jake single-handedly for years, leaving her with physical disabilities. Jake had made it clear for about six months that he wanted to die. He was given antibiotics for a chest infection one day and the next morning Nicole found that he had died suddenly overnight. He was a spinal cord donor and the post mortem report mentioned infection around removed toenails, as Nicole had signed the consent for the procedure she was left feeling guilty for this and because she didn't call an ambulance for his chest. He had wanted

to die at home however and that fact that he did gave her comfort; she felt he would not have forgiven her if she had transferred him to hospital. Though her family think she has come to terms with his death, Nicole does not think any amount of counselling will help and she still suffers with flashbacks of finding him dead and worries if other people stay in his room that they won't wake up. Jake died 9 years before Nicole posted.

Abigail and Stella

A year before Stella died she had a fall and moved into a care home. Staff were great but not always aware of Stella's needs due to the rarity of MSA; luckily the specialist team visited the care home and gave information sessions to staff on several occasions. Stella was clear about her wishes and her daughter helped her to document them, in collaboration with the community palliative care team. Being a brain donor was very important to her. At the end of Stella's life Abigail was able to stay with her in her room, the palliative care team helped with pain relief and Stella died peacefully with her family present. Abigail felt that although discussing the future could be challenging it was hugely important to understand what was best for her mum. Being open also meant her mum told her she was ready to die and she felt that was important for both of them. The fact that the family did so much to honour Stella's wishes, with the care home and church doing the same, gives Abigail some peace in her bereavement. Stella died 5 months before Abigail posted.

Julie and David

David and his wife worked fulltime to pay off the mortgage and had two children, a son Mark and a daughter Julie. David was diagnosed with MSA aged 47, he felt as though he was drunk when he walked; they were not told that the condition was palliative. He maintained his sense of humour whilst he lost his mobility and his speech, and maintained his cognitive function throughout. He brought up the subject of euthanasia once or twice but had not written down any concrete plans. The family were preparing to get a DNAR order sorted when he became suddenly unwell and suffered a cardiac arrest. He was admitted to ICU. There were conflicting feelings between son and daughter about how aggressive to be with his care and at the point a tracheostomy was mentioned Julie went to find his neurologist

who came to the ICU and suggested end of life care would be more appropriate, given David's disease and prior wishes. He died on ICU aged 53 and his daughter feels this gave them a chance to be with him and say goodbye. She felt the staff on the ICU were caring and supportive. He had a huge funeral, as he was a popular guy, and they raised a lot of money for the MSA trust. He died in 2007, eight years before this interview took place. Caring for her father left Julie with a lot of financial problems. His death resulted in a depression and she even attempted suicide; this was a couple of years after he died and she received counselling at that point. She now lives life with a positive outlook but maintains that she strongly believes in the right to die. She is a member of 'Dignitas' and if she were diagnosed with MSA she would want an assisted death.

Helen and Tony

Tony worked in farming and loved being outdoors; Helen worked full time as well. Tony started to notice he was unsteady at work and after several medical reviews he was diagnosed with MSA. They were told he'd be in a wheelchair in 5-10 years and were both devastated by the news. Tony did not want to know about what the future held and so they did not discuss future plans. As Tony deteriorated Helen gave up work to care for him full time, they both wanted him to stay at home and she thought he was worth more than the amount of care social services could provide. Overtime they used a lot of equipment and inventive ways to enable Tony to live life as much as possible. Helen found it frustrating that people did not try to communicate with Tony once his speech went as his mind was still there and he was still the same person. People who recognised this and did communicate with him were held in high esteem. He was undergoing treatment for a chest infection when he suddenly stopped breathing one night, she started CPR and he was transferred to the hospital. Once there the decision was made to withdraw medical treatment and he died, though Helen feels really he had died at home. He died in 2008 seven years before this interview took place. Helen found his death incredibly hard to deal with as he had been her world and reason for living, she became depressed and found the healthcare services to be of little useful support, but she got though it with the support of her sister.

Vincent and Beatrice

Beatrice was a highly intelligent businesswoman who delivered training all over the world. When she started having mobility problems she began researching potential diagnoses on the internet and felt that MSA was the most likely diagnosis. She had difficulty in persuading local services that this was the case and it was by chance, when abroad at their holiday home she spoke with someone who saw a neurologist for PD. They got in touch with this neurologist who confirmed MSA was likely and recommended a neurologist in the UK. The UK neurologist was based at a research hub and Vincent felt that going there and seeing that neurologist helped Beatrice, as being involved with research gave her purpose. He felt all staff at the research hospital cared about an individual as a person and built confidence, which was a complete contrast to the local district hospital where he felt a lot of staff treated patients as bed numbers and had a poor vocational work ethic. Over the years Beatrice and Vincent discussed death and dying but had not made any concrete plans because they were managing well. One day Beatrice became unwell and collapsed, requiring CPR, she was admitted to hospital and diagnosed with pneumonia. Vincent felt the way that DNAR was discussed with him on admission was presumptive and uncaring. Beatrice improved and was due to go home but then one night she suddenly died. He was most upset that the doctor who was completing the death certificate was not going to record MSA as COD because he felt saying she had died of pneumonia was incorrect. He did not get bereavement support so although he felt it might have helped he can't be sure.

Paul and Emmy

Emmy was a healthcare professional and was close to retirement, she started having difficulty with her bladder and mobility. When she was diagnosed Paul asked the MSA nurse to inform him of the prognosis, she told him and said most people steadily decline and die peacefully. He felt he watched his wife deteriorate every day and he could see through her deterioration that she was dying. Although Emmy did make plans she preferred to discuss them with her pastor and friends, rather than with Paul; he felt she was in some way trying to protect him. Towards the latter stage of the illness she had told friends she was waiting to die. She was admitted to hospital with a suspected urine infection but the medical team could not find anything wrong; Paul knew that meant they had reached the end. The ward

sister suggested the hospice might be appropriate and Paul and the sister asked Emmy if she would want that and she agreed. She was in the hospice for three weeks and then died. Paul continued to go to support groups after she died but now feels he has to move on. He would have liked more information about what the end of life in MSA could look like.

Elaine and Stephen

Elaine and Stephen had always been open about discussing death, for a long time before Stephen was diagnosed with MSA. He was eventually diagnosed due to increasing problems with mobility, but years after he had a long term catheter placed for continence issues. He had recurrent urine infections and was admitted to hospital when the latest course of oral antibiotics failed to help his confusion. Once in hospital he was boarded to an orthopaedic ward and despite Elaine's concerns his antibiotics were kept the same as at home and no-one seemed to understand he was not getting better. Elaine found it very frustrating that no-one understood what MSA was and despite her suggestion that they contacted Stephen's consultant no-one seemed to care about the fact he had MSA. Because Stephen had attended the local hospice as a day patient for some time Elaine, in her despair, contacted the consultant there and after a couple of days he was transferred. The improvement in communication, care and environment was huge but unfortunately Stephen was diagnosed with pneumonia. The consultant explained he was likely to die and his family were all with him when he died the next day. Whilst at the hospice Elaine had pre-bereavement counselling and she continued to see the counsellor for a year after Stephen's death, she feel this helped her immeasurably. Throughout Stephen's illness Elaine had gained a huge amount for MSA support groups and she continues to interact with online support groups, including an MSA widow's site.

Aileen and John

When John was diagnosed with MSA he and Aileen made the decision to move across the UK to be closer to family. This meant leaving a lot of their support network behind and their jobs. Benefit agencies with little knowledge of MSA made matters worse. John was clear from the start that he never wanted a PEG tube and that he planned to kill himself before

the MSA took over. One day he fell down the stairs, sustaining a head injury that took him into hospital. He was in hospital for months and kept deteriorating. He already had a lot of communication difficulties and Aileen did not feel able to leave him because no-one understood what he needed and he also suffered with intractable pain. Eventually the palliative care team got involved and pain relief provided a little help, but never completely alleviated his pain. He was transferred to a community hospital and although staff did not know about MSA they were willing to learn more and because he was there for months Aileen and the staff built up an understanding and respect, even if they did not always agree. Eventually it was clear John was not going to get better and Aileen bluntly raised this in a best interest meeting; she refused to have him transferred to a care home as even in hospital his pain was not controlled. After he died she did not want bereavement support as she feel able to manage on her own, however, she feels it might be beneficial for her daughter who still struggles with the memories of her dad's last weeks. She now runs a support group and is gratified that more have started, as she would have gained a lot if one had been available when they first moved.

Charles and Anna

Anna had never wanted to think about or discuss what the future might bring and so never discussed the future with Charles. She was devoted to her grandchildren and loved to spend time with them. They remained determined to live life to the full and continued to travel and go out to restaurants, with help from carers. One of the most difficult things was that she lost the strength in her voice and yet was unable to manage communication devices due to her co-ordination. Charles found that there was a lack of co-ordination within the health and social care service that he found disconcerting, he also found it contrasted with his experience of the travel industry. Anna had considered the possibility of a care home if she deteriorated and she tried one out but it was not a success and neither was a respite stay in the hospice, home was best for her. They managed to keep her at home through continuing healthcare funding (which it was a challenge to get) and had a series of live in carers who looked after her well. At the end Anna developed pneumonia, the doctor reviewed her at home and admitted her to hospital. The family were told she was dying and were able to be with her; Charles feels Anna must have known but preferred to use denial to cope. She was

a brain donor but because of the sudden nature of her deterioration with pneumonia, Charles forgot to mention this on admission. He feel staff should actively seek this information out. He was not offered bereavement support but would have refused it anyway as he managed with his family and accepting external help was not in his character.

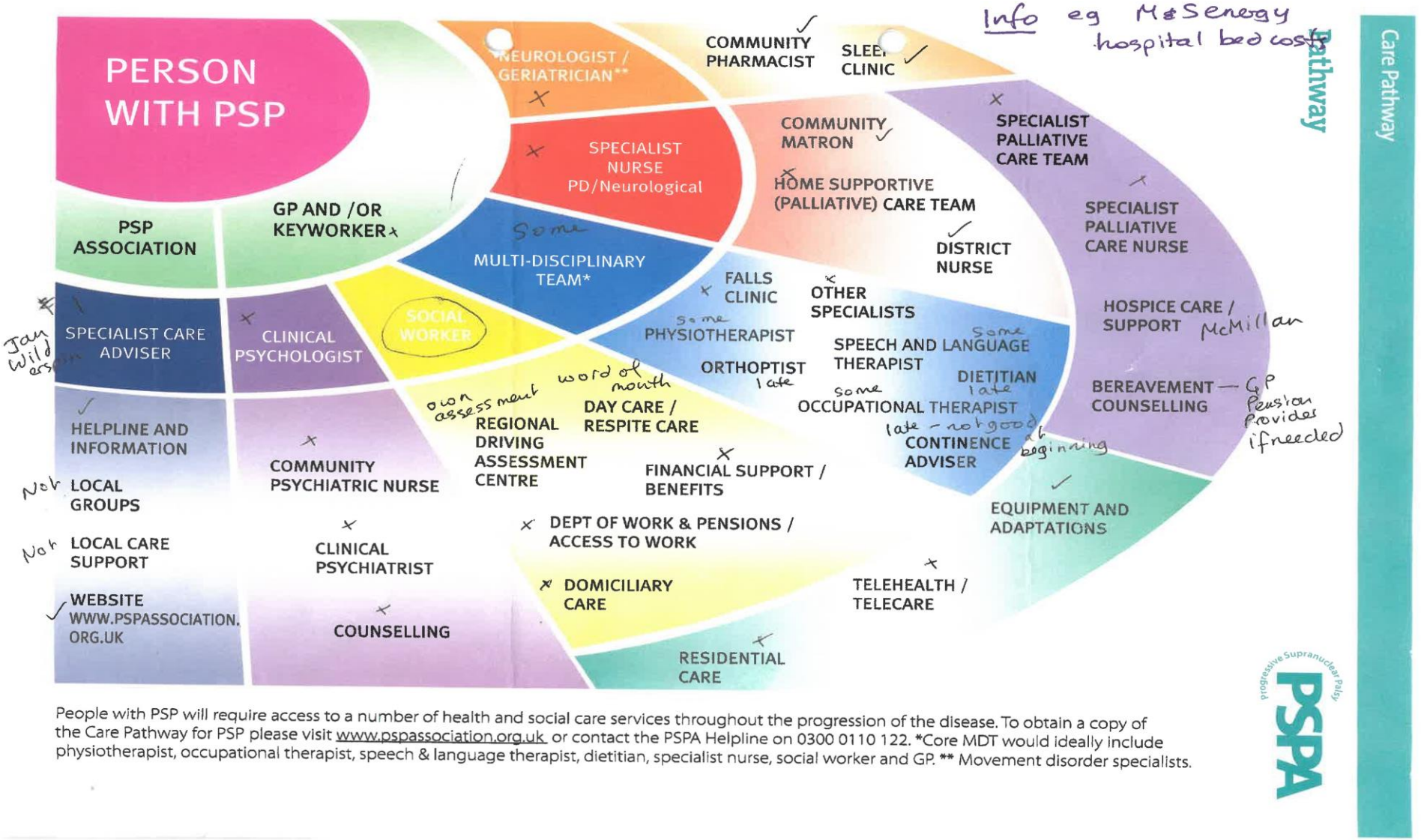
Philip and Thelma

Thelma started having trouble with her legs and after a while she saw a private neurologist who diagnosed her with PD. As the medication he prescribed did not help she was referred on and the MSA diagnosis was made. The neurologist made it clear she was never to stop her tablets and her condition could worsen a great deal, and this information stuck with Philip. As the MSA progressed many different health and social care workers were encountered and Philip labelled them the goodies and the baddies. The district nurses were helpful and taught his a lot and the hospice day care were always amazing. The social care assessors were less well received. Thelma loved her GP who offered excellent continuity of care and always tried to keep her at home as much as possible, but he then retired. Wen Thelma became unwell one day the new GP refused to visit and she was admitted into the hospital. Because she was unwell she was made nil by mouth and this led Philip to panic because she was not getting her medication. Communication was not good. He felt the hospital never understood how important she was as a person, whereas the hospice did. She was diagnosed with pancreatitis and her MSA was overlooked, no-one seemed to understand why Philip felt it was important. Philip was told Thelma was likely to die and he asked that she be transferred to the hospice, as they had previously agreed that Thelma would want to die in the hospice, or at home if the hospice were unavailable. However, the transfer did not happen because a different doctor told him Thelma had improved. When it became clear she hadn't and the palliative care team in the hospital reviewed her it was too late to transfer her. They gave her increasing pain relief and Philip feels this killed her. He still regrets she died in the hospital. He now volunteers in the hospice to help other carers.

Sebastian and Jade

Jade had symptoms for six years before she was diagnosed with MSA. They ended up with live in carers, who were variable and the co-ordination between different care agencies and the district nurses left a lot to be desired. Due to a lack of knowledge about MSA Sebastian carried information with him to give to anyone new involved in Jade's care. He also found that a lack of knowledge in the hospice and concern for health and safety meant Jade lost her mobility on a respite stay. They had discussed PPOD and Jade wanted to be at home, so when she developed a chest infection the GP gave her antibiotics and discussed equipment that could be brought in if needed. Their GP was good, was honest about her lack of knowledge regarding MSA but keen to look it up, something Sebastian appreciated. Jade was a Christian and had never had any trouble discussing the future. She had asked their pastor if it was alright to ask God to take her for a few months before she died. Sebastian had a leaflet about bereavement support from the hospice but felt adequately supported by his local pastor who was terrific.

Appendix I: **A care pathway for PSP**



People with PSP will require access to a number of health and social care services throughout the progression of the disease. To obtain a copy of the Care Pathway for PSP please visit www.pspassociation.org.uk or contact the PSPA Helpline on 0300 0110 122. *Core MDT would ideally include physiotherapist, occupational therapist, speech & language therapist, dietitian, specialist nurse, social worker and GP. ** Movement disorder specialists.

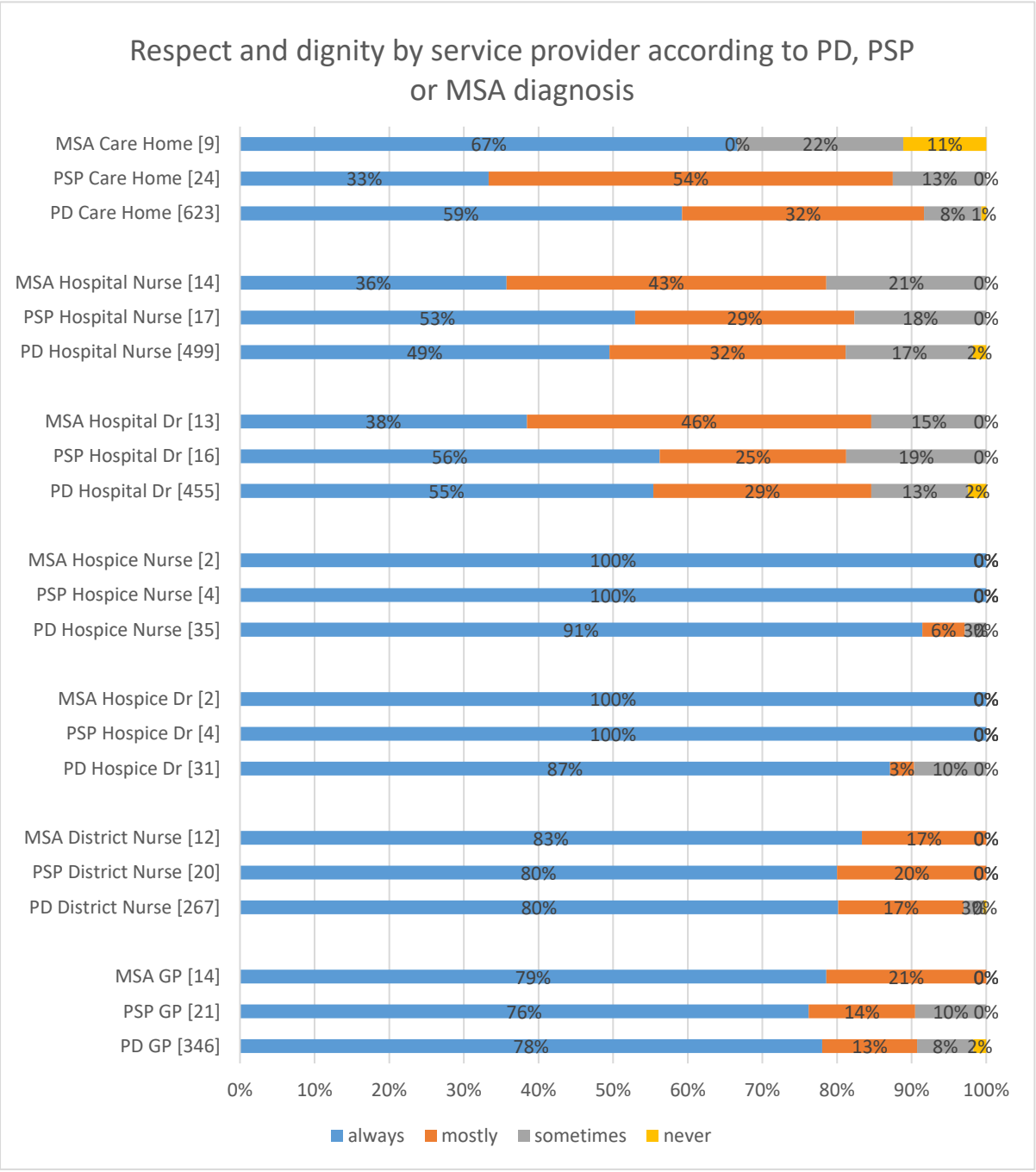
Appendix J: VOICES graphs and stats

i. Respect and Dignity by service provider for those with PD,PSP,MSA, England 2012-15

Likelihood of always being treated with respect and dignity by hospital nurses in the last 3months of life compared to other service providers

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Hospital Nurses			148.328	6	0.000			
Hospital Doctor	-0.229	0.126	3.305	1	0.069	0.795	0.621	1.018
Care Home	-0.369	0.118	9.837	1	0.002	0.692	0.549	0.871
GP	-1.293	0.151	73.272	1	0.000	0.274	0.204	0.369
District Nurse	-1.433	0.169	71.667	1	0.000	0.239	0.171	0.332
Hospice Doctor	-2.140	0.537	15.916	1	0.000	0.118	0.041	0.337
Hospice Nurse	-2.569	0.606	17.976	1	0.000	0.077	0.023	0.251
Constant	0.030	0.087	0.121	1	0.728	1.031		

ii. Respect and Dignity by service provider according to PD, PSP or MSA diagnosis



Likelihood of Always being shown Respect and Dignity by Care Home

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Step 1[a]	PD			6.110	2	0.047			
	PSP	1.067	0.441	5.860	1	0.015	2.906	1.225	6.891
	MSA	-0.320	0.712	0.202	1	0.653	0.726	0.180	2.931
	Constant	-0.373	0.082	20.983	1	0.000	0.688		

Likelihood of Always being shown Respect and Dignity by Hospital Nurse

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Step 1[a]	PD			1.105	2	0.576			
	PSP	-0.138	0.494	0.078	1	0.780	0.871	0.331	2.295
	MSA	0.568	0.565	1.010	1	0.315	1.764	0.583	5.339
	Constant	0.020	0.090	0.050	1	0.823	1.020		

Likelihood of Always being shown Respect and Dignity by Hospital Doctor

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Step 1[a]	PD			1.421	2	0.491			
	PSP	-0.035	0.513	0.005	1	0.945	0.966	0.353	2.637
	MSA	0.686	0.578	1.410	1	0.235	1.986	0.640	6.164
	Constant	-0.216	0.094	5.256	1	0.022	0.806		

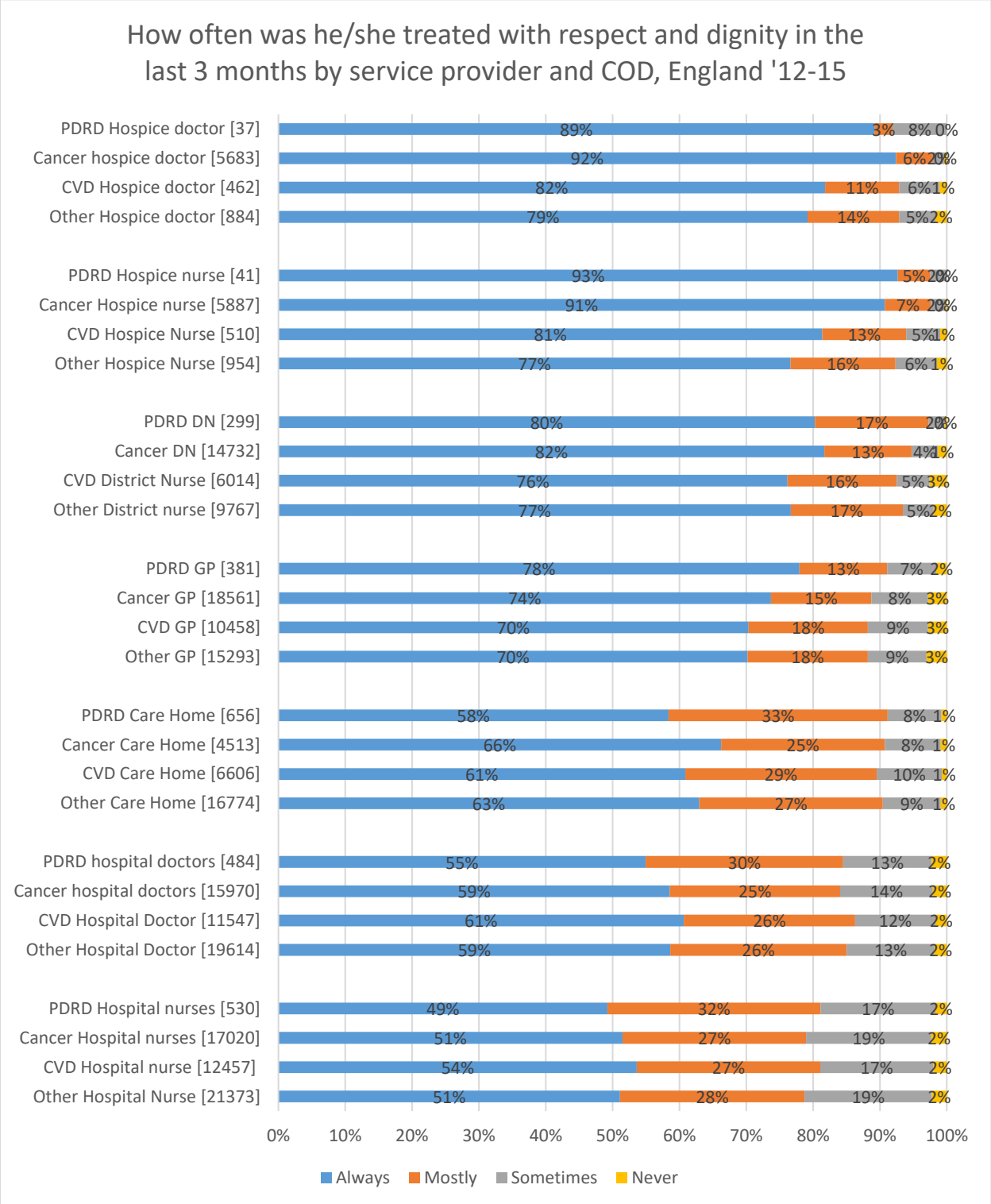
Likelihood of Always being shown Respect and Dignity by District Nurse

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Step 1[a]	PD			0.074	2	0.964			
	PSP	0.009	0.580	0.000	1	0.987	1.009	0.324	3.144
	MSA	-0.214	0.790	0.073	1	0.787	0.808	0.172	3.796
	Constant	-1.396	0.153	82.747	1	0.000	0.248		

Likelihood of Always being shown Respect and Dignity by GP

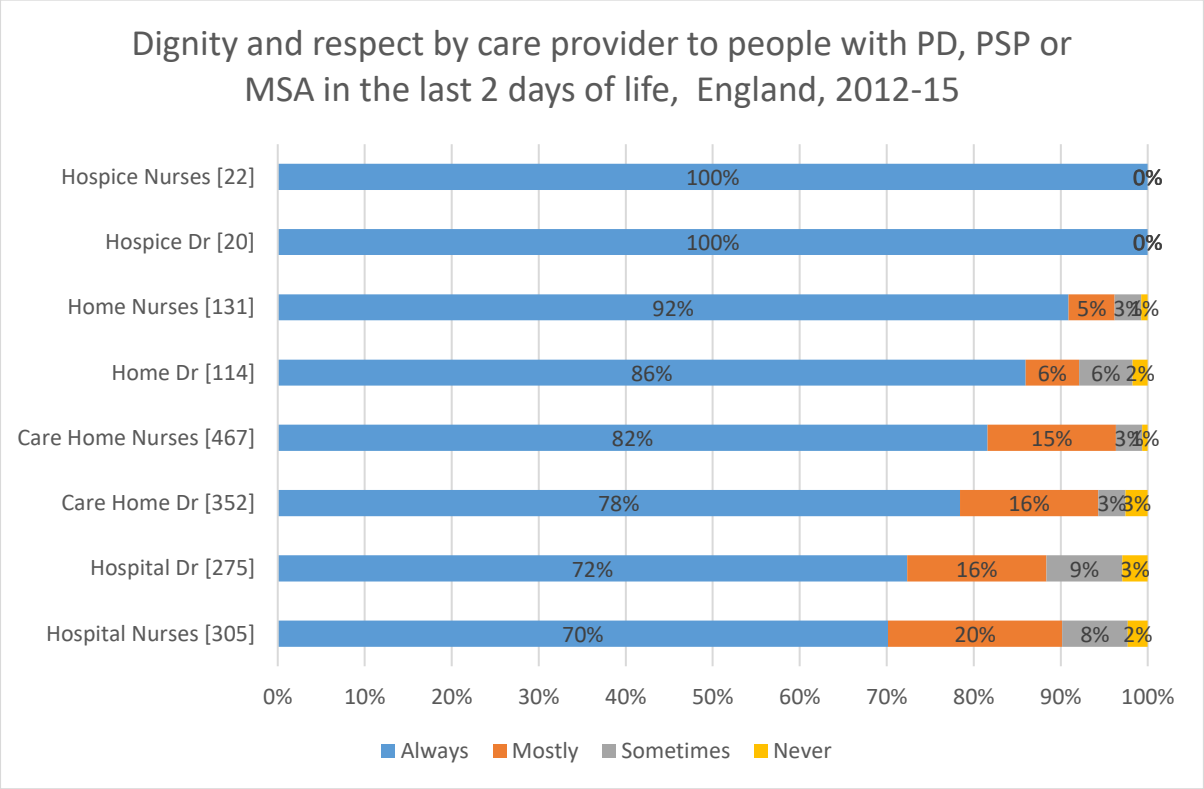
								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Step 1[a]	PD			0.042	2	0.979			
	PSP	0.105	0.529	0.039	1	0.843	1.110	0.394	3.128
	MSA	-0.032	0.664	0.002	1	0.962	0.969	0.264	3.561
	Constant	-1.268	0.130	95.307	1	0.000	0.281		

iii. Respect and Dignity by service provider in the last 3 months, according to COD

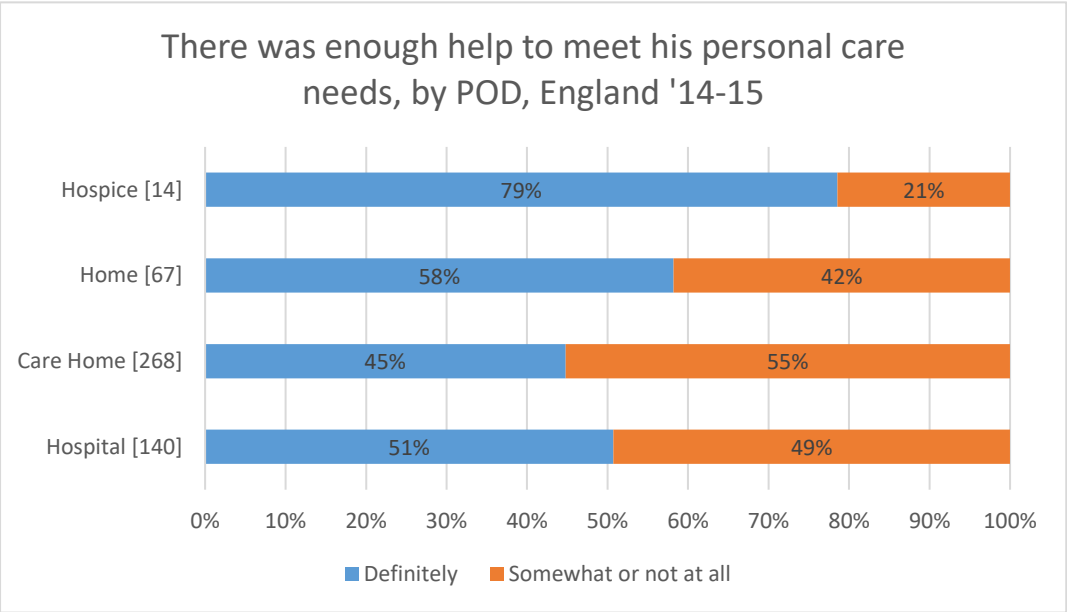


Likelihood of always being treated with respect and dignity according to service provider and COD			
PD/PSP/MSA	Vs Cancer	Vs CVD	Vs Other
Care Home	**OR 0.715 (0.61 to 0.85) p<0.001**	OR 0.90 (0.77 to 1.06) p=0.21	**OR 0.83 (0.70 to 0.97) p=0.02**
Hospital Dr	OR 0.86 (0.72 to 1.04) p=0.114	**OR 0.79 (0.66 to 0.95) p=0.012**	OR 0.86 (0.72 to 1.03) p=0.106
Hospital Nurse	OR 0.91 (0.77 to 1.09) p=0.307	**OR 0.84 (0.71 to 0.99) p=0.048**	OR 0.88 (0.74 to 1.05) p=0.151
Hospice Dr	OR 0.68 (0.24 to 1.92) p=0.463	OR 1.83 (0.63 to 5.31) p=0.264	OR 2.17 (0.76 to 6.20) p=0.149
Hospice nurse	OR 1.30 (0.40 to 4.20) p=0.667	OR 2.9 (0.88 to 9.59) p= 0.081	**OR 3.86 (1.18 to 12.64) p=0.025**
District Nurse	OR 0.91 (0.68 to 1.21) p=0.528	OR 1.27 (0.95 to 1.70) p=0.105	OR 1.24 (0.93 to 1.65) p= 0.146
GP	OR 1.26 (0.99 to 1.61) p=0.062	**OR 1.49 (1.17 to 1.91) p=0.001**	**OR 1.50 (1.18 to 1.92) p=0.001**

iv. Respect and Dignity by service provider in the last 2 days



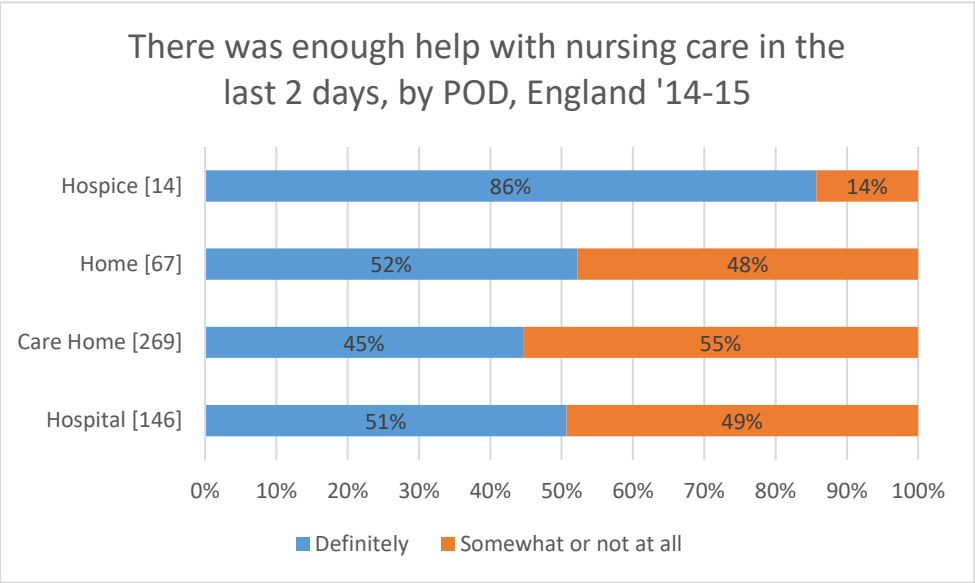
v. Personal Care Needs, such as toileting, in the last 2 days



Likelihood of personal care needs definitely being met in the last 2 days, by POD, England '14-15

POD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Hospice			8.548	3	0.036			
Hospital	1.271	0.673	3.566	1	0.059	3.563	0.953	13.325
Care Home	1.509	0.663	5.183	1	0.023	4.522	1.234	16.579
Home	0.968	0.697	1.929	1	0.165	2.632	0.672	10.316

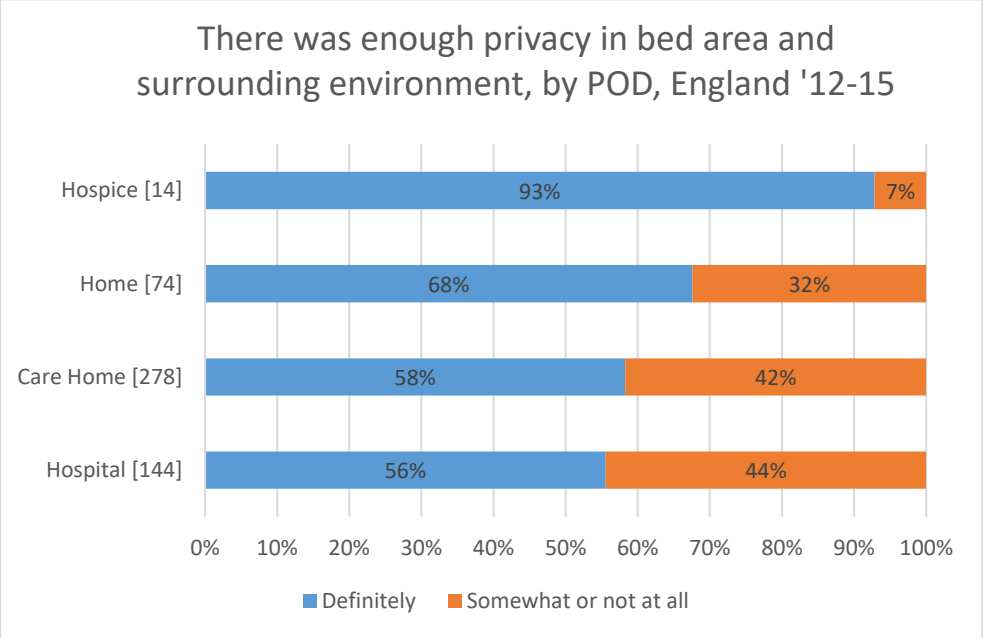
vi. Nursing needs, such as medication, in the last 2 days



Likelihood of there definitely being enough help for nursing needs, by POD, England

POD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Hospice			8.139	3	0.043			
Hospital	1.764	0.781	5.097	1	0.024	5.838	1.262	27.006
Care Home	2.008	0.774	6.740	1	0.009	7.450	1.636	33.931
Home	1.702	0.802	4.505	1	0.034	5.486	1.139	26.416

vii. Privacy of bed area and surrounding environment in the last 2 days



Likelihood of there being enough privacy in the bed area, by POD, England '12-15

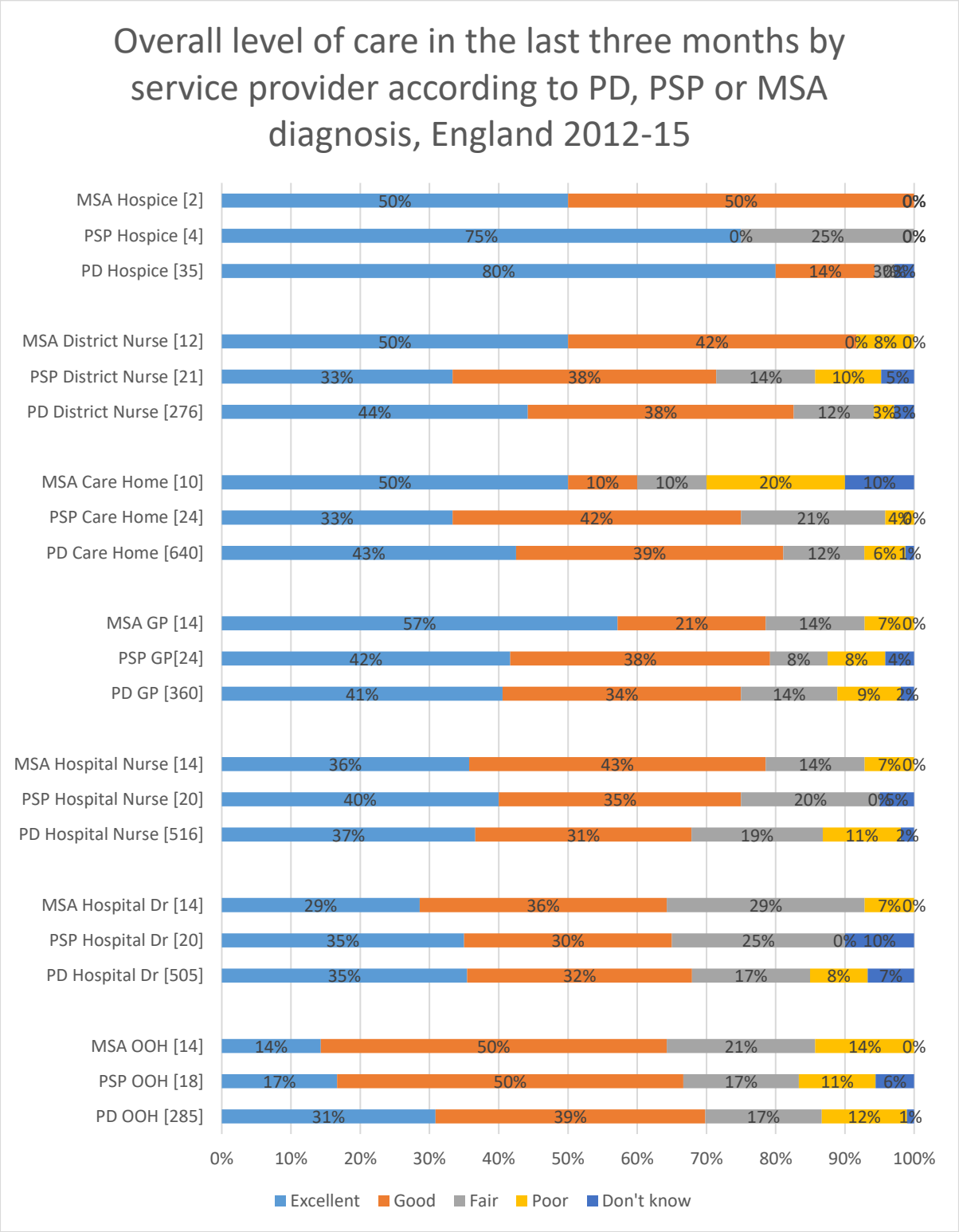
POD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Hospice			7.476	3	0.058			
Hospital	2.342	1.051	4.963	1	0.026	10.400	1.325	81.626
Care Home	2.231	1.045	4.559	1	0.033	9.309	1.201	72.155
Home	1.831	1.067	2.944	1	0.086	6.240	0.771	50.519

viii. Overall ratings of care by service provider in the last 3 months of life

Likelihood of overall care for those dying of PD, PSP or MSA being excellent in the last 3 months of life, by service provider, England 2012-15

Service	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
OOH			44.005	6	0.000			
Hospital Doctor	-0.271	0.153	3.146	1	0.076	0.763	0.565	1.029
Hospital Nurse	-0.335	0.152	4.874	1	0.027	0.715	0.531	0.963
GP	-0.524	0.160	10.714	1	0.001	0.592	0.433	0.811
Care Home	-0.568	0.146	15.147	1	0.000	0.567	0.426	0.754
District Nurse	-0.625	0.168	13.780	1	0.000	0.535	0.385	0.744
Hospice	-2.148	0.397	29.268	1	0.000	0.117	0.054	0.254
Constant	0.879	0.123	50.780	1	0.000	2.409		

ix. Overall ratings of care by service provider in the last 3 months of life according to PD, PSP or MSA diagnosis



Likelihood of care from OOH teams being rated as excellent, by PD,PSP, MSA diagnosis, England 2012-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	PD			3.070	2	0.215			
	PSP	0.804	0.645	1.551	1	0.213	2.234	0.631	7.912
	MSA	0.986	0.774	1.621	1	0.203	2.680	0.587	12.229
	Constant	0.806	0.128	39.503	1	0.000	2.239		

Likelihood of care from Hospital Doctors being rated as excellent, by PD,PSP, MSA diagnosis, England 2012-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	PD			0.280	2	0.869			
	PSP	0.020	0.478	0.002	1	0.967	1.020	0.400	2.602
	MSA	0.317	0.599	0.280	1	0.597	1.373	0.424	4.440
	Constant	0.600	0.093	41.531	1	0.000	1.821		

Likelihood of care from Hospital Nurses being rated as excellent, by PD,PSP, MSA diagnosis, England 2012-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	PD			0.100	2	0.951			
	PSP	-0.143	0.465	0.094	1	0.759	0.867	0.348	2.159
	MSA	0.040	0.565	0.005	1	0.944	1.040	0.344	3.150
	Constant	0.548	0.091	35.996	1	0.000	1.730		

Likelihood of care from GPs being rated as excellent, by PD,PSP, MSA diagnosis, England 2012-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	PD			1.483	2	0.476			
	PSP	-0.046	0.428	0.012	1	0.915	0.955	0.413	2.209
	MSA	-0.670	0.551	1.481	1	0.224	0.512	0.174	1.506
	Constant	0.382	0.107	12.689	1	0.000	1.466		

Likelihood of care from Care Homes being rated as excellent, by PD,PSP, MSA diagnosis, England 2012-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	PD			1.032	2	0.597			
	PSP	0.391	0.440	0.788	1	0.375	1.478	0.624	3.504
	MSA	-0.302	0.637	0.225	1	0.635	0.739	0.212	2.578
	Constant	0.302	0.080	14.291	1	0.000	1.353		

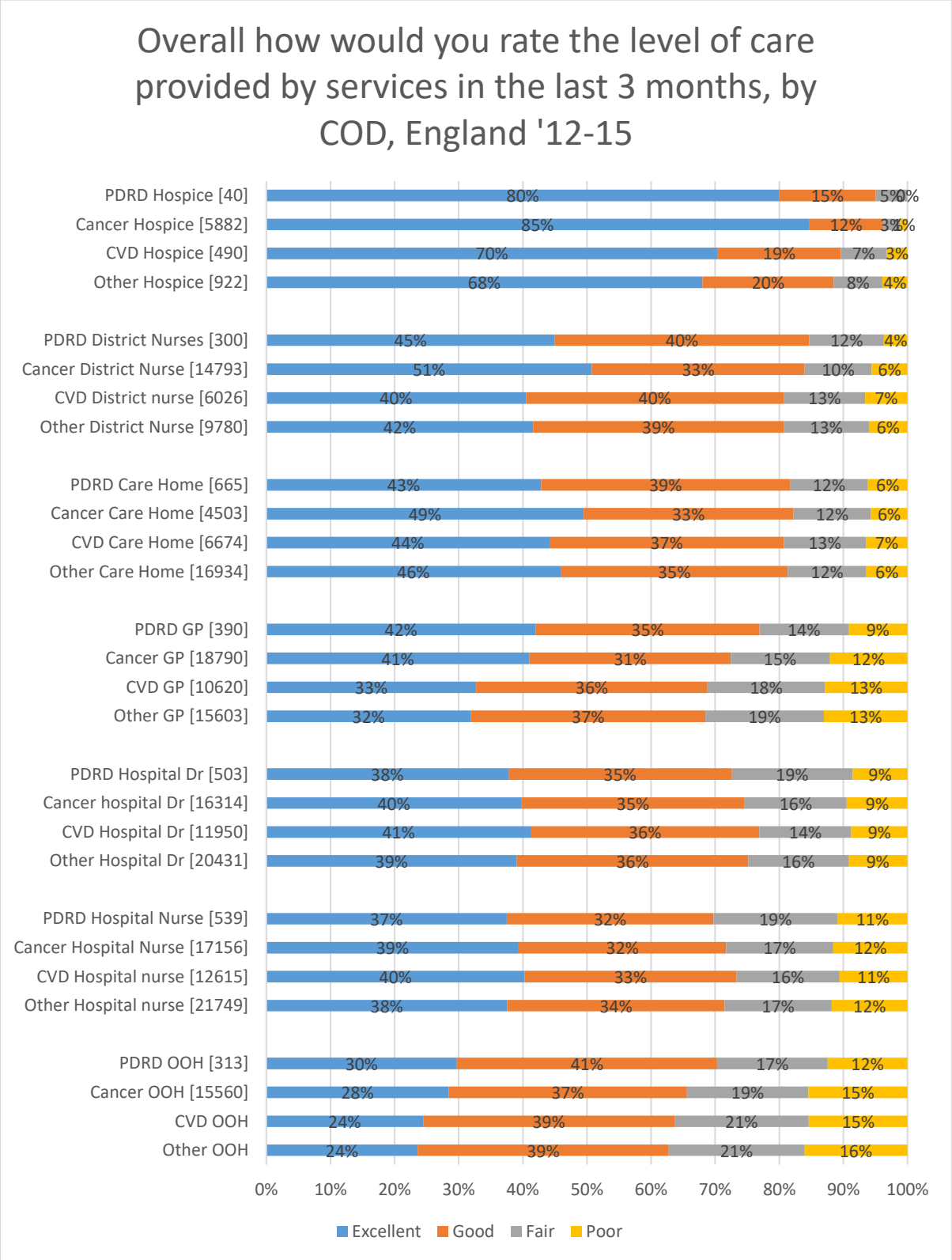
Likelihood of care from District Nurses being rated as excellent, by PD,PSP, MSA

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	PD			1.123	2	0.570			
	PSP	0.460	0.479	0.925	1	0.336	1.584	0.620	4.047
	MSA	-0.233	0.590	0.156	1	0.693	0.792	0.249	2.518
	Constant	0.233	0.121	3.693	1	0.055	1.262		

Likelihood of care from Hospice Staff being rated as excellent, by PD,PSP, MSA diagnosis, England 2012-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	PD			0.902	2	0.637			
	PSP	0.288	1.230	0.055	1	0.815	1.333	0.120	14.845
	MSA	1.386	1.476	0.882	1	0.348	4.000	0.222	72.183
	Constant	-1.386	0.423	10.762	1	0.001	0.250		

x. Overall rating of care comparing PDRD to other causes of death



Likelihood of care being rated as excellent according to service provider and cod			
PD from…	Vs Cancer	Vs CVD	Vs Other
Hospice	OR 0.73 (0.33 to 1.58) p=0.423	OR 1.68 (0.76 to 3.74) p=0.202	OR 1.88 (0.86 to 4.13) p=0.115
District Nurse	**OR 0.79 (0.63 to 0.99) p=0.049**	OR 1.2 (0.95 to 1.52) p=0.120	OR 1.15 (0.91 to 1.45) p=0.24
Care Home	**OR 0.77 (0.65 to 0.90) p=0.001**	OR 0.95 (p.81 to 1.11) p=0.52	OR 0.88 (0.76 to 1.03) p=0.12
GP	*OR 1.04 (0.85 to 1.28) p=0.69*	***OR 1.49 (1.22 to 1.83) p<0.001***	***OR 1.55 (1.26 to 1.90) p<0.001***
Hospital Nurses	OR 0.92 (0.77 to 1.1) p=0.38	OR 0.89 (0.74 to 1.06) p=0.19	OR 0.996 (0.34 to 1.19) p=0.96
Hospital Doctor	OR 0.92 (0.77 to 1.10) p=0.37	OR 0.87 (0.72 to 1.04) p=0.12	OR 0.95 (0.79 to 1.14) p=0.55
OOH	OR 1.07 (0.83 to 1.36) p=-0.616	**OR 1.31 (1.02 to 1.67) p=0.035**	**OR 1.37 (1.07 to 1.75) p=0.013**

xi. Emotional and spiritual support for those dying from PD/PSP/MSA by location, England 2014-15

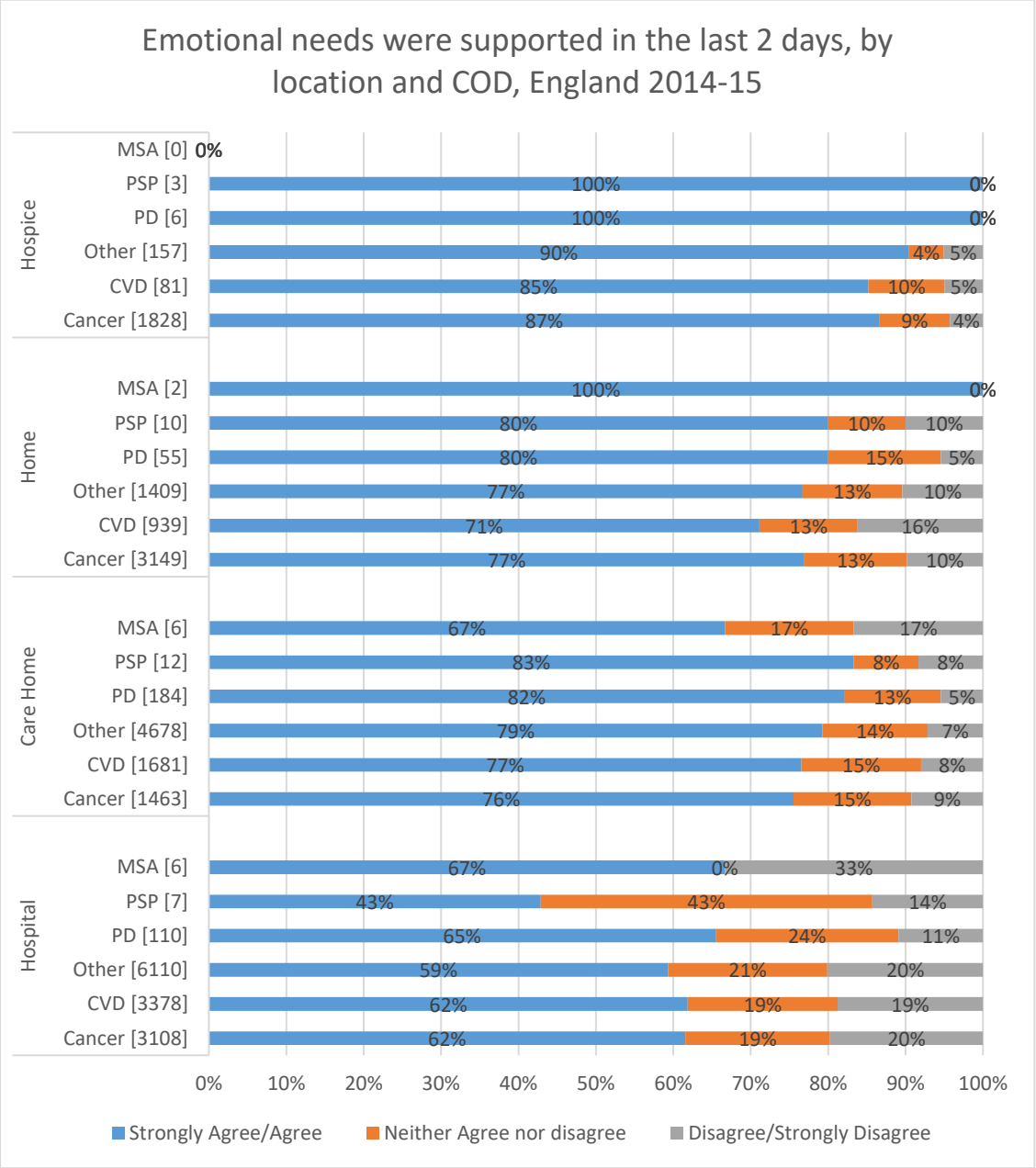
Likelihood of emotional needs being supported for those dying from PD/PSP/MSA, by location, England 2014-15

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Hospital			13.295	3	0.004			
Care Home	-0.910	0.262	12.088	1	0.001	0.403	0.241	0.672
Home	-0.839	0.362	5.378	1	0.020	0.432	0.213	0.878
Hospice	-20.618	13397.657	0.000	1	0.999	0.000	0.000	
Constant	-0.585	0.188	9.680	1	0.002	0.557		

Likelihood of spiritual needs being supported for those dying from PD/PSP/MSA, by location, England 2014-15

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Hospita			1.101	3	0.777			
Care Home	-0.275	0.270	1.034	1	0.309	0.760	0.447	1.290
Home	-0.251	0.383	0.431	1	0.512	0.778	0.367	1.647
Hospice	-20.866	13397.657	0.000	1	0.999	0.000	0.000	
Constant	-0.336	0.207	2.642	1	0.104	0.714		

xii. Emotional support, by COD and location, England 2014-15



Likelihood of emotional needs being supported in hospital, by COD England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Step 1[a]	PD			9.652	5	0.086			
	Cancer	0.169	0.204	0.684	1	0.408	1.184	0.794	1.765
	CVD	0.155	0.204	0.580	1	0.446	1.168	0.783	1.740
	Other	0.261	0.202	1.673	1	0.196	1.299	0.874	1.931
	PSP	0.927	0.790	1.377	1	0.241	2.526	0.537	11.875
	MSA	-0.054	0.889	0.004	1	0.952	0.947	0.166	5.410
	Constant	-0.639	0.201	10.159	1	0.001	0.528		

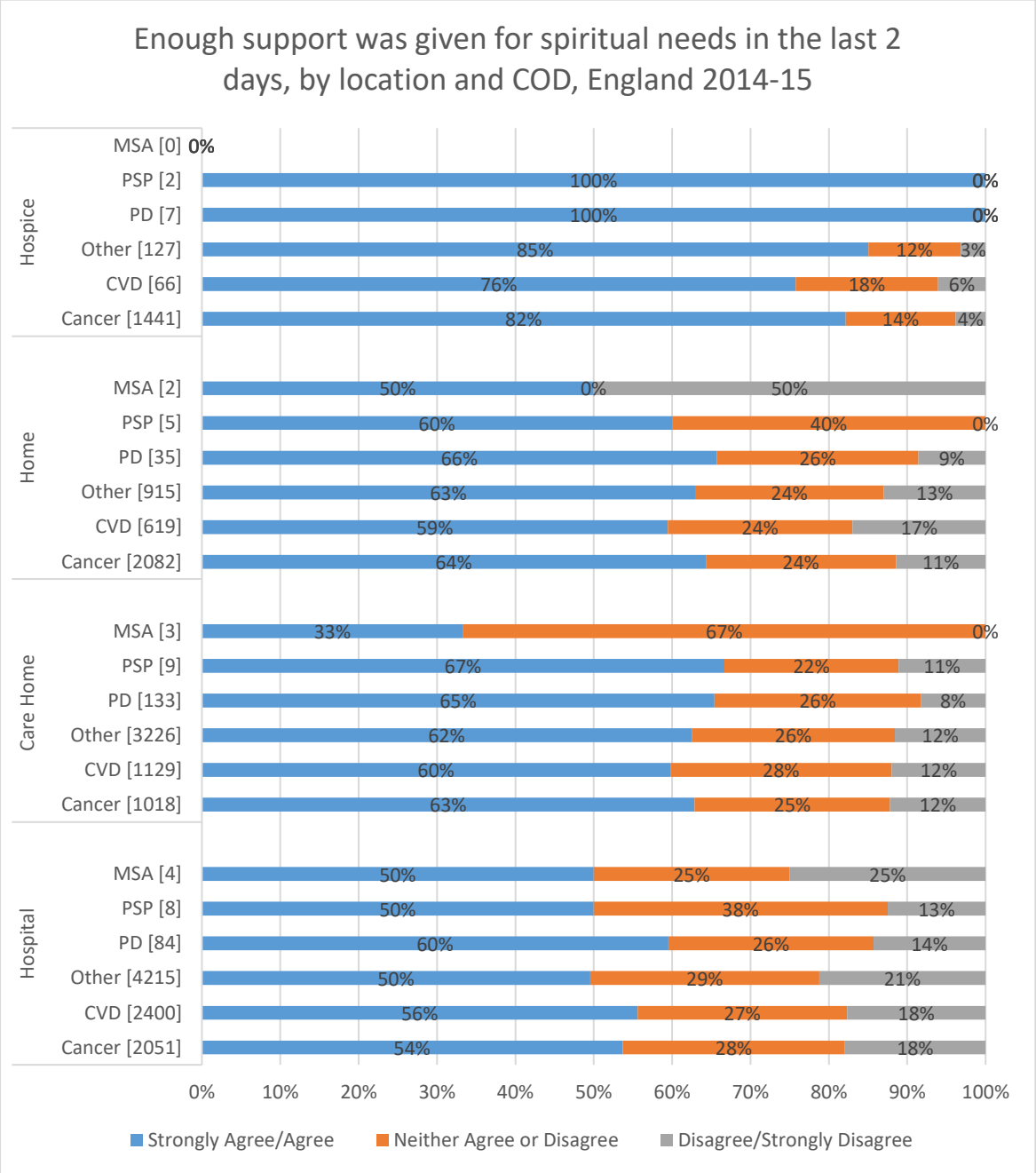
Likelihood of emotional needs being supported in care home, by COD England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Step 1[a]	PD			13.827	5	0.017			
	Cancer	0.394	0.202	3.816	1	0.051	1.482	0.999	2.201
	CVD	0.337	0.201	2.823	1	0.093	1.401	0.945	2.076
	Other	0.181	0.196	0.858	1	0.354	1.199	0.817	1.758
	PSP	-0.089	0.798	0.012	1	0.912	0.915	0.192	4.373
	MSA	0.828	0.887	0.870	1	0.351	2.288	0.402	13.017
	Constant	-1.521	0.192	62.633	1	0.000	0.219		

Likelihood of emotional needs being supported in own home, by COD England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Step 1[a]	PD			14.568	5	0.012			
	Cancer	0.181	0.340	0.284	1	0.594	1.199	0.616	2.333
	CVD	0.484	0.345	1.972	1	0.160	1.623	0.826	3.189
	Other	0.194	0.343	0.319	1	0.572	1.214	0.620	2.377
	PSP	0.000	0.859	0.000	1	1.000	1.000	0.186	5.390
	MSA	-19.817	28420.722	0.000	1	0.999	0.000	0.000	
	Constant	-1.386	0.337	16.912	1	0.000	0.250		

xiii. Spiritual support, by COD and location, England 2014-15



Likelihood of spiritual support being received in hospital, by COD England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Step 1[a]	PD			26.617	5	0.000			
	Cancer	0.238	0.227	1.104	1	0.293	1.269	0.814	1.979
	CVD	0.160	0.226	0.499	1	0.480	1.173	0.753	1.827
	Other	0.403	0.224	3.228	1	0.072	1.497	0.964	2.323
	PSP	0.386	0.741	0.271	1	0.603	1.471	0.344	6.287
	MSA	0.386	1.024	0.142	1	0.707	1.471	0.197	10.951
	Constant	-0.386	0.222	3.010	1	0.083	0.680		

Likelihood of spiritual support being received in care home, by COD England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Step 1[a]	PD			4.665	5	0.458			
	Cancer	0.111	0.193	0.327	1	0.567	1.117	0.764	1.632
	CVD	0.241	0.192	1.569	1	0.210	1.272	0.873	1.854
	Other	0.127	0.186	0.465	1	0.495	1.135	0.789	1.634
	PSP	-0.056	0.730	0.006	1	0.939	0.946	0.226	3.956
	MSA	1.330	1.238	1.154	1	0.283	3.783	0.334	42.833
	Constant	-0.637	0.182	12.220	1	0.000	0.529		

Likelihood of spiritual support being received in own home, by COD England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Step 1[a]	PD			5.123	5	0.401			
	Cancer	0.062	0.359	0.029	1	0.864	1.064	0.526	2.150
	CVD	0.268	0.365	0.538	1	0.463	1.307	0.639	2.675
	Other	0.120	0.363	0.110	1	0.740	1.128	0.554	2.296
	PSP	0.245	0.980	0.063	1	0.802	1.278	0.187	8.720
	MSA	0.651	1.458	0.199	1	0.656	1.917	0.110	33.412
	Constant	-0.651	0.356	3.338	1	0.068	0.522		

xiv. Pain and 'other' symptoms

Likelihood of support for pain being offered for those dying of PD/PSP/MSA by location, England 2014-15

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Hospital			7.027	3	0.071			
Care Home	-0.847	0.334	6.426	1	0.011	0.429	0.223	0.825
Home	-0.108	0.418	0.067	1	0.796	0.897	0.395	2.037
Hospice	-19.764	12118.636	0.000	1	0.999	0.000	0.000	
Constant	-1.439	0.232	38.510	1	0.000	0.237		

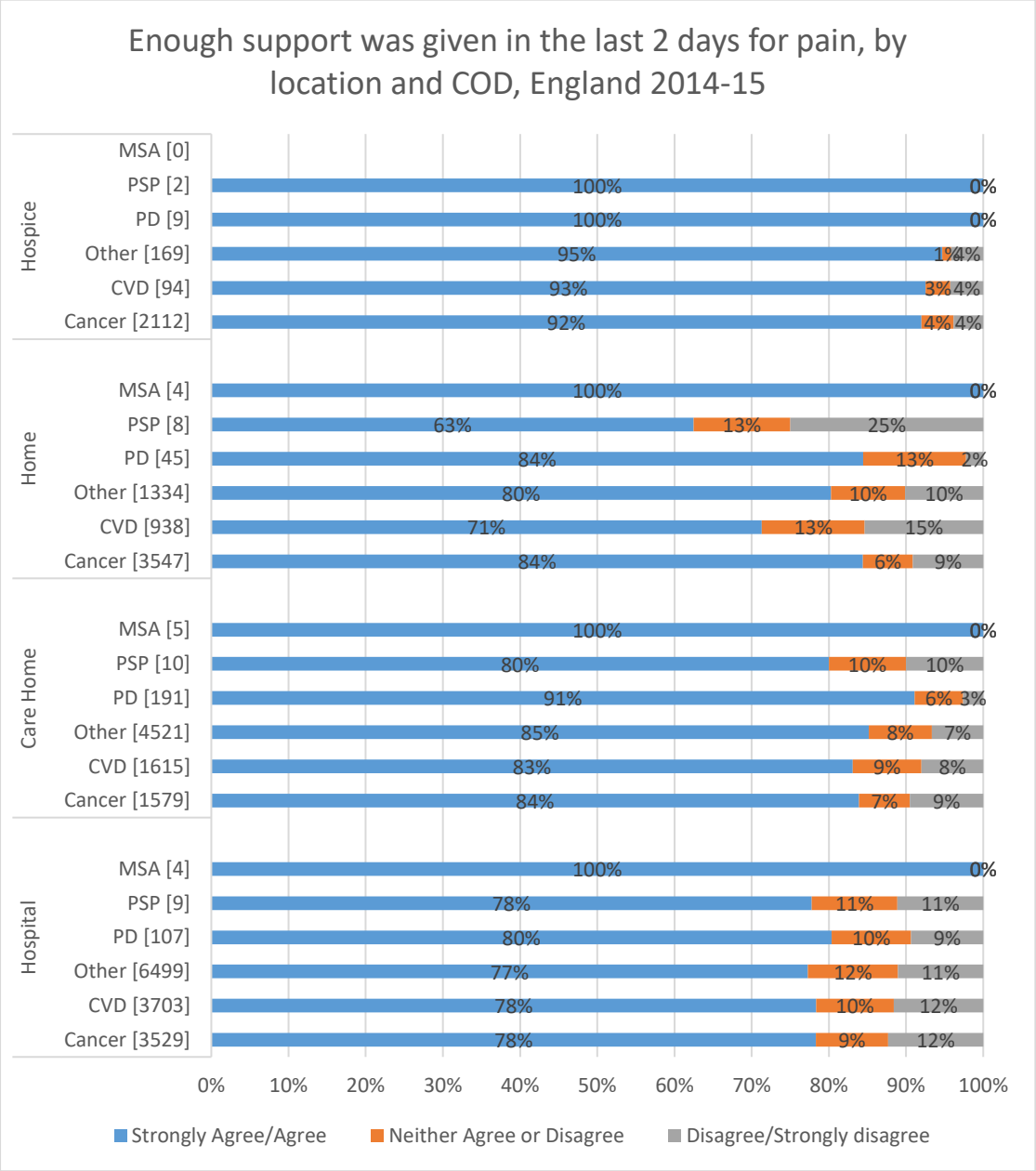
a. Variable(s) entered on step 1: Place.

Likelihood of support for symptoms other than pain, nutrition or hydration being offered for those dying of PD/PSP/MSA by location, England 2014-15

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Hospital			6.523	3	0.089			
Care Home	-0.718	0.281	6.518	1	0.011	0.488	0.281	0.846
Home	-0.397	0.376	1.114	1	0.291	0.672	0.322	1.405
Hospice	-20.024	11147.524	0.000	1	0.999	0.000	0.000	
Constant	-1.179	0.202	33.995	1	0.000	0.308		

a. Variable(s) entered on step 1: Place.

xv. Likelihood of support for pain being offered by COD and location, England 2014-15



Likelihood of support for pain being given in hospital, by COD England 2014-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	PD			2.558	5	0.768			
	Cancer	0.125	0.247	0.258	1	0.612	1.133	0.699	1.839
	CVD	0.124	0.247	0.253	1	0.615	1.132	0.698	1.836
	Other	0.185	0.245	0.570	1	0.450	1.203	0.744	1.946
	PSP	0.157	0.838	0.035	1	0.851	1.170	0.226	6.046
	MSA	-19.793	20096.485	0.000	1	0.999	0.000	0.000	
	Constant	-1.410	0.243	33.548	1	0.000	0.244		

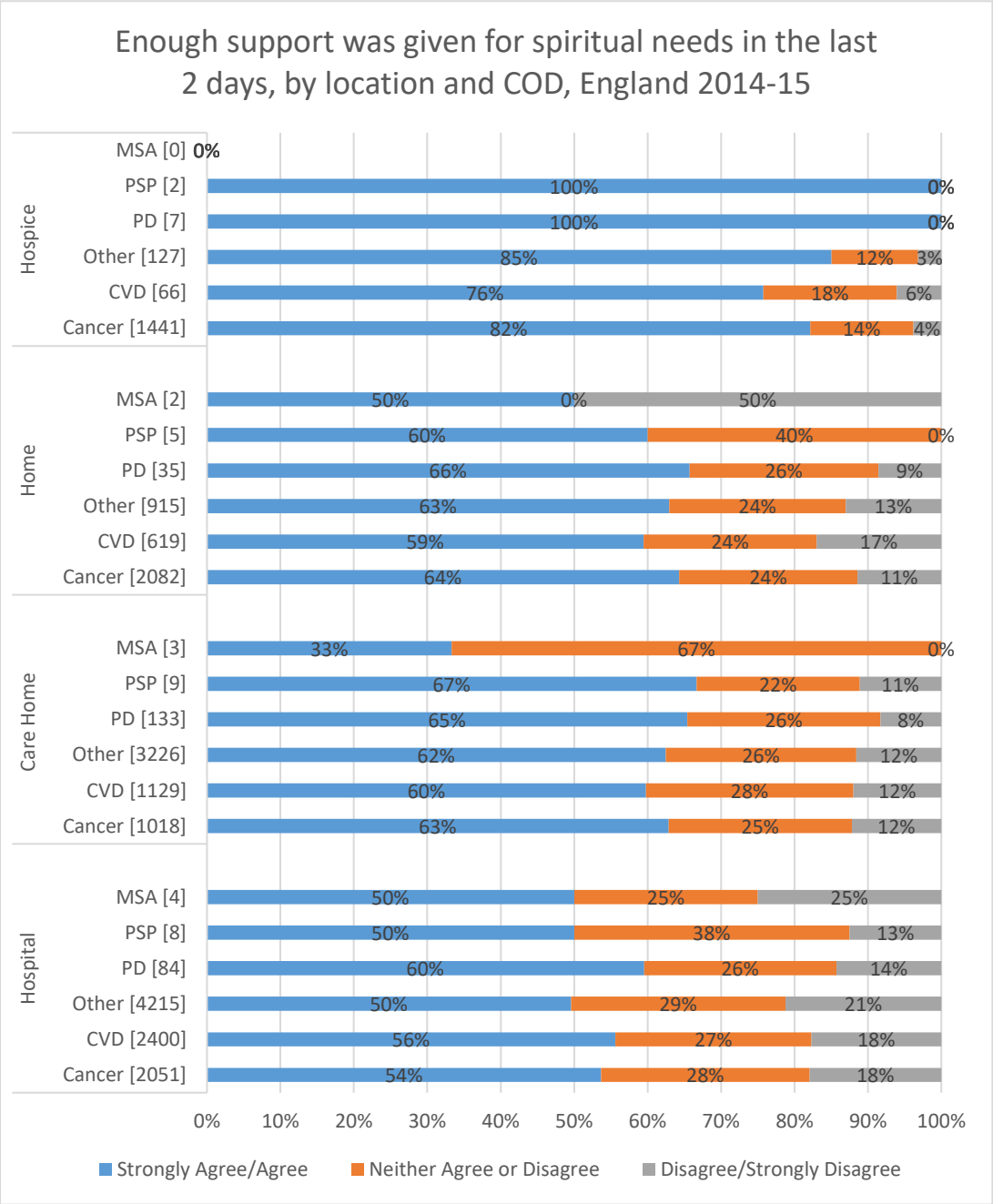
Likelihood of support for pain being given in care home, by COD England 2014-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	PD			10.696	5	0.058			
	Cancer	0.674	0.263	6.559	1	0.010	1.962	1.171	3.287
	CVD	0.733	0.263	7.798	1	0.005	2.082	1.244	3.484
	Other	0.577	0.258	5.020	1	0.025	1.781	1.075	2.950
	PSP	0.940	0.830	1.280	1	0.258	2.559	0.503	13.028
	MSA	-18.877	17974.843	0.000	1	0.999	0.000	0.000	
	Constant	-2.326	0.254	83.777	1	0.000	0.098		

Likelihood of support for pain being given at home, by COD England 2014-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	PD			84.826	5	0.000			
	Cancer	0.003	0.414	0.000	1	0.995	1.003	0.445	2.257
	CVD	0.781	0.418	3.494	1	0.062	2.183	0.963	4.948
	Other	0.287	0.417	0.475	1	0.491	1.333	0.589	3.019
	PSP	1.181	0.838	1.985	1	0.159	3.257	0.630	16.837
	MSA	-19.511	20096.485	0.000	1	0.999	0.000	0.000	
	Constant	-1.692	0.411	16.916	1	0.000	0.184		

xvi. Likelihood of support for 'other' symptoms being offered by COD and location, England 2014-15



Likelihood of other symptoms being controlled in hospital by COD, England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
COD	PD			14.012	5	0.016			
	Cancer	0.388	0.215	3.248	1	0.071	1.474	0.967	2.249
	CVD	0.241	0.215	1.251	1	0.263	1.272	0.834	1.940
	Other	0.375	0.214	3.070	1	0.080	1.454	0.957	2.211
	PSP	0.493	0.892	0.306	1	0.580	1.638	0.285	9.403
	MSA	-0.423	1.116	0.144	1	0.705	0.655	0.074	5.836
	Constant	-1.187	0.212	31.282	1	0.000	0.305		

a. Variable(s) entered on step 1: COD.

Likelihood of other symptoms being controlled in Care Home by COD, England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
COD	PD			10.726	5	0.057			
	Cancer	0.368	0.217	2.890	1	0.089	1.445	0.945	2.209
	CVD	0.350	0.215	2.651	1	0.103	1.420	0.931	2.164
	Other	0.200	0.210	0.907	1	0.341	1.221	0.810	1.841
	PSP	-0.566	1.061	0.284	1	0.594	0.568	0.071	4.544
	MSA	1.226	0.890	1.897	1	0.168	3.407	0.595	19.506
	Constant	-1.919	0.206	86.715	1	0.000	0.147		

a. Variable(s) entered on step 1: COD.

Likelihood of other symptoms being controlled at Home by COD, England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
COD	PD			16.331	5	0.006			
	Cancer	0.000	0.339	0.000	1	1.000	1.000	0.514	1.944
	CVD	0.340	0.345	0.973	1	0.324	1.405	0.715	2.761
	Other	0.040	0.343	0.014	1	0.906	1.041	0.532	2.038
	PSP	-0.788	1.106	0.508	1	0.476	0.455	0.052	3.976
	MSA	-19.794	20096.485	0.000	1	0.999	0.000	0.000	
	Constant	-1.409	0.336	17.543	1	0.000	0.244		#NAME?

xvii. Hydration and Nutrition

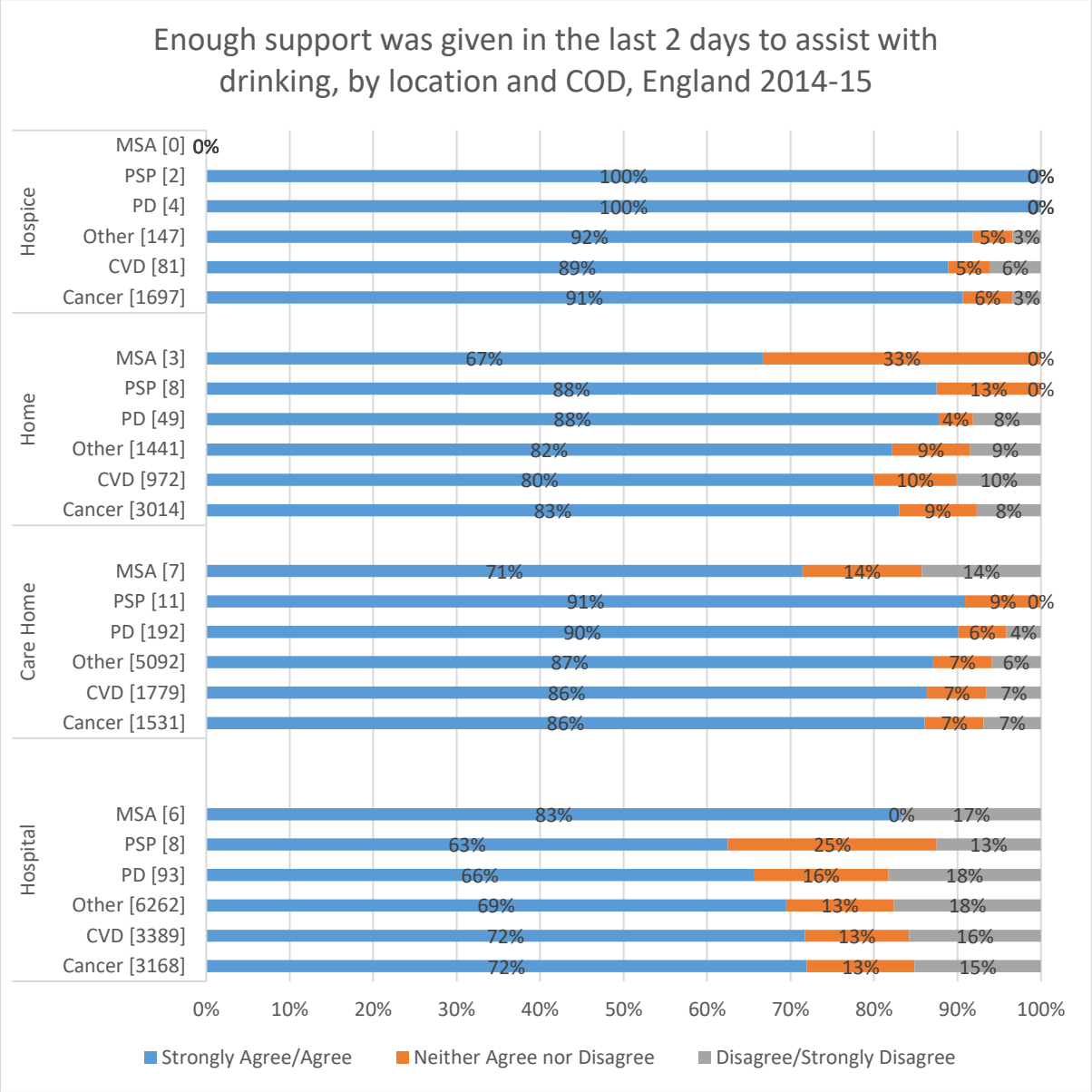
Likelihood of enough support for drinking being offered for those dying from PD/PSP/MSA by location, England 2014-15

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Hospital			24.888	3	0.000			
Care Home	-1.466	0.304	23.208	1	0.000	0.231	0.127	0.419
Home	-1.193	0.431	7.643	1	0.006	0.303	0.130	0.707
Hospice	-20.524	16408.711	0.000	1	0.999	0.000	0.000	
Constant	-0.679	0.205	11.018	1	0.001	0.507		

Likelihood of enough support for eating being offered for those dying from PD/PSP/MSA by location, England 2014-15

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Hospital			16.948	3	0.001			
Care Home	-1.255	0.315	15.853	1	0.000	0.285	0.154	0.529
Home	-1.061	0.443	5.744	1	0.017	0.346	0.145	0.824
Hospice	-20.493	17974.843	0.000	1	0.999	0.000	0.000	
Constant	-0.710	0.223	10.128	1	0.001	0.492		

xviii. Likelihood of support for drinking being offered by COD and location, England 2014-15



Likelihood of enough support being given for drinking in hospital by COD, England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
COD	PD			15.521	5	0.008			
	Cancer	-0.042	0.240	0.030	1	0.862	0.959	0.599	1.535
	CVD	-0.127	0.240	0.282	1	0.595	0.880	0.550	1.408
	Other	0.056	0.238	0.056	1	0.813	1.058	0.663	1.687
	PSP	-0.019	0.898	0.000	1	0.983	0.981	0.169	5.702
	MSA	-0.712	1.143	0.388	1	0.533	0.491	0.052	4.609
	Constant	-0.674	0.236	8.137	1	0.004	0.509		

a. Variable(s) entered on step 1: COD.

Likelihood of enough support being given for drinking in care home by COD, England 2014-15

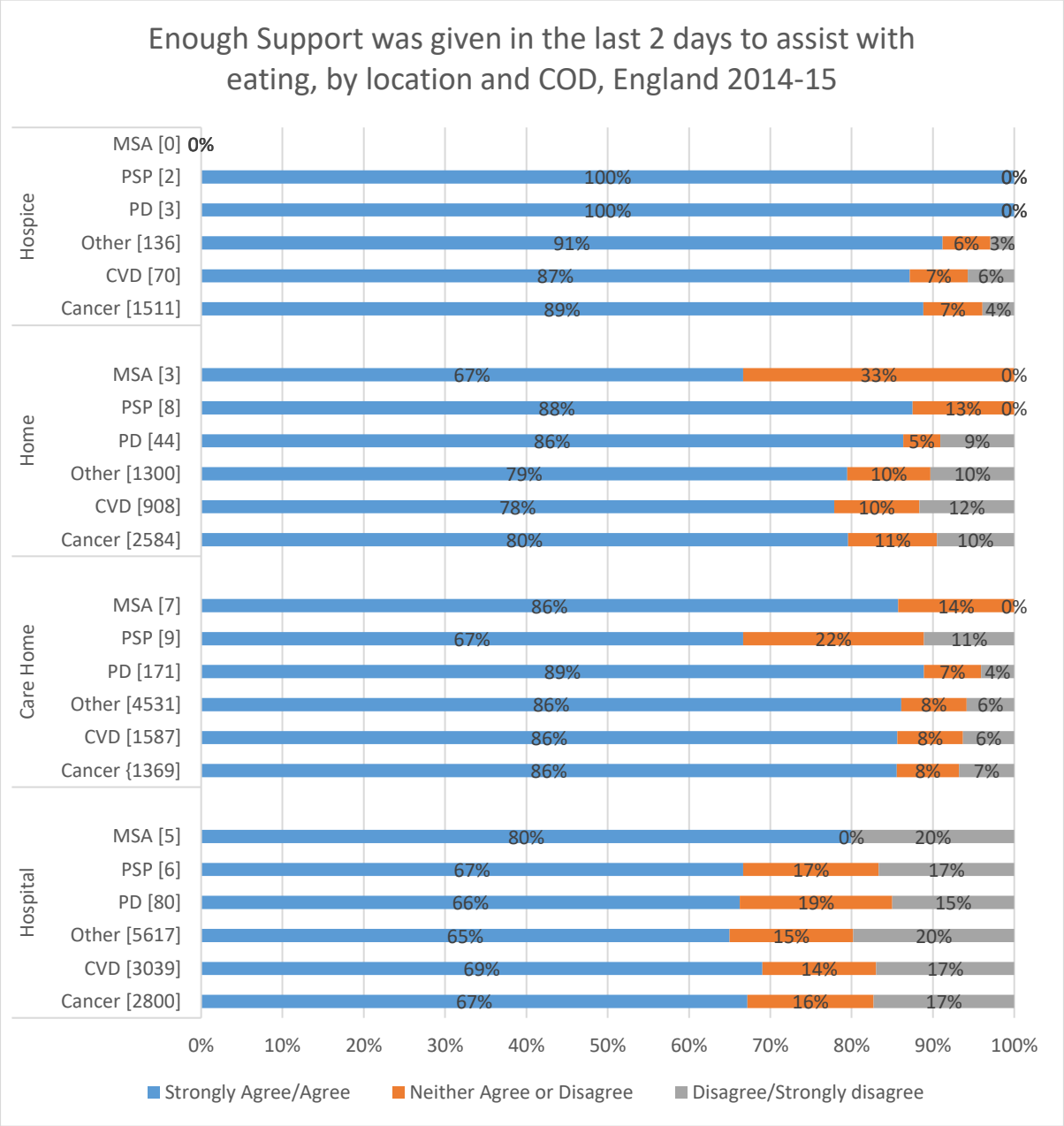
								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
COD	PD			4.117	5	0.533			
	Cancer	0.302	0.255	1.402	1	0.236	1.353	0.820	2.231
	CVD	0.294	0.254	1.346	1	0.246	1.342	0.816	2.206
	Other	0.256	0.247	1.075	1	0.300	1.292	0.796	2.097
	PSP	1.386	0.748	3.437	1	0.064	4.000	0.924	17.322
	MSA	0.288	1.107	0.068	1	0.795	1.333	0.152	11.678
	Constant	-2.079	0.243	73.029	1	0.000	0.125		

a. Variable(s) entered on step 1: COD.

Likelihood of enough support being given for drinking in own home by COD, England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
COD	PD			3.179	5	0.672			
	Cancer	0.486	0.442	1.211	1	0.271	1.626	0.684	3.868
	CVD	0.588	0.447	1.735	1	0.188	1.801	0.750	4.320
	Other	0.493	0.445	1.229	1	0.268	1.637	0.685	3.913
	PSP	-0.100	1.156	0.007	1	0.931	0.905	0.094	8.716
	MSA	1.153	1.301	0.785	1	0.376	3.167	0.247	40.564
	Constant	-1.846	0.439	17.655	1	0.000	0.158		

xix. Likelihood of support for eating being offered by COD and location, England 2014-15



Likelihood of enough support being given for eating in hospital by COD, England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
COD	PD			10.424	5	0.064			
	Cancer	-0.298	0.222	1.802	1	0.179	0.742	0.481	1.147
	CVD	-0.285	0.222	1.650	1	0.199	0.752	0.487	1.161
	Other	-0.178	0.220	0.652	1	0.419	0.837	0.544	1.289
	PSP	0.134	0.762	0.031	1	0.860	1.144	0.257	5.095
	MSA	-0.964	1.117	0.745	1	0.388	0.381	0.043	3.404
	Constant	-0.645	0.218	8.736	1	0.003	0.525		

a. Variable(s) entered on step 1: COD.

Likelihood of enough support being given for eating in care home by COD, England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
COD	PD			4.657	5	0.459			
	Cancer	0.386	0.253	2.336	1	0.126	1.471	0.897	2.415
	CVD	0.365	0.251	2.108	1	0.146	1.440	0.880	2.358
	Other	0.301	0.245	1.506	1	0.220	1.351	0.836	2.185
	PSP	-0.094	1.076	0.008	1	0.931	0.911	0.110	7.506
	MSA	1.293	0.871	2.203	1	0.138	3.642	0.661	20.074
	Constant	-2.209	0.242	83.528	1	0.000	0.110		

a. Variable(s) entered on step 1: COD.

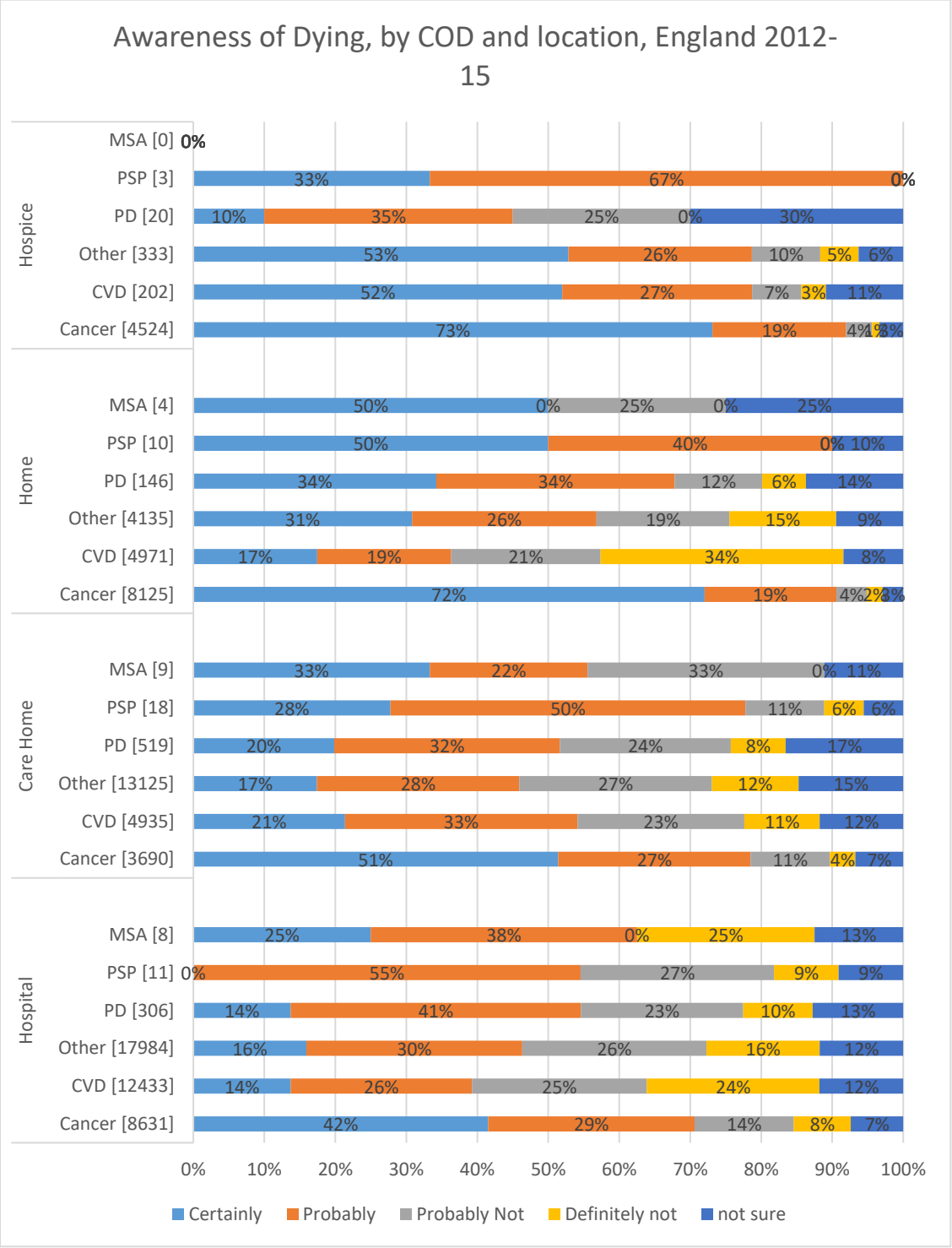
Likelihood of enough support being given for eating in own home by COD, England 2014-15

								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
COD	PD			6.379	5	0.271			
	Cancer	0.383	0.438	0.763	1	0.383	1.467	0.621	3.464
	CVD	0.587	0.443	1.755	1	0.185	1.799	0.755	4.286
	Other	0.442	0.441	1.003	1	0.317	1.556	0.655	3.694
	PSP	0.024	1.154	0.000	1	0.984	1.024	0.107	9.838
	MSA	1.276	1.300	0.964	1	0.326	3.583	0.280	45.796
	Constant	-1.969	0.436	20.423	1	0.000	0.140		

xx. Awareness of Dying by Location, for those dying from PD/PSP/MSA

Likelihood of person who died from PD/PSP/MSA being certainly aware that they were dying, by POD, England 2012-15									
								95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
POD	Home			31.369	3	0.000			
	Hospital	1.262	0.231	29.771	1	0.000	3.534	2.246	5.562
	Care Home	0.774	0.196	15.542	1	0.000	2.169	1.476	3.187
	Hospice	1.305	0.641	4.151	1	0.042	3.689	1.051	12.953
	Constant	0.592	0.165	12.846	1	0.000	1.807		

xxi. Awareness of Dying by COD and location



Likelihood of person who died in Hospital being certainly aware that they were dying, by COD, England 2012-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
COD	PD			2663.842	5	0.000			
	Cancer	-1.496	0.168	79.764	1	0.000	0.224	0.161	0.311
	CVD	0.002	0.168	0.000	1	0.992	1.002	0.720	1.393
	Other	-0.175	0.167	1.097	1	0.295	0.839	0.605	1.165
	PSP	19.365	12118.636	0.000	1	0.999	########	0.000	
	MSA	-0.740	0.833	0.788	1	0.375	0.477	0.093	2.443
	Constant	1.838	0.166	122.449	1	0.000	6.286		

Likelihood of person who died in Care Home being certainly aware that they were dying, by COD, England 2012-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
COD	PD			1666.897	5	0.000			
	Cancer	-1.452	0.115	159.826	1	0.000	0.234	0.187	0.293
	CVD	-0.092	0.115	0.642	1	0.423	0.912	0.727	1.143
	Other	0.160	0.112	2.021	1	0.155	1.173	0.941	1.463
	PSP	-0.440	0.538	0.671	1	0.413	0.644	0.224	1.846
	MSA	-0.703	0.716	0.965	1	0.326	0.495	0.122	2.013
	Constant	1.396	0.110	160.882	1	0.000	4.039		

Likelihood of person who died in their own Home being certainly aware that they were dying, by COD, England 2012-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
COD	PD			3755.757	5	0.000			
	Cancer	-1.597	0.176	82.177	1	0.000	0.203	0.143	0.286
	CVD	0.902	0.178	25.594	1	0.000	2.465	1.738	3.497
	Other	0.158	0.178	0.789	1	0.374	1.171	0.827	1.659
	PSP	-0.652	0.656	0.989	1	0.320	0.521	0.144	1.884
	MSA	-0.652	1.015	0.413	1	0.520	0.521	0.071	3.808
	Constant	0.652	0.174	13.990	1	0.000	1.920		

Likelihood of person who died in Hospice being certainly aware that they were dying, by COD, England 2012-15

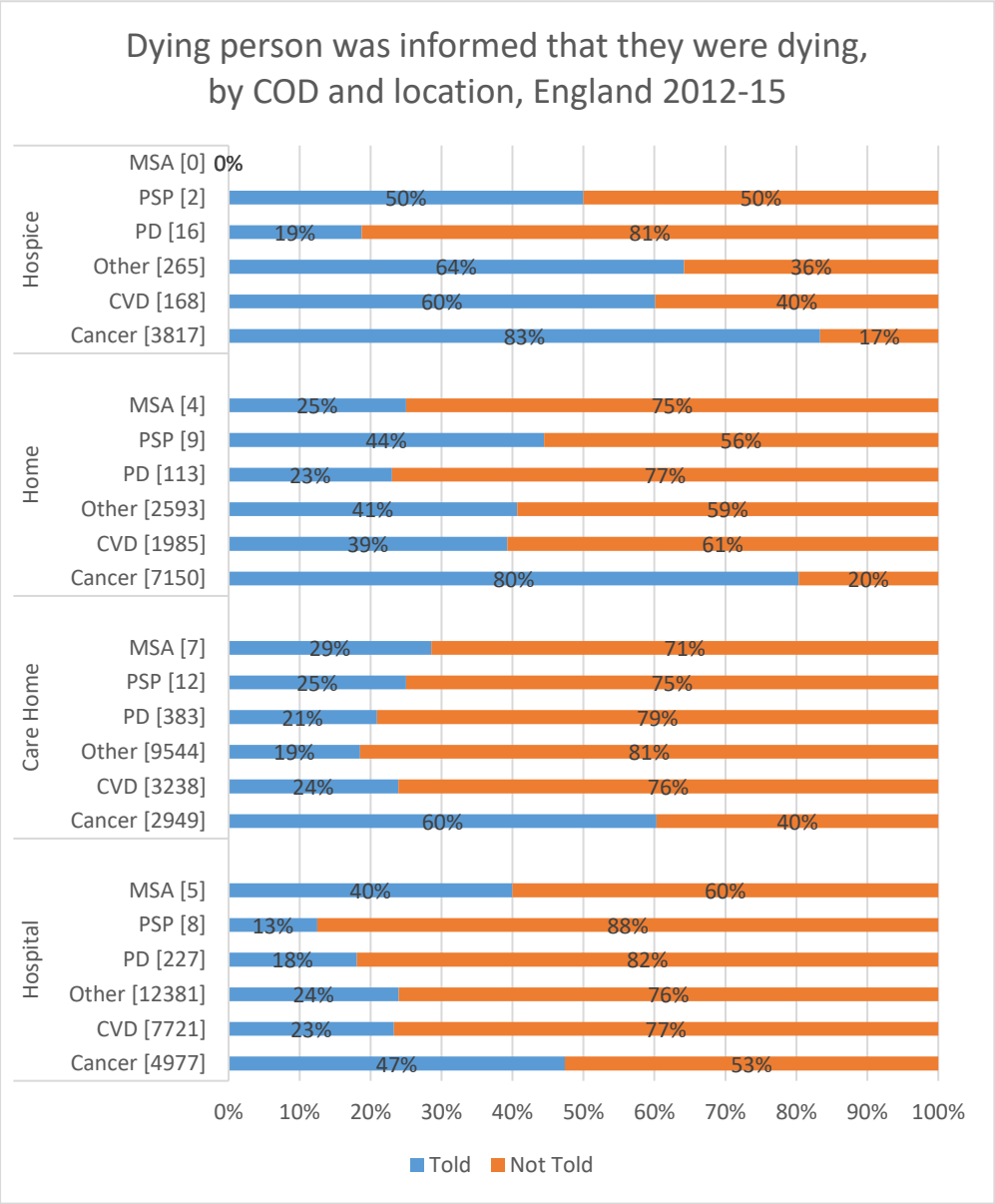
		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
COD	PD			112.643	4	0.000			
	Cancer	-3.198	0.746	18.372	1	0.000	0.041	0.009	0.176
	CVD	-2.276	0.759	9.007	1	0.003	0.103	0.023	0.454
	Other	-2.311	0.753	9.413	1	0.002	0.099	0.023	0.434
	PSP	-1.504	1.434	1.101	1	0.294	0.222	0.013	3.691
	Constant	2.197	0.745	8.690	1	0.003	9.000		

xxii. Did healthcare staff tell the dying person that they were dying?

Likelihood of person dying from PD/PSP/MSA being told that they were dying by healthcare staff, by location, England 2012-15

							95% C.I.for EXP(B)	
		B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
POD	Home			2.028	3	0.567			
	Hospital	0.374	0.266	1.981	1	0.159	1.454	0.863	2.447
	Care Home	0.196	0.240	0.668	1	0.414	1.217	0.760	1.949
	Hospice	0.133	0.604	0.048	1	0.826	1.142	0.350	3.727
	Constant	1.120	0.207	29.313	1	0.000	3.065		

xxiii. Likelihood of person dying being told that they were dying by staff, by COD and location



Likelihood of person who died in hospital having being told that they were dying by healthcare staff, by COD England 2012-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
COD	PD			1064.753	5	0.000			
	Cancer	-1.408	0.175	64.845	1	0.000	0.245	0.174	0.345
	CVD	-0.319	0.175	3.343	1	0.067	0.727	0.516	1.023
	Other	-0.357	0.174	4.221	1	0.040	0.700	0.498	0.984
	PSP	0.434	1.083	0.160	1	0.689	1.543	0.185	12.886
	MSA	-1.107	0.929	1.419	1	0.234	0.331	0.054	2.042
	Constant	1.512	0.173	76.820	1	0.000	4.537		

Likelihood of person who died in Care Home having being told that they were dying by healthcare staff, by COD England 2012-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
COD	PD			1760.723	5	0.000			
	Cancer	-1.749	0.131	177.745	1	0.000	0.174	0.134	0.225
	CVD	-0.174	0.132	1.725	1	0.189	0.841	0.649	1.089
	Other	0.149	0.128	1.355	1	0.244	1.161	0.903	1.494
	PSP	-0.233	0.678	0.118	1	0.731	0.792	0.210	2.994
	MSA	-0.415	0.846	0.241	1	0.623	0.660	0.126	3.465
	Constant	1.332	0.126	112.241	1	0.000	3.787		

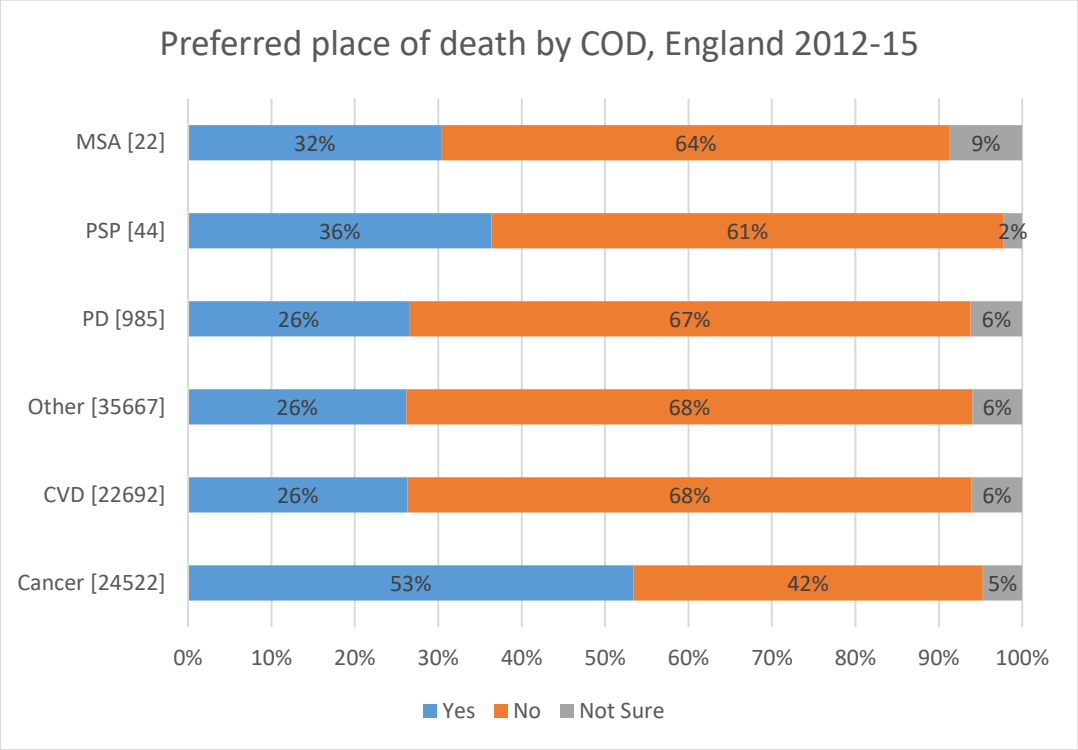
Likelihood of person who died in their own Home having being told that they were dying by healthcare staff, by COD England 2012-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
COD	PD			1889.535	5	0.000			
	Cancer	-2.616	0.225	134.614	1	0.000	0.073	0.047	0.114
	CVD	-0.773	0.228	11.472	1	0.001	0.462	0.295	0.722
	Other	-0.829	0.227	13.339	1	0.000	0.436	0.280	0.681
	PSP	-0.985	0.707	1.939	1	0.164	0.374	0.093	1.494
	MSA	-0.109	1.176	0.009	1	0.926	0.897	0.089	8.989
	Constant	1.208	0.224	29.202	1	0.000	3.346		

Likelihood of person who died in a Hospice having being told that they were dying by healthcare staff, by COD England 2012-15

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
COD	PD			124.610	4	0.000			
	Cancer	-3.078	0.642	22.987	1	0.000	0.046	0.013	0.162
	CVD	-1.877	0.660	8.096	1	0.004	0.153	0.042	0.558
	Other	-2.048	0.653	9.833	1	0.002	0.129	0.036	0.464
	PSP	-1.466	1.553	0.892	1	0.345	0.231	0.011	4.838
	Constant	1.466	0.641	5.241	1	0.022	4.333		

xxiv. PPOD by COD



Likelihood of having a PPOD by COD, England 2012-15

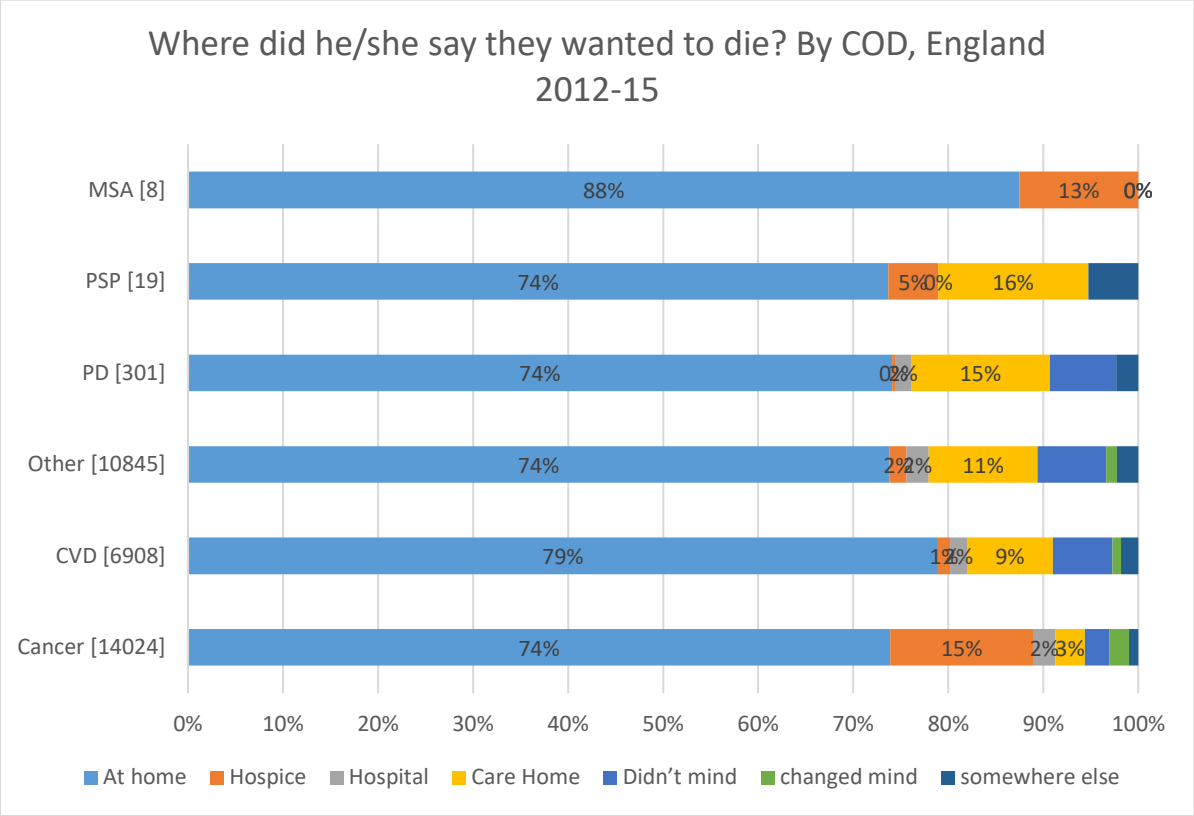
COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			5408.660	5	0.000			
	Cancer	-1.176	0.074	250.726	1	0.000	0.309	0.267	0.357
	CVD	0.012	0.075	0.027	1	0.870	1.012	0.875	1.172
	Other	0.020	0.074	0.073	1	0.788	1.020	0.882	1.180
	PSP	-0.409	0.324	1.595	1	0.207	0.664	0.352	1.253
	MSA	-0.239	0.469	0.260	1	0.610	0.787	0.314	1.973
	Constant	0.932	0.073	162.761	1	0.000	2.540		

xxv. PPOD for those dying from PD/PSP/MSA by POD

Likelihood of person dying from PD/PSP/MSA having a PPOD by POD, England 2012-15

POD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Home			113.337	3	0.000			
Hospital	1.860	0.216	74.049	1	0.000	6.423	4.205	9.810
Care Home	2.101	0.203	107.568	1	0.000	8.174	5.496	12.158
Hospice	1.628	0.512	10.122	1	0.001	5.096	1.869	13.897
Constant	-0.712	0.169	17.695	1	0.000	0.491		

xxvi. Where did he/she want to die, by COD, England 2012-15

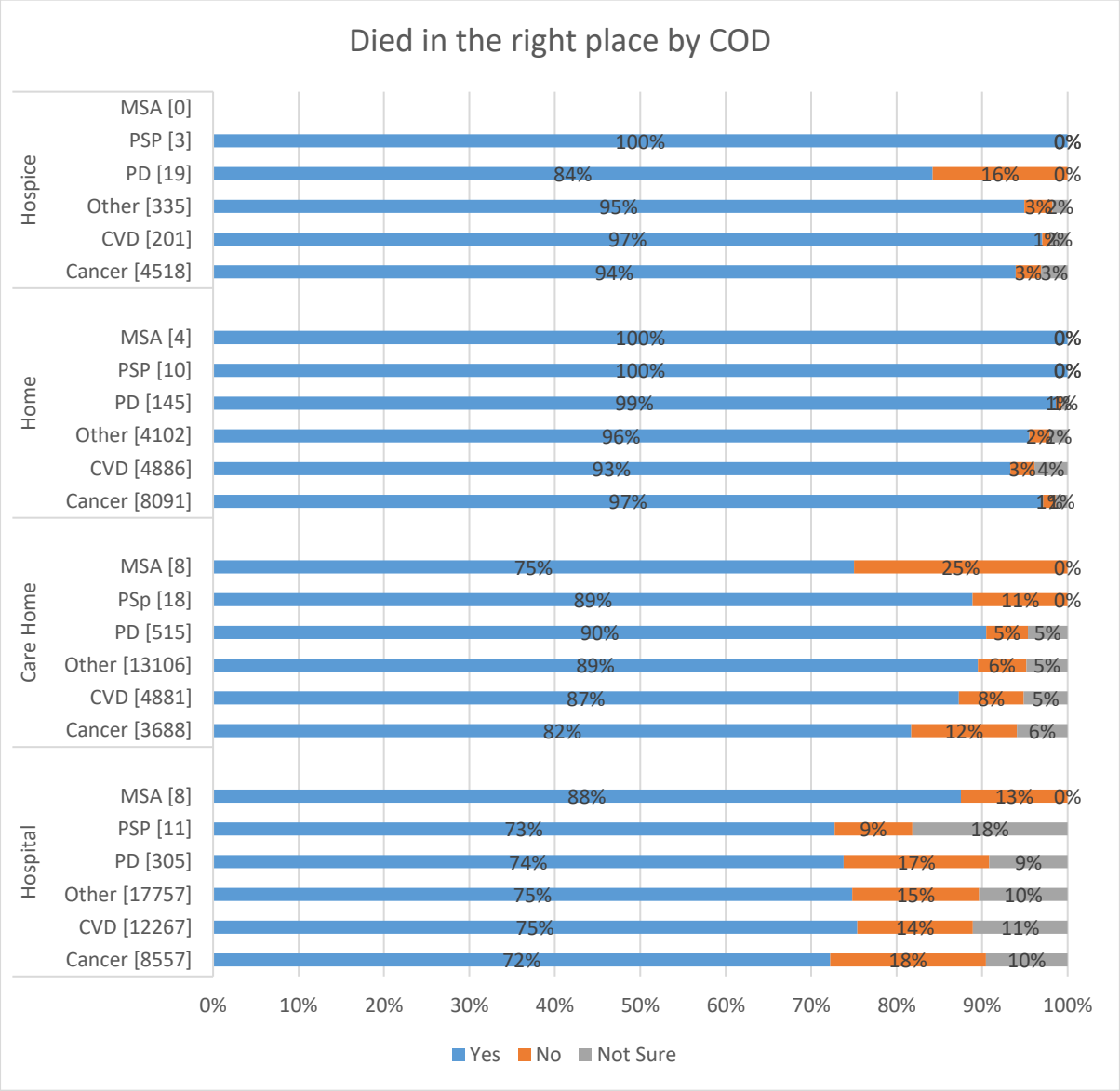


xxvii. Died in the right place

Likelihood of person who died from PD/PSP/MSA dying in the right place according to their carer, by POD, England 2012-15

POD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Home			38.249	3	0.000			
Hospital	2.861	0.727	15.478	1	0.000	17.484	4.203	72.727
Care Home	1.613	0.735	4.813	1	0.028	5.018	1.188	21.205
Hospice	2.524	0.945	7.137	1	0.008	12.474	1.959	79.442
Constant	-4.369	0.712	37.707	1	0.000	0.013		

xxviii. Right place to die by COD



Likelihood that Hospital was felt to be the right place to die, by COD, England

COD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
PD			29.833	5	0.000			
Cancer	0.079	0.132	0.358	1	0.550	1.082	0.835	1.403
CVD	-0.085	0.132	0.415	1	0.519	0.919	0.709	1.189
Other	-0.053	0.131	0.162	1	0.687	0.948	0.733	1.227
PSP	0.053	0.689	0.006	1	0.938	1.055	0.273	4.073
MSA	-0.912	1.077	0.717	1	0.397	0.402	0.049	3.317
Constant	-1.034	0.130	63.107	1	0.000	0.356		

Likelihood that a Care Home was felt to be the right place to die, by COD,

COD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
PD			163.308	5	0.000			
Cancer	0.756	0.156	23.430	1	0.000	2.129	1.568	2.892
CVD	0.329	0.156	4.424	1	0.035	1.389	1.023	1.886
Other	0.111	0.153	0.528	1	0.468	1.117	0.828	1.508
PSP	0.173	0.765	0.051	1	0.821	1.189	0.265	5.323
MSA	1.154	0.830	1.931	1	0.165	3.170	0.623	16.134
Constant	-2.252	0.150	224.933	1	0.000	0.105		

Likelihood that Home was felt to be the right place to die, by COD, England 2012-

COD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
PD			107.179	5	0.000			
Cancer	0.743	0.715	1.078	1	0.299	2.101	0.517	8.536
CVD	1.638	0.714	5.259	1	0.022	5.145	1.269	20.866
Other	1.211	0.716	2.862	1	0.091	3.358	0.825	13.663
PSP	-16.933	12710.133	0.000	1	0.999	0.000	0.000	
MSA	-16.933	20096.485	0.000	1	0.999	0.000	0.000	
Constant	-4.270	0.712	35.958	1	0.000	0.014		

Likelihood that Hospice was felt to be the right place to die, by COD, England

COD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
PD			6.600	4	0.159			
Cancer	-1.062	0.632	2.823	1	0.093	0.346	0.100	1.193
CVD	-1.807	0.753	5.754	1	0.016	0.164	0.037	0.718
Other	-1.255	0.677	3.440	1	0.064	0.285	0.076	1.074
PSP	-19.529	23205.422	0.000	1	0.999	0.000	0.000	
MSA	-1.674	0.629	7.079	1	0.008	0.188		

xxix. Kept informed and had time to discuss care

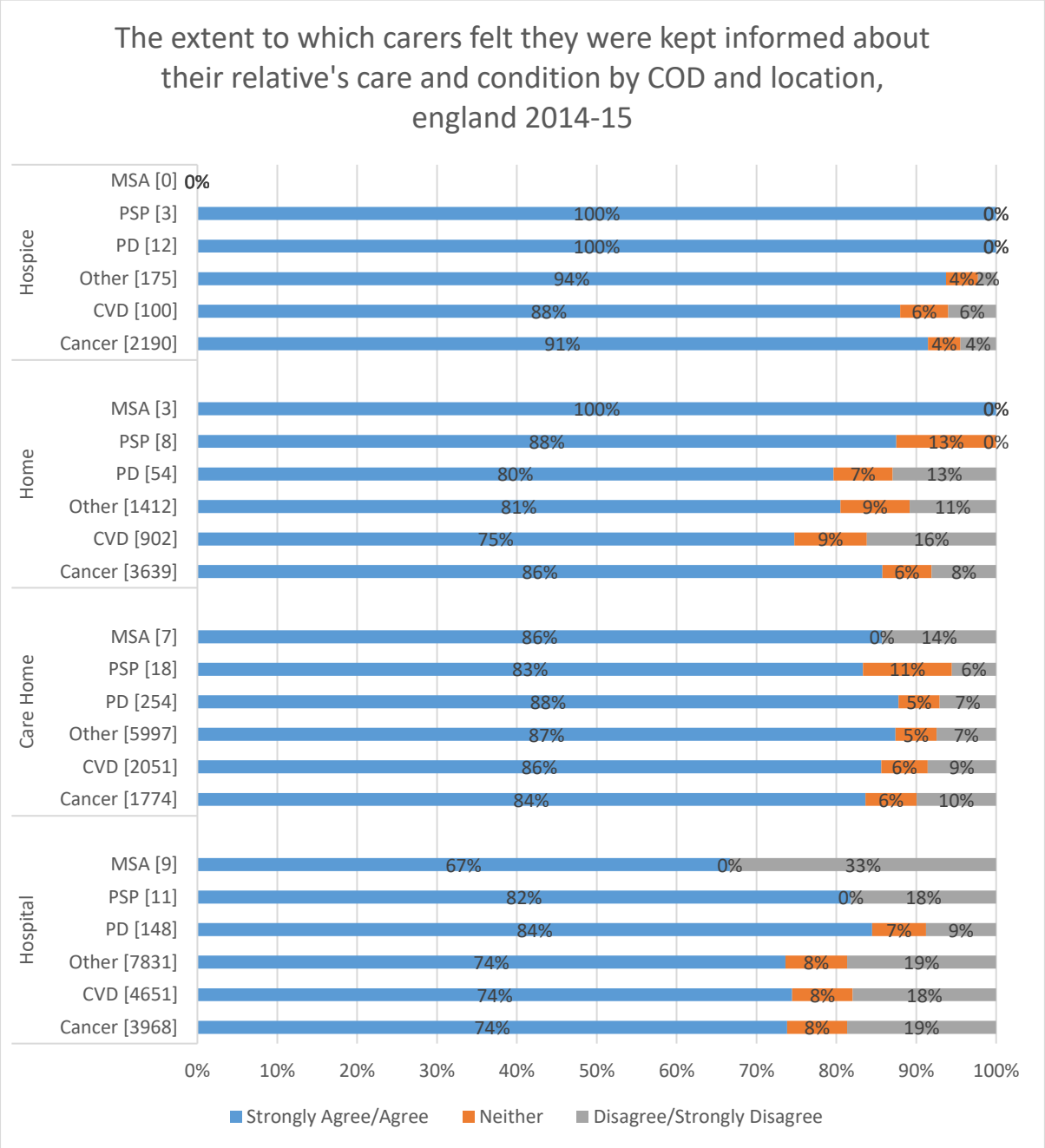
Likelihood of carer of person dying from PD/PSP/MSA strongly agreeing/agreeing to being kept informed about care, by location, England 2014-15

POD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
	Hospital			2.272	3	0.518			
	Care Home	-0.332	0.275	1.463	1	0.226	0.717	0.419	1.229
	Home	0.124	0.381	0.106	1	0.745	1.132	0.537	2.388
	Hospice	-19.593	10377.780	0.000	1	0.998	0.000	0.000	
	Constant	-1.609	0.207	60.440	1	0.000	0.200		

Likelihood of carer of person dying from PD/PSP/MSA strongly agreeing/agreeing to having enough time to discuss care, by location, England 2014-15

POD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
	Hospital			3.072	3	0.381			
	Care Home	-0.338	0.254	1.767	1	0.184	0.713	0.434	1.174
	Home	0.173	0.352	0.240	1	0.624	1.188	0.596	2.370
	Hospice	-19.846	10377.780	0.000	1	0.998	0.000	0.000	
	Constant	-1.356	0.192	49.745	1	0.000	0.258		

xxx. Carers kept informed by COD and location



Likelihood that carer strongly agreed/agreed that they were kept informed when their relative died in hospital, by COD, England 2014-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			9.886	5	0.079			
	Cancer	0.656	0.230	8.163	1	0.004	1.928	1.229	3.024
	CVD	0.623	0.229	7.377	1	0.007	1.864	1.189	2.923
	Other	0.667	0.228	8.524	1	0.004	1.948	1.245	3.047
	PSP	0.189	0.814	0.054	1	0.817	1.208	0.245	5.954
	MSA	1.000	0.743	1.812	1	0.178	2.717	0.634	11.648
	Constant	-1.693	0.227	55.667	1	0.000	0.184		

a. Variable(s) entered on step 1: COD.

Likelihood that carer strongly agreed/agreed that they were kept informed when their relative died in a care home, by COD, England 2014-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			18.145	5	0.003			
	Cancer	0.341	0.202	2.838	1	0.092	1.406	0.946	2.089
	CVD	0.189	0.202	0.881	1	0.348	1.208	0.814	1.795
	Other	0.035	0.196	0.033	1	0.856	1.036	0.706	1.520
	PSP	0.364	0.661	0.303	1	0.582	1.439	0.394	5.254
	MSA	0.181	1.097	0.027	1	0.869	1.199	0.140	10.293
	Constant	-1.973	0.192	105.966	1	0.000	0.139		

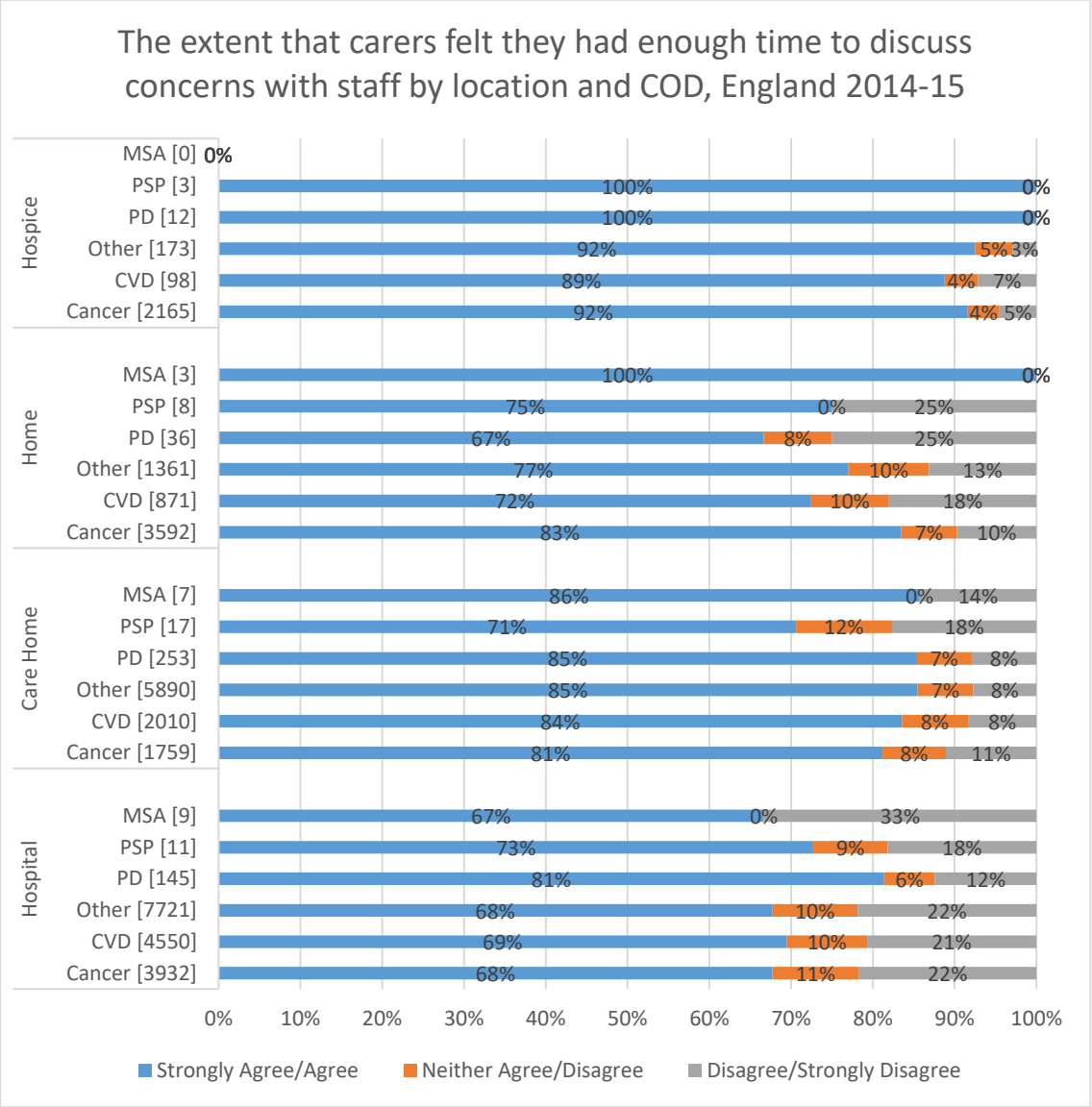
a. Variable(s) entered on step 1: COD.

Likelihood that carer strongly agreed/agreed that they were kept informed when their relative died in their own home, by COD, England 2014-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			68.106	5	0.000			
	Cancer	-0.433	0.341	1.608	1	0.205	0.649	0.332	1.266
	CVD	0.279	0.346	0.650	1	0.420	1.322	0.671	2.608
	Other	-0.056	0.345	0.026	1	0.871	0.945	0.481	1.857
	PSP	-0.583	1.121	0.270	1	0.603	0.558	0.062	5.027
	MSA	-19.840	23205.422	0.000	1	0.999	0.000	0.000	
	Constant	-1.363	0.338	16.280	1	0.000	0.256		

a. Variable(s) entered on step 1: COD.

xxxi. Carers had time to discuss by COD and location



Likelihood that carer strongly agreed/agreed that they had enough time to discuss issues with staff when their relative died in hospital, by COD, England 2014-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			16.043	5	0.007			
	Cancer	0.734	0.216	11.531	1	0.001	2.083	1.364	3.181
	CVD	0.652	0.216	9.119	1	0.003	1.918	1.257	2.928
	Other	0.735	0.215	11.733	1	0.001	2.087	1.370	3.178
	PSP	0.494	0.710	0.484	1	0.486	1.639	0.408	6.588
	MSA	0.782	0.739	1.120	1	0.290	2.185	0.514	9.293
	Constant	-1.475	0.213	47.794	1	0.000	0.229		

a. Variable(s) entered on step 1: COD.

Likelihood that carer strongly agreed/agreed that they had enough time to discuss issues with staff when their relative died in a care home, by COD, England 2014-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			22.099	5	0.001			
	Cancer	0.302	0.188	2.586	1	0.108	1.353	0.936	1.956
	CVD	0.141	0.188	0.560	1	0.454	1.151	0.796	1.663
	Other	-0.006	0.182	0.001	1	0.974	0.994	0.696	1.419
	PSP	0.889	0.561	2.508	1	0.113	2.432	0.810	7.308
	MSA	-0.027	1.095	0.001	1	0.980	0.973	0.114	8.316
	Constant	-1.764	0.178	98.335	1	0.000	0.171		

a. Variable(s) entered on step 1: COD.

Likelihood that carer strongly agreed/agreed that they had enough time to discuss issues with staff when their relative died in their own home, by COD, England 2014-15

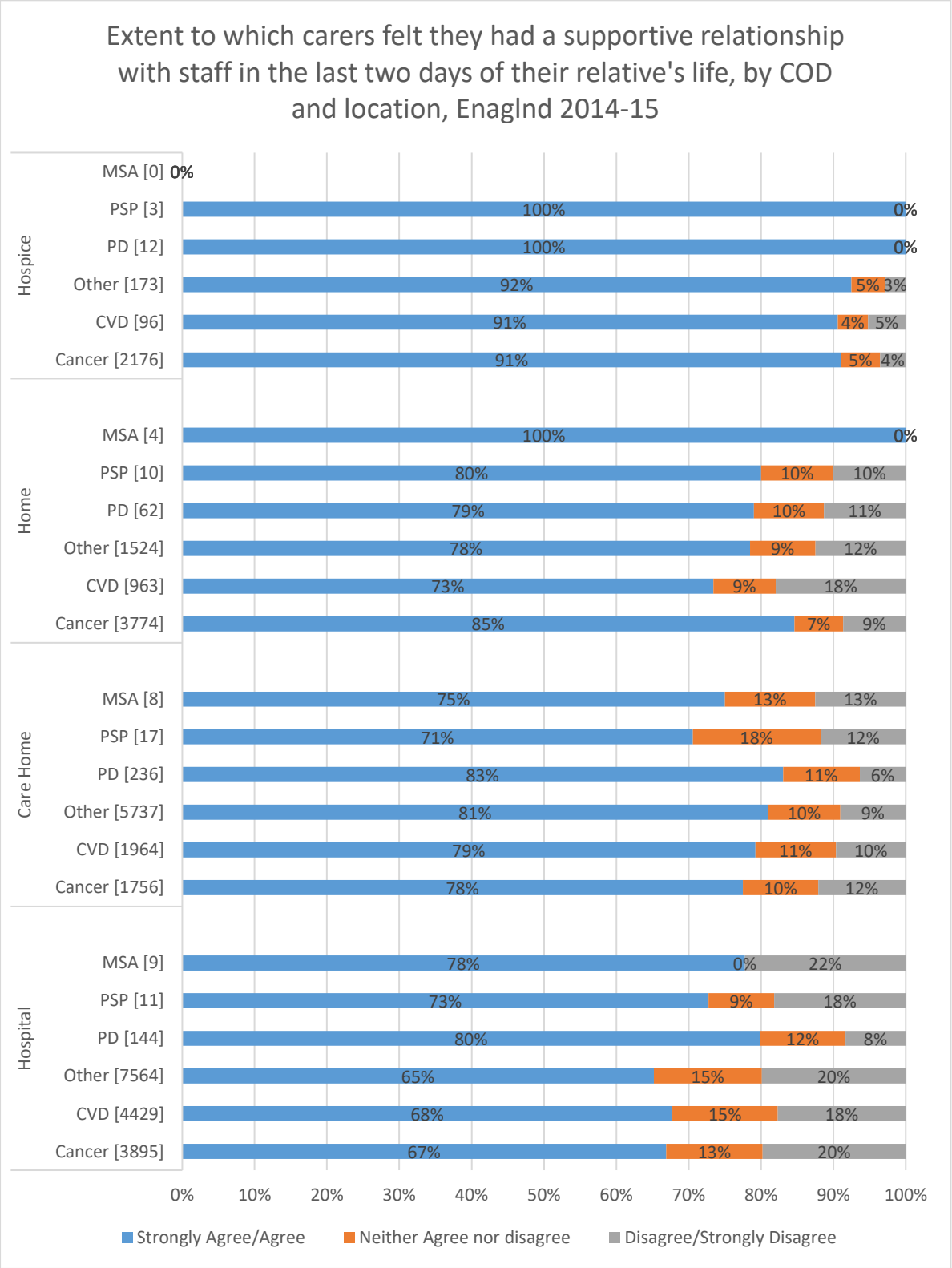
COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			68.968	5	0.000			
	Cancer	-0.926	0.356	6.746	1	0.009	0.396	0.197	0.797
	CVD	-0.274	0.362	0.572	1	0.449	0.761	0.374	1.545
	Other	-0.515	0.359	2.056	1	0.152	0.597	0.295	1.208
	PSP	-0.405	0.890	0.208	1	0.649	0.667	0.117	3.813
	MSA	-20.510	23205.422	0.000	1	0.999	0.000	0.000	
	Constant	-0.693	0.354	3.844	1	0.050	0.500		

xxxii. Carers had a supportive relationship with staff in the last 2 days of life

Likelihood of carer of person dying from PD/PSP/MSA strongly agreeing/agreeing to having a supportive relationship with staff in the last two days, by POD, England 2014-15

POD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
								Lower	Upper
	Hospital			0.288	3	0.962			
	Care Home	-0.133	0.249	0.284	1	0.594	0.875	0.537	1.427
	Home	-0.062	0.347	0.032	1	0.859	0.940	0.477	1.855
	Hospice	-19.862	10377.780	0.000	1	0.998	0.000	0.000	
	Constant	-1.341	0.193	48.478	1	0.000	0.262		

xxxiii. Carers had a supportive relationship with staff in the last 2 days of life by COD and POD



Likelihood of carer agreeing that they had a supportive relationship with staff in the last 2 days of their relative's life when POD was hospital, by COD

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			20.728	5	0.001			
	Cancer	0.675	0.211	10.272	1	0.001	1.964	1.300	2.967
	CVD	0.636	0.210	9.149	1	0.002	1.889	1.251	2.852
	Other	0.750	0.209	12.841	1	0.000	2.116	1.404	3.189
	PSP	0.397	0.708	0.314	1	0.575	1.487	0.371	5.958
	MSA	0.125	0.828	0.023	1	0.880	1.133	0.223	5.745
	Constant	-1.378	0.208	43.954	1	0.000	0.252		

a. Variable(s) entered on step 1: COD.

Likelihood of carer agreeing that they had a supportive relationship with staff in the last 2 days of their relative's life when POD was Care Home, by COD

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			13.303	5	0.021			
	Cancer	0.352	0.183	3.716	1	0.054	1.422	0.994	2.034
	CVD	0.251	0.182	1.892	1	0.169	1.285	0.899	1.836
	Other	0.141	0.177	0.641	1	0.423	1.152	0.815	1.629
	PSP	0.714	0.560	1.625	1	0.202	2.042	0.681	6.117
	MSA	0.491	0.835	0.345	1	0.557	1.633	0.318	8.387
	Constant	-1.589	0.173	83.904	1	0.000	0.204		

a. Variable(s) entered on step 1: COD.

Likelihood of carer agreeing that they had a supportive relationship with staff in the last 2 days of their relative's life when POD was their own Home, by COD

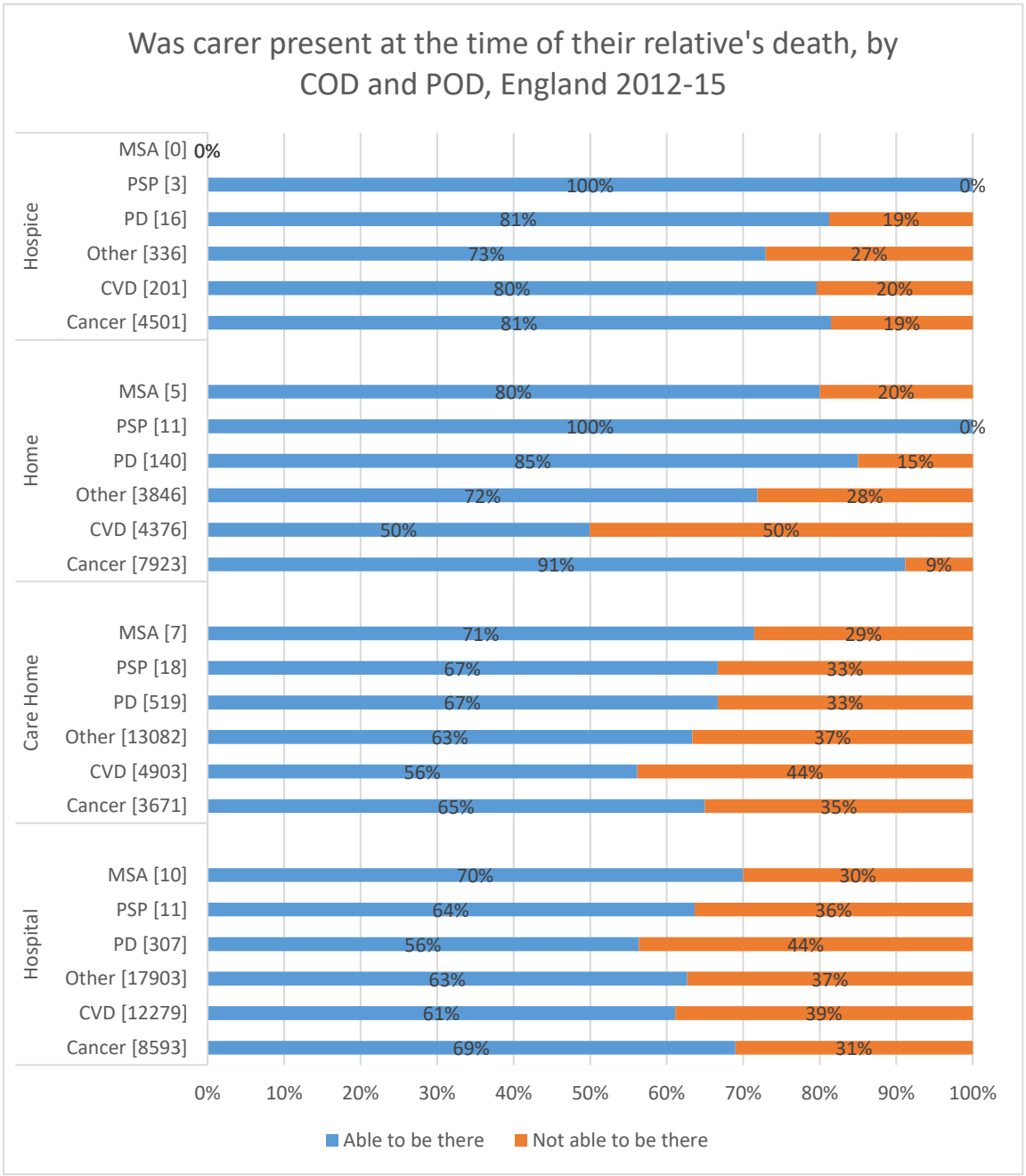
COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			73.575	5	0.000			
	Cancer	-0.377	0.315	1.431	1	0.232	0.686	0.370	1.272
	CVD	0.311	0.320	0.942	1	0.332	1.365	0.728	2.557
	Other	0.033	0.318	0.011	1	0.917	1.034	0.554	1.928
	PSP	-0.059	0.850	0.005	1	0.944	0.942	0.178	4.985
	MSA	-19.876	20096.485	0.000	1	0.999	0.000	0.000	
	Constant	-1.327	0.312	18.089	1	0.000	0.265		

xxxiv. Carer present at time of death

Likelihood that a carer of a person who died from PD/PSP/MSA was able to be present at the time of their relative's death, by POD, England 2012-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	Hospital			39.056	3	0.000			
	Care Home	-0.414	0.144	8.255	1	0.004	0.661	0.499	0.877
	Home	-1.524	0.256	35.558	1	0.000	0.218	0.132	0.359
	Hospice	-1.392	0.639	4.743	1	0.029	0.249	0.071	0.870
	Constant	-0.282	0.112	6.409	1	0.011	0.754		

xxxv. Carer present at time of death by COD



Likelihood of carer being present when their relative in died in a hospital by COD, England 2012-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			152.848	5	0.000			
	Cancer	-0.544	0.117	21.467	1	0.000	0.580	0.461	0.731
	CVD	-0.197	0.117	2.865	1	0.091	0.821	0.653	1.032
	Other	-0.263	0.116	5.137	1	0.023	0.769	0.612	0.965
	PSP	-0.304	0.637	0.228	1	0.633	0.738	0.212	2.572
	MSA	-0.592	0.700	0.716	1	0.398	0.553	0.140	2.180
	Constant	-0.255	0.115	4.928	1	0.026	0.775		

a. Variable(s) entered on step 1: cod.

Likelihood of carer being present when their relative in died in a Care Home by COD, England 2012-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			99.694	5	0.000			
	Cancer	0.074	0.099	0.559	1	0.455	1.077	0.887	1.309
	CVD	0.445	0.097	20.856	1	0.000	1.561	1.289	1.889
	Other	0.146	0.095	2.359	1	0.125	1.157	0.961	1.393
	PSP	0.000	0.509	0.000	1	1.000	1.000	0.369	2.710
	MSA	-0.223	0.842	0.070	1	0.791	0.800	0.154	4.165
	Constant	-0.693	0.093	55.412	1	0.000	0.500		

a. Variable(s) entered on step 1: cod.

Likelihood of carer being present when their relative in died at Home by COD, England 2012-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			2218.323	5	0.000			
	Cancer	-0.601	0.240	6.270	1	0.012	0.548	0.343	0.878
	CVD	1.737	0.239	53.013	1	0.000	5.682	3.560	9.070
	Other	0.797	0.239	11.077	1	0.001	2.218	1.388	3.546
	PSP	-19.468	12118.636	0.000	1	0.999	0.000	0.000	
	MSA	0.348	1.143	0.093	1	0.761	1.417	0.151	13.306
	Constant	-1.735	0.237	53.708	1	0.000	0.176		

a. Variable(s) entered on step 1: cod.

Likelihood of carer being present when their relative in died in a Hospice by COD, England 2012-15

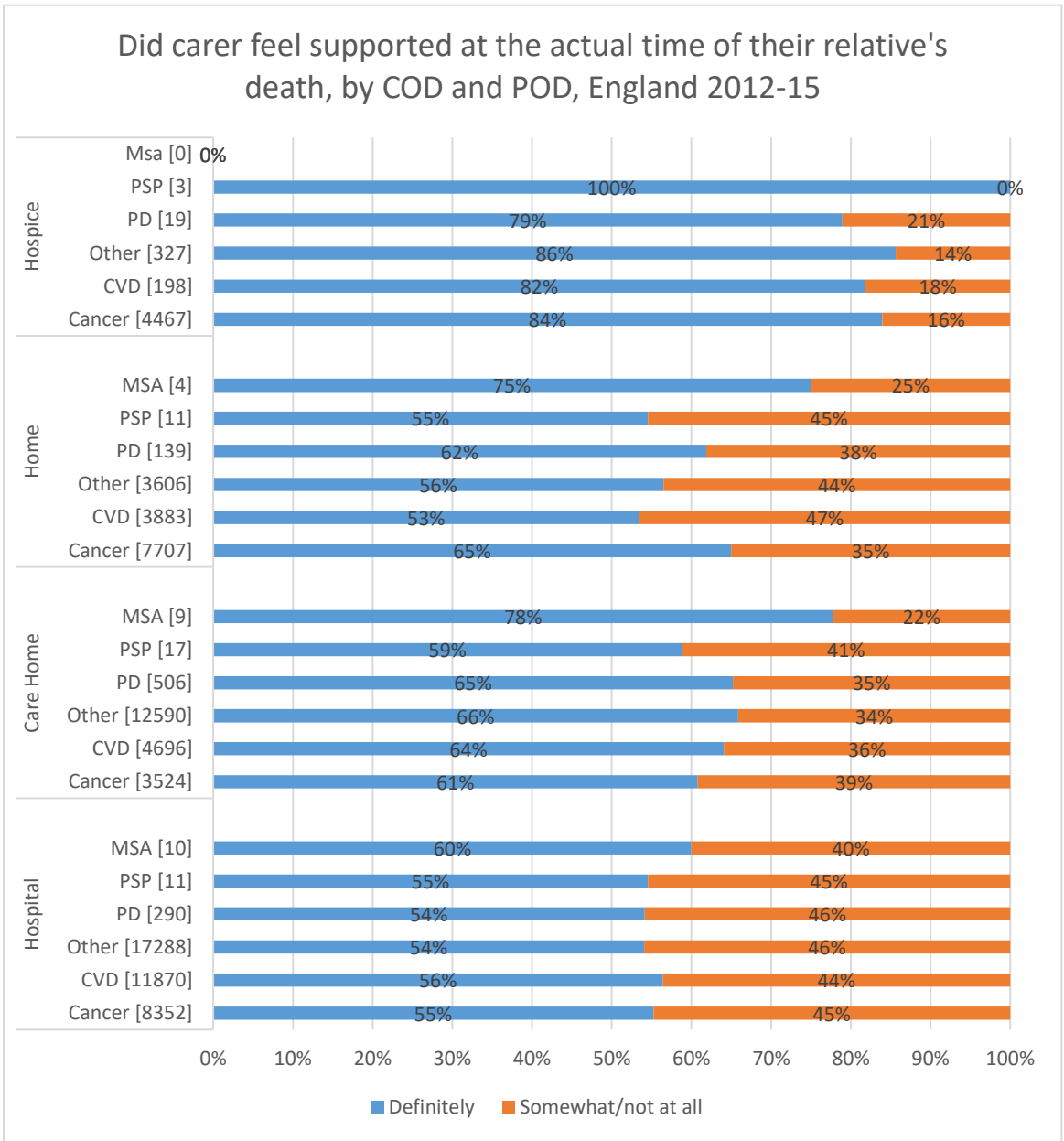
		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			14.725	4	0.005			
	Cancer	-0.015	0.642	0.001	1	0.982	0.986	0.280	3.466
	CVD	0.105	0.664	0.025	1	0.875	1.110	0.302	4.080
	Other	0.476	0.652	0.533	1	0.466	1.610	0.448	5.779
	PSP	-19.737	23205.422	0.000	1	0.999	0.000	0.000	
	Constant	-1.466	0.641	5.241	1	0.022	0.231		

xxxvi. Support at actual time of death for PD/PSP/MSA carers by POD England 2012-15

Likelihood of carers of those who died from PD/PSP/MSA feeling they were definitely supported at the time of death by POD, England 2012-15

POD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	Hospital			13.308	3	0.004			
	Care Home	-0.455	0.146	9.739	1	0.002	0.635	0.477	0.844
	Home	-0.302	0.201	2.260	1	0.133	0.739	0.498	1.096
	Hospice	-1.330	0.564	5.554	1	0.018	0.264	0.087	0.799
	Constant	-0.174	0.114	2.338	1	0.126	0.840		

xxxvii. Support at actual time of death by COD and POD, England 2012-15



Likelihood of carer feeling supported in the hospital at the actual time of their relative's death, by COD, England 2012-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			15.885	5	0.007			
	Cancer	-0.045	0.120	0.139	1	0.710	0.956	0.756	1.210
	CVD	-0.092	0.119	0.594	1	0.441	0.912	0.722	1.152
	Other	0.003	0.119	0.000	1	0.982	1.003	0.794	1.266
	PSP	-0.016	0.617	0.001	1	0.979	0.984	0.294	3.296
	MSA	-0.240	0.656	0.133	1	0.715	0.787	0.217	2.848
	Constant	-0.166	0.118	1.982	1	0.159	0.847		

Likelihood of carer feeling supported in the care home at the actual time of their relative's death, by COD, England 2012-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			32.652	5	0.000			
	Cancer	0.190	0.100	3.661	1	0.056	1.210	0.995	1.470
	CVD	0.051	0.098	0.269	1	0.604	1.052	0.868	1.275
	Other	-0.028	0.095	0.088	1	0.767	0.972	0.807	1.172
	PSP	0.272	0.502	0.294	1	0.588	1.313	0.491	3.508
	MSA	-0.624	0.807	0.598	1	0.439	0.536	0.110	2.606
	Constant	-0.629	0.093	45.356	1	0.000	0.533		

Likelihood of carer feeling supported at home at the actual time of their relative's death, by COD, England 2012-15

COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			167.207	5	0.000			
	Cancer	-0.134	0.176	0.579	1	0.447	0.875	0.619	1.235
	CVD	0.345	0.178	3.781	1	0.052	1.412	0.997	2.000
	Other	0.223	0.178	1.573	1	0.210	1.250	0.882	1.771
	PSP	0.302	0.630	0.229	1	0.632	1.352	0.393	4.650
	MSA	-0.615	1.168	0.277	1	0.599	0.541	0.055	5.335
	Constant	-0.484	0.175	7.683	1	0.006	0.616		

Likelihood of carer feeling supported in the hospice at the actual time of their relative's death, by COD, England 2012-15

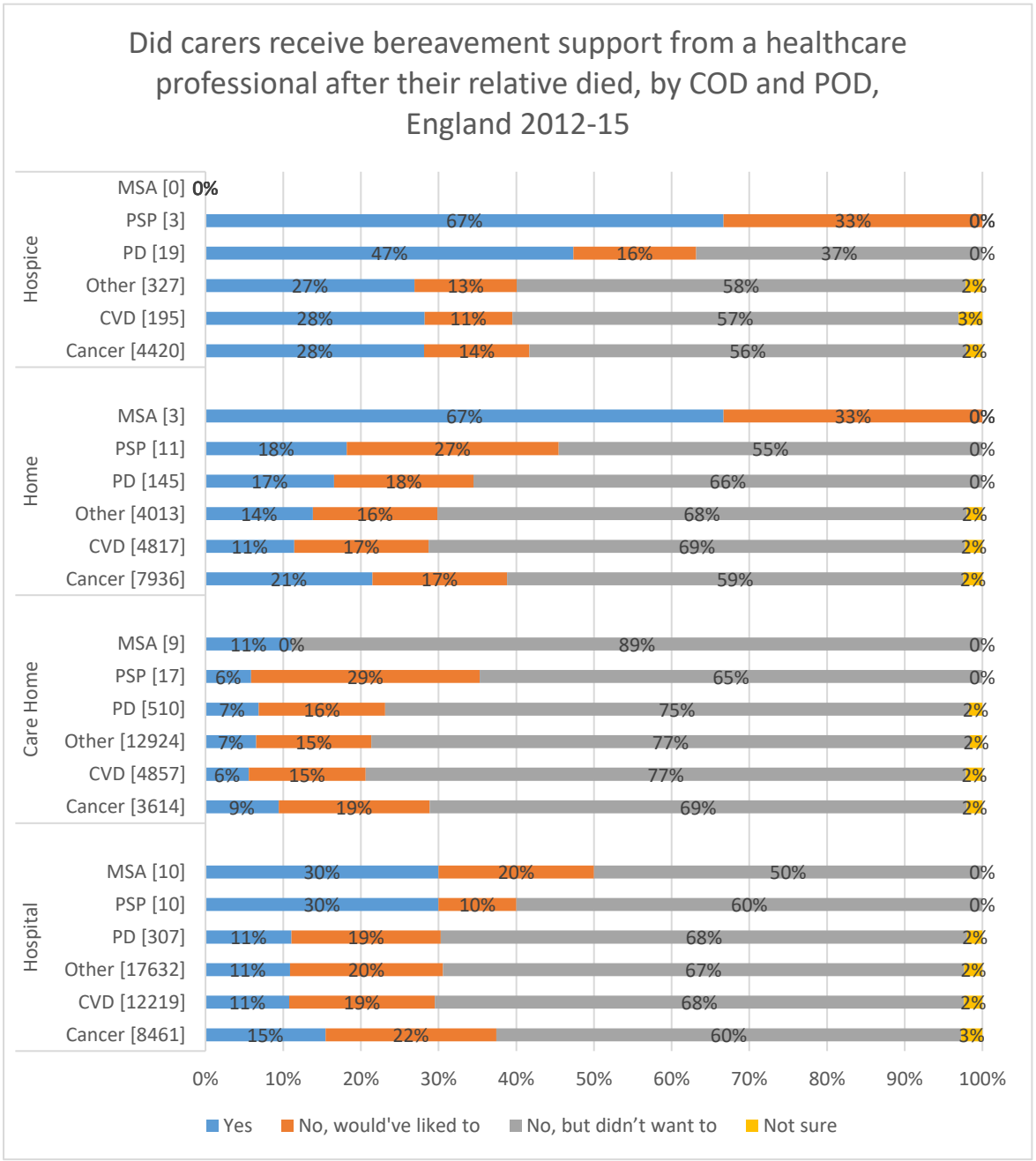
COD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	PD			1.697	4	0.791			
	Cancer	-0.331	0.564	0.344	1	0.557	0.718	0.238	2.170
	CVD	-0.182	0.592	0.095	1	0.758	0.833	0.261	2.660
	Other	-0.463	0.584	0.627	1	0.428	0.629	0.200	1.979
	PSP	-19.881	23205.422	0.000	1	0.999	0.000	0.000	
	Constant	-1.322	0.563	5.517	1	0.019	0.267		

xxxviii. Bereavement support for PD/PSP/MSA carers by POD, England 2012-15

Likelihood that PD/PSP/MSA carers had spoken to a health professional after their relative's death, by POD, England 2012-15

POD		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
	Hospice			38.157	3	0.000			
	Hospital	1.999	0.459	18.952	1	0.000	7.385	3.002	18.166
	Care Home	2.602	0.459	32.102	1	0.000	13.486	5.483	33.171
	Home	1.595	0.476	11.231	1	0.001	4.926	1.939	12.516
	Constant	0.000	0.426	0.000	1	1.000	1.000		

xxxix. Bereavement support by COD and POD, England 2012-15



Likelihood of carer receiving bereavement support from a healthcare professional if their relative died in hospital, by COD, England 2012-15

COD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
PD			142.021	5	0.000			
Cancer	-0.394	0.185	4.548	1	0.033	0.675	0.470	0.969
CVD	0.025	0.184	0.018	1	0.893	1.025	0.714	1.472
Other	0.018	0.184	0.009	1	0.924	1.018	0.710	1.459
PSP	-1.214	0.714	2.892	1	0.089	0.297	0.073	1.203
MSA	-1.214	0.714	2.892	1	0.089	0.297	0.073	1.203
Constant	2.061	0.182	128.095	1	0.000	7.853		

Likelihood of carer receiving bereavement support from a healthcare professional if their relative died in a care home, by COD, England 2012-15

COD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
PD			52.333	5	0.000			
Cancer	-0.347	0.184	3.536	1	0.060	0.707	0.493	1.015
CVD	0.221	0.186	1.413	1	0.235	1.248	0.866	1.797
Other	0.059	0.179	0.108	1	0.743	1.060	0.747	1.506
PSP	0.184	1.046	0.031	1	0.860	1.202	0.155	9.328
MSA	-0.509	1.075	0.225	1	0.636	0.601	0.073	4.941
Constant	2.589	0.175	218.185	1	0.000	13.314		

Likelihood of carer receiving bereavement support from a healthcare professional if their relative died at home, by COD, England 2012-15

COD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
PD			251.520	5	0.000			
Cancer	-0.353	0.225	2.454	1	0.117	0.703	0.452	1.093
CVD	0.406	0.228	3.165	1	0.075	1.500	0.960	2.346
Other	0.190	0.228	0.695	1	0.405	1.209	0.773	1.891
PSP	-0.114	0.813	0.020	1	0.889	0.893	0.181	4.392
MSA	-2.311	1.245	3.445	1	0.063	0.099	0.009	1.138
Constant	1.618	0.223	52.414	1	0.000	5.042		

Likelihood of carer receiving bereavement support from a healthcare professional if their relative died in a hospice, by COD, England 2012-15

COD	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
PD			5.010	4	0.286			
Cancer	0.803	0.461	3.035	1	0.082	2.231	0.904	5.504
CVD	0.785	0.487	2.604	1	0.107	2.193	0.845	5.691
Other	0.864	0.476	3.292	1	0.070	2.373	0.933	6.034
PSP	-0.799	1.308	0.373	1	0.542	0.450	0.035	5.843
Constant	0.105	0.459	0.053	1	0.819	1.111		

Appendix K: Background summary of each ambition

i. Ambition 1

Ambition 1 explains that people who are dying fear having their wishes ignored and overridden. It explains that people want to be involved in their care, and decisions made about them, and should be helped with this, in terms of information and support. Though talking about the future might be difficult, it explains that people want to repeated opportunities to decide on whether they are ready to discuss the future or not. When death seems imminent it explains that this should be identified and communicated, alongside any uncertainty that exists.

ii. Ambition 2/4

Ambition 2 explains that that care is harder to access for people in rural areas and that there are unacceptable inequalities regarding palliative/end of life care for those with dementia and non-malignant conditions. It also points out there are unacceptable variation in access to pain control across different care settings.

Ambition 4 explains that fragmented care and a lack of co-ordinated care cause distress and points out that poor communication between services is not good enough. It suggests social care should be provided regardless of financial circumstances and that palliative services should be available 24/7. Lastly it points out that access to, and trust in, community services is paramount to providing care outside of hospitals, where most people prefer to be

iii. Ambition 3

This ambition explains that many people approaching the end of life are fearful of being in pain and that dying is a source of emotional distress and social isolation. It explains that pain is something that can be relived through expert palliative care and that palliative care from an early stage improves quality of life. It also indicates that witnessing a peaceful death can help adjustment in bereavement.

iv. Ambition 5

The background to this ambition is that looking after the dying is difficult and often staff are not supported to undertake their roles in terms of education and training. If staff are

unsupported then providing compassionate care becomes harder. In order to make dying at home more achievable paid carers need to be provided with enough support as well; something which is currently lacking.

v. Ambition 6

The background to this ambition is related to the denial of dying thesis. It states that death and dying are not health or social care events but effect every person and community, despite this people feel disconnected when going through the experience. There should be more public openness about dying and communities should be able to provide support, with the voluntary sector already having a huge, yet undervalued role in shaping communities.

Chapter 9 References

1. NICE NIfCE. Improving Supportive and Pallitaive Care for Adults with Cancer: The Manual. London: NICE; 2004.

2. WHO WHO. Palliative Care 2018 [Available from: http://www.who.int/news-room/fact-sheets/detail/palliative-care.

3. NICE. End of life care for adults: Quality standard [QS13]. London: NICE; 2017.

4. Giles S, Miyasaki J. Palliative stage Parkinson's disease: patient and family experiences of health-care services. Palliative Med. 2009;23(2):120-5.

5. Hasson F, Kernohan WG, McLaughlin M, Waldron M, McLaughlin D, Chambers H, et al. An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease. Palliative Med. 2010;24(7):731-6.

6. Higginson IJ, Gao W, Saleem TZ, Chaudhuri KR, Burman R, McCrone P, et al. Symptoms and Quality of Life in Late Stage Parkinson Syndromes: A Longitudinal Community Study of Predictive Factors. Plos One. 2012;7(11).

7. Hudson PL, Toye C, Kristjanson LJ. Would people with Parkinson's disease benefit from palliative care? Palliative Med. 2006;20(2):87-94.

8. Tuck KK, Brod L, Nutt J, Fromme EK. Preferences of Patients With Parkinson's Disease for Communication About Advanced Care Planning. Am J Hosp Palliat Me. 2015;32(1):68-77.

9. Fox S, Cashell A, Kernohan WG, Lynch M, McGlade C, O'brien T, et al. Palliative care for Parkinson's disease: Patient and carer's perspectives explored through qualitative interview. Palliative medicine. 2017;31(7):634-41.

10. Boersma I, Jones J, Carter J, Bekelman D, Miyasaki J, Kutner J, et al. Parkinson disease patients' perspectives on palliative care needs What are they telling us? Neurology: Clinical Practice. 2016;6(3):209-19.

11. Saleem TZ, Higginson IJ, Chaudhuri KR, Martin A, Burman R, Leigh PN. Symptom prevalence, severity and palliative care needs assessment using the Palliative Outcome Scale: A cross-sectional study of patients with Parkinson's disease and related neurological conditions. Palliative Med. 2013;27(8):722-31.

12. Goy ER, Carter J, Ganzini L. Neurologic disease at the end of life: Caregiver descriptions of Parkinson disease and amyotrophic lateral sclerosis. J Palliat Med. 2008;11(4):548-54.

13. Dayal AM, Jenkins ME, Jog MS, Kimpinski K, MacDonald P, Gofton TE. Palliative Care Discussions in Multiple System Atrophy: A Retrospective Review. Canadian Journal of Neurological Sciences. 2017;44(3):276-82.

14. Bükki J, Nübling G, Lorenzl S. Managing advanced progressive supranuclear palsy and corticobasal degeneration in a palliative care unit: admission triggers and outcomes. American Journal of Hospice and Palliative Medicine®. 2016;33(5):477-82.

15. Lee MA, Prentice WM, Hildreth AJ, Walker RW. Measuring symptom load in Idiopathic Parkinson's disease. Parkinsonism Relat D. 2007;13(5):284-9.

16. Schrag A, Geser F, Stampfer-Kountchev M, Seppi K, Sawires M, Köllensperger M, et al. Health-related quality of life in multiple system atrophy. Movement Disord. 2006;21(6):809-15.

17. Schrag A, Selai C, Davis J, Lees AJ, Jahanshahi M, Quinn N. Health-related quality of life in patients with progressive supranuclear palsy. Movement disorders: official journal of the Movement Disorder Society. 2003;18(12):1464-9.

18. Wiblin L, Lee M, Burn D. Palliative care and its emerging role in Multiple System Atrophy and Progressive Supranuclear Palsy. Parkinsonism Relat D. 2017;34:7-14.

19. Snell K, Pennington S, Lee M, Walker R. The place of death in Parkinson's disease. Age Ageing. 2009;38(5):617-9.

20. Sleeman KE, Ho YK, Verne J, Glickman M, Silber E, Gao W, et al. Place of death, and its relation with underlying cause of death, in Parkinson's disease, motor neurone disease, and multiple sclerosis: A population-based study. Palliative Med. 2013;27(9):840-6.

21. Pubic Health England. Deaths Associated with Neurological Conditions in England 2001 to 2014. London: Public Health Englans; 2018 January 2018.

22. Pollock K. Is home always the best and preferred place of death? bmj. 2015;351:h4855.

23. NHS England. End of life care: NHS England workstreams 2018 [Available from: https://www.england.nhs.uk/ourwork/ltc-op-eolc/improving-eolc/nhs-england-workstreams/.

24. Office of National Statistics. National Survey of Bereaved People (VOICES): England, 2015. Office of National Statisics,; 2016.

25. Roger KS, Medved M. Living with Parkinson's disease—managing identity together. International Journal of Qualitative Studies on Health and Well-being. 2010;5(2):5129.

26. Gibb WRG, Lees AJ. The Relevance of the Lewy Body to the Pathogenesis of Idiopathic Parkinsons-Disease. J Neurol Neurosur Ps. 1988;51(6):745-52.

27. von Campenhausen S, Bornschein B, Wick R, Botzel K, Sampaio C, Poewe W, et al. Prevalence and incidence of Parkinson's disease in Europe. Eur Neuropsychopharm. 2005;15(4):473-90.

28. Schrag A, Ben-Shlomo Y, Quinn NP. Prevalence of progressive supranuclear palsy and multiple system atrophy: a cross-sectional study. Lancet. 1999;354(9192):1771-5.

29. Tison F, Yekhlef F, Chrysostome V, Sourgen C. Prevalence of multiple system atrophy. Lancet. 2000;355(9202):495-6.

30. Vanacore N. Epidemiological evidence on multiple system atrophy. J Neural Transm. 2005;112(12):1605-12.

31. Vanacore N, Bonifati V, Colosimo C, Fabbrini G, De Michele G, Marconi R, et al. Epidemiology of progressive supranuclear palsy. Neurol Sci. 2001;22(1):101-3.

32. Vanacore N, Bonifati V, Fabbrini G, Colosimo C, De Michele G, Marconi R, et al. Epidemiology of multiple system atrophy. Neurol Sci. 2001;22(1):97-9.

33. Moore DJ, West AB, Dawson VL, Dawson TM. Molecular pathophysiology of Parkinson's disease. Annu Rev Neurosci. 2005;28:57-87.

34. Fanciulli A, Wenning GK. Multiple-system atrophy. New England Journal of Medicine. 2015;372(3):249-63.

35. Höglinger GU, Respondek G, Stamelou M, Kurz C, Josephs KA, Lang AE, et al. Clinical diagnosis of progressive supranuclear palsy: the movement disorder society criteria. Movement Disord. 2017;32(6):853-64.

36. Litvan I, Agid Y, Calne D, Campbell G, Dubois B, Duvoisin RC, et al. Clinical research criteria for the diagnosis of progressive supranuclear palsy (Steele-Richardson-Olszewski syndrome): Report of the NINDS-SPSP International Workshop. Neurology. 1996;47(1):1-9.

37. Gilman S, Wenning GK, Low PA, Brooks DJ, Mathias CJ, Trojanowski JQ, et al. Second consensus statement on the diagnosis of multiple system atrophy. Neurology. 2008;71(9):670-6.

38. Goetz CG, Poewe W, Rascol O, Sampaio C, Stebbins GT, Counsell C, et al. Movement disorder society task force report on the Hoehn and Yahr staging scale: Status and recommendations. Movement Disorders. 2004;19(9):1020-8.

39. Goetz CG, Poewe W, Rascol O, Sampaio C, Stebbins GT, Fahn S, et al. The Unified Parkinson's Disease Rating Scale (UPDRS): Status and recommendations. Movement Disord. 2003;18(7):738-50.

40. Chaudhuri KR, Healy DG, Schapira AHV. Non-motor symptoms of Parkinson's disease: diagnosis and management. Lancet Neurol. 2006;5(3):235-45.

41. Goetz CG, Tilley BC, Shaftman SR, Stebbins GT, Fahn S, Martinez-Martin P, et al. Movement Disorder Society-Sponsored Revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS): Scale Presentation and Clinimetric Testing Results. Movement Disord. 2008;23(15):2129-70.

42. Golbe LI, Ohman-Strickland PA. A clinical rating scale for progressive supranuclear palsy. Brain. 2007;130(6):1552-65.

43. Wenning GK, Tison F, Seppi K, Sampaio C, Diem A, Yekhlef F, et al. Development and validation of the unified multiple system atrophy rating scale (UMSARS). Movement Disord. 2004;19(12):1391-402.

44. MacMahon DG, Thomas S. Practical approach to quality of life in Parkinson's disease: the nurse's role. J Neurol. 1998;245:S19-S22.

45. Williams DR, Lees AJ. Progressive supranuclear palsy: clinicopathological concepts and diagnostic challenges. Lancet Neurol. 2009;8(3):270-9.

46. Low PA, Reich SG, Jankovic J, Shults CW, Stern MB, Novak P, et al. Natural history of multiple system atrophy in the USA: a prospective cohort study. Lancet Neurol. 2015;14(7):710-9.

47. Xu J, Gong DD, Man CF, Fan Y. Parkinson's disease and risk of mortality: meta-analysis and systematic review. Acta Neurol Scand. 2014;129(2):71-9.

48. Macleod AD, Taylor KSM, Counsell CE. Mortality in Parkinson's Disease: A Systematic Review and Meta-analysis. Movement Disord. 2014;29(13):1615-22.

49. Savica R, Grossardt BR, Bower JH, Ahlskog JE, Boeve BF, Graff-Radford J, et al. Survival and causes of death among people with clinically diagnosed synucleinopathies with parkinsonism: a population-based study. JAMA neurology. 2017;74(7):839-46.

50. NHS Choices. [updated 02/04/2014. Available from: http://www.nhs.uk/Conditions/Parkinsons-disease/Pages/Introduction.aspx.

51. NHS Choices. [updated 04/12/2013. Available from: http://www.nhs.uk/Conditions/Progressive-supranuclear-palsy/Pages/Introduction.aspx.

52. UK Ps. [Available from: http://www.parkinsons.org.uk/content/how-does-parkinsons-progress.

53. Foundation MJF. [Available from: https://www.michaeljfox.org/understanding-parkinsons/i-have-got-what.php.

54. Benshlomo Y, Marmot MG. Survival and Cause of Death in a Cohort of Patients with Parkinsonism - Possible Clues to Etiology. J Neurol Neurosur Ps. 1995;58(3):293-9.

55. Pennington S, Snell K, Lee M, Walker R. The cause of death in idiopathic Parkinson's disease. Parkinsonism Relat D. 2010;16(7):434-7.

56. Fall PA, Saleh A, Fredrickson M, Olsson JE, Granerus AK. Survival time, mortality, and cause of death in elderly patients with Parkinson's disease: A 9-year follow-up. Movement Disord. 2003;18(11):1312-6.

57. Hobson P, Meara J. Mortality and quality of death certification in a cohort of patients with Parkinson's disease and matched controls in North Wales, UK at 18 years: a community-based cohort study. Bmj Open. 2018;8(2):e018969.

58. Nath U, Thomson R, Wood R, Ben-Shlomo Y, Lees A, Rooney C, et al. Population based mortality and quality of death certification in progressive supranuclear palsy (Steele-Richardson-Olszewski syndrome). J Neurol Neurosur Ps. 2005;76(4):498-502.

59. Shimohata T, Ozawa T, Nakayama H, Tomita M, Shinoda H, Nishizawa M. Frequency of nocturnal sudden death in patients with multiple system atrophy. J Neurol. 2008;255(10):1483-5.

60. Silber MH, Levine S. Stridor and death in multiple system atrophy. Movement Disord. 2000;15(4):699-704.

61. Papapetropoulos S, Tuchman A, Laufer D, Papatsoris AG, Papapetropoulos N, Mash DC. Causes of death in multiple system atrophy. J Neurol Neurosur Ps. 2007;78(3):327-9.

62. Zhang L, Cao B, Zou Y, Wei Q-Q, Ou R, Liu W, et al. Causes of death in chinese patients with multiple system atrophy. Aging and disease. 2018;9(1):102.

63. Moscovich M, Boschetti G, Moro A, Teive HA, Hassan A, Munhoz RP. Death certificate data and causes of death in patients with parkinsonism. Parkinsonism Relat D. 2017;41:99-103.

64. Organization WH. Cancer pain relief and palliative care: report of a WHO expert committee [meeting held in Geneva from 3 to 10 July 1989]. 1990.

65. WHO. [Available from: http://www.who.int/cancer/palliative/definition/en/.

66. Strupp J, Kunde A, Galushko M, Voltz R, Golla H. Severely Affected by Parkinson Disease: The Patient's View and Implications for Palliative Care. The American journal of hospice & palliative care. 2018;35(4):579-85.

67. PSP Association. [Available from: www.pspasssociation.org.uk.

68. Trust M. [Available from: www.msatrust.org.uk.

69. Oliver D, Borasio GD, Caraceni A, de Visser M, Grisold W, Lorenzl S, et al. Palliative care in chronic and progressive neurological disease: summary of a consensus review. European Journal of Palliative Care. 2016;23(5):232-5.

70. Fox S, Cashell A, Kernohan WG, Lynch M, McGlade C, O'Brien T, et al. Interviews with Irish healthcare workers from different disciplines about palliative care for people with Parkinson's disease: a definite role but uncertainty around terminology and timing. Bmc Palliat Care. 2016;15(1):15.

71. CASP CASP. CASP Qualitative checklist 2018.

72. Wiblin L. Quality of life and palliative care need in multiple system atrophy and progressive supranuclear palsy: a pilot study using quantitative and qualitative methods. Newcastle: Newcastle; 2017.

73. Badger NJ, Frizelle D, Adams D, Johnson MJ. Impact of specialist palliative care on coping with Parkinson's disease: patients and carers. BMJ supportive & palliative care. 2018;8(2):180-3.

74. Veronese S, Gallo G, Valle A, Cugno C, Chiò A, Calvo A, et al. Specialist palliative care improves the quality of life in advanced neurodegenerative disorders: NE-PAL, a pilot randomised controlled study. BMJ supportive & palliative care. 2017;7(2):164-72.

75. Hepgul N, Gao W, Evans CJ, Jackson D, van Vliet LM, Byrne A, et al. Integrating palliative care into neurology services: what do the professionals say? BMJ supportive & palliative care. 2017:bmjspcare-2017-001354.

76. Wilson R, Hepgul N, Saha RA, Higginson IJ, Gao W. Symptom dimensions in people affected by long-term neurological conditions: a factor analysis of a patient-centred palliative care outcome symptom scale. Scientific reports. 2019;9(1):4972.

77. National P, End of Life Care P. Ambitions for palliative and end of life care: a national framework for local action 2015–2020. NHS England London; 2015.

78. Stein GL, Fineberg IC. Advance care planning in the USA and UK: a comparative analysis of policy, implementation and the social work role. British Journal of Social Work. 2013;43(2):233-48.

79. Addington-Hall J, McPherson C. After-death interviews with surrogates/bereaved family members: Some issues of validity. J Pain Symptom Manag. 2001;22(3):784-90.

80. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? Soc Sci Med. 2003;56(1):95-109.

81. Sebring K, Shattuck J, Berk J, Boersma I, Sillau S, Kluger BM. Assessing the validity of proxy caregiver reporting for potential palliative care outcome measures in Parkinson's disease. Palliative medicine. 2018;32(9):1522-8.

82. Department of Health. End of Life Care Strategy – promoting high quality care for all adults at the end of life. London: Department of Health; 2008.

83. Neuberger J, Guthrie C, Aaronovitch D. More care, less pathway: a review of the Liverpool Care Pathway. Department of Health, Crown Copyright. 2013.

84. Addingtonhall J, Mccarthy M. Regional Study of Care for the Dying - Methods and Sample Characteristics. Palliative Med. 1995;9(1):27-35.

85. Hunt KJ, Shlomo N, Richardson A, Addington-Hall J. VOICES redesign and testing to inform a national end of life care survey. 2011.

86. Statistics OoN. National Surevy of Bereaved People, 2014. 2015.

87. Statistics OoN. National Survey of Bereaved People, 2013. 2014.

88. Ariès P. Western attitudes toward death: from the Middle Ages to the present: JHU Press; 1975.

89. Elias N. Loneliness of the Dying: Bloomsbury Publishing; 2001.

90. Exley C, Allen D. A critical examination of home care: end of life care as an illustrative case. Soc Sci Med. 2007;65(11):2317-27.

91. Howarth G. Death and dying: A sociological introduction: Polity; 2007.

92. Elias N. The Loneliness of the Dying, translated by Edmund Jephcott. Oxford: Blackwell; 1985.

93. Illich I. Limits to medicine: Marion Boyars; 1976.

94. Kübler-Ross E. On death and dying: Routledge; 1973.

95. Glaser BG, Strauss AL. Awareness of dying: Transaction Publishers; 1966.

96. Clark D. Between hope and acceptance: the medicalisation of dying. Bmj. 2002;324(7342):905-7.

97. Network NEoLCI. What We Know Now 2014. Public Health England London; 2015.

98. Office of National Statistics, editor. National Bereavement Survey (VOICES) QMI2016.

99. Statistics OoN. National Survey of Bereaved People (VOICES) by NHS Area Team (England), 2012 to 2013. 2015.

100. Gomes B, Calanzani N, Higginson IJ. Local preferences and place of death in regions within England 2010. London: Cicely Saunders International. 2011.

101. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. Bmc Palliative Care. 2013;12.

102. Ryder S. A time and a place: what people want at the end of life. London, UK: Demos. 2013.

103. Royal college of Physicians NCfPC, British Society of Rehabilitation Medicine, British Geriatrics Society, Alzheimer's Society, Royal College of Nursing, Royal College of Psychiatrists, Help the Aged, Royal College of General Practitioner. Advance care planning. London: RCP; 2009.

104. National End of Life Care Programme NA, National Council for Palliative Care department of Health. End of life care in long term neurological conditions: a framework for implementation. 2011.

105. Pollock K, Wilson E. Care and communication between health professionals and patients affected by severe or chronic illness in community care settings: a qualitative study of care at the end of life. 2015.

106. Preston H, Fineberg IC, Callagher P, Mitchell DJ. The Preferred Priorities for Care document in Motor Neurone Disease: Views of bereaved relatives and carers. Palliative Med. 2012;26(2):132-8.

107. Whitehead B, O'Brien MR, Jack BA, Mitchell D. Experiences of dying, death and bereavement in motor neurone disease: A qualitative study. Palliative Med. 2012;26(4):368-78.

108. LACDP LAftCoDP. One Chance to get it right. 2014.

109. Hart B, Sainsbury P, Short S. Whose dying? A sociological critique of the'good death'. Mortality. 1998;3(1):65-77.

110. Seale C, Addington-Hall J, McCarthy M. Awareness of dying: prevalence, causes and consequences. Soc Sci Med. 1997;45(3):477-84.

111. Copp G, Field D. Open awareness and dying: the use of denial and acceptance as coping strategies by hospice patients. NT Research. 2002;7(2):118-27.

112. Johnson B, Gray R. A history of philosophical and theoretical issues for mixed methods research. In: Tashakkori A, Teddlie C, editors. SAGE handbbok of Mixed Methods in Social & Behavioural Research. 2nd ed. USA: SAGE Publications, Inc; 2010. p. 69-94.

113. Gorard S. Research deisgn, as independednt of methods. In: Tashakkori A, Teddlie C, editors. Sage Handbook of Mixed Methods in Social & Behavioural Research. Second ed: SAGE; 2010. p. 237-52.

114. Crotty M. The foundations of social research: Meaning and perspective in the research process: Sage; 1998.

115. Broom A, Willis E. Competing paradigms and health research. Researching health: qualitative, quantitative and mixed methods. 2007:16-30.

116. Doyle L, Brady A-M, Byrne G. An overview of mixed methods research. Journal of Research in Nursing. 2009;14(2):175-85.

117. Johnson RB, Onwuegbuzie AJ. Mixed methods research: A research paradigm whose time has come. Educational researcher. 2004;33(7):14-26.

118. Bryman A. The debate about quantitative and qualitative research: a question of method or epistemology? British journal of Sociology. 1984:75-92.

119. Morgan DL. Paradigms Lost and Pragmatism Regained Methodological Implications of Combining Qualitative and Quantitative Methods. Journal of Mixed Methods Research. 2007;1(1):48-76.

120. Howe KR. Against the quantitative-qualitative incompatibility thesis or dogmas die hard. Educational researcher. 1988;17(8):10-6.

121. Biesta G. Pragmatism and the philosophical foundations of mixed methods research. Sage handbook of mixed methods in social and behavioral research. 2010;2:95-118.

122. Tashakkori A, Teddlie C. Sage handbook of mixed methods in social & behavioral research: Sage; 2010.

123. Greene JC. Is mixed methods social inquiry a distinctive methodology? Journal of Mixed Methods Research. 2008;2(1):7-22.

124. Greene JC, Caracelli VJ, Graham WF. Toward a conceptual framework for mixed-method evaluation designs. Educational evaluation and policy analysis. 1989;11(3):255-74.

125. Hunt KJ, Addington-Hall J.M. A Toolkit for the Design and Planning of Locally-led VOICES Surveys. Southampton: University of Southampton; 2011.

126. ICO. Personal data in research: a view from the ICO 2014 [Available from: https://ico.org.uk/media/about-the-ico/events-and-webinars/1043335/personal-data-in-research-vicky-cetinkaya-20141203.pdf.

127. Rodham K, Gavin J. The ethics of using the internet to collect qualitative research data. Research Ethics. 2006;2(3):92-7.

128. Small N, Barnes S, Gott M, Payne S, Parker C, Seamark D, et al. Dying, death and bereavement: a qualitative study of the views of carers of people with heart failure in the UK. Bmc Palliat Care. 2009;8(1):6.

129. Bentley B, O'Connor M. Conducting Research Interviews with Bereaved Family Carers: When Do We Ask? J Palliat Med. 2015;18(3):241-5.

130. Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. J Clin Oncol. 2010;28(29):4457-64.

131. Crowther J, Wilson KC, Horton S, Lloyd-Williams M. Compassion in healthcare–lessons from a qualitative study of the end of life care of people with dementia. Journal of the Royal Society of Medicine. 2013;106(12):492-7.

132. Mason M, editor Sample size and saturation in PhD studies using qualitative interviews. Forum qualitative Sozialforschung/Forum: qualitative social research; 2010.

133. Braun V, Clarke V. Successful qualitative research: A practical guide for beginners: sage; 2013.

134. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Quality & Quantity. 2017:1-15.

135. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology. 2006;3(2):77-101.

136. Young AJ, Rogers A, Dent L, Addington-Hall JM. Experiences of hospital care reported by bereaved relatives of patients after a stroke: a retrospective survey using the VOICES questionnaire. J Adv Nurs. 2009;65(10):2161-74.

137. Schwartz SJ, Luyckx K, Vignoles VL. Handbook of identity theory and research: Springer; 2011.

138. Walter T. Facing death without tradition. Contemporary issues in the sociology of death, dying and disposal: Springer; 1996. p. 193-204.

139. Bury M. Chronic illness as biographical disruption. Sociology of health & illness. 1982;4(2):167-82.

140. Charmaz K. Loss of self: a fundamental form of suffering in the chronically ill. Sociology of health & illness. 1983;5(2):168-95.

141. Locock L, Ziebland S, Dumelow C. Biographical disruption, abruption and repair in the context of motor neurone disease. Sociology of health & illness. 2009;31(7):1043-58.

142. Small JA, Geldart K, Gutman G, Scott MAC. The discourse of self in dementia. Ageing & Society. 1998;18(3):291-316.

143. Sabat SR. 18 Mind, meaning, and personhood in dementia: the effects of positioning. Dementia mind, meaning, and the person. 2006:287.

144. Sweeting H, Gilhooly M. Dementia and the phenomenon of social death. Sociology of Health & Illness. 1997;19(1):93-117.

145. Caddell LS, Clare L. The impact of dementia on self and identity: A systematic review. Clinical psychology review. 2010;30(1):113-26.

146. Foster C, Herring J. Identity, personhood and the law: Springer; 2017.

147. Martin SC. Relational issues within couples coping with Parkinson's disease: implications and ideas for family-focused care. Journal of family nursing. 2016;22(2):224-51.

148. McLaughlin D, Hasson F, Kernohan WG, Waldron M, McLaughlin M, Cochrane B, et al. Living and coping with Parkinson's disease: perceptions of informal carers. Palliative Med. 2011;25(2):177-82.

149. Mulkay M, Ernst J. The changing profile of social death. European Journal of Sociology/Archives Européennes de Sociologie. 1991;32(1):172-96.

150. Sudnow D. Passing on: The social organization of dying: Prentice-Hall; 1967.

151. Bramley N, Eatough V. The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study. Psychology & Health. 2005;20(2):223-35.

152. Timmermans S. Social Death as Self-Fulfilling Prophecy: David Sudnow's Passing On Revisited. Sociological Quarterly. 1998;39(3):453-72.

153. Chan HM. Sharing death and dying: advance directives, autonomy and the family. Bioethics. 2004;18(2):87-103.

154. Taylor C. The person. The category of the person: Anthropology, philosophy, history. 1985:257-81.

155. Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, Balaguer A. The wish to hasten death: a review of clinical studies. Psycho-Oncology. 2011;20(8):795-804.

156. Lorenzl S, Butzhammer L, Nuebling G, editors. Assisted suicide of patients with parkinsonian syndromes in Switzerland-the need of early and continuous integration of palliative care and dignitiy therapy. Movement Disord; 2017: WILEY 111 RIVER ST, HOBOKEN 07030-5774, NJ USA.

157. Kummer A, Cardoso F, Teixeira AL. Suicidal ideation in Parkinson's disease. CNS spectrums. 2009;14(8):431-6.

158. Nazem S, Siderowf AD, Duda JE, Brown GK, Ten Have T, Stern MB, et al. Suicidal and death ideation in Parkinson's disease. Movement disorders: official journal of the Movement Disorder Society. 2008;23(11):1573-9.

159. Kostić VS, Pekmezović T, Tomić A, Ječmenica-Lukić M, Stojković T, Špica V, et al. Suicide and suicidal ideation in Parkinson's disease. Journal of the neurological sciences. 2010;289(1-2):40-3.

160. Dumitru MM. Suicidal ideation in Parkinson's disease. Parkinsonism Relat D. 2016;22:e56.

161. Schrag A, Sheikh S, Quinn NP, Lees AJ, Selai C, Mathias C, et al. A comparison of depression, anxiety, and health status in patients with progressive supranuclear palsy and multiple system atrophy. Movement Disord. 2010;25(8):1077-81.

162. Connolly S, Galvin M, Hardiman O. End-of-life management in patients with amyotrophic lateral sclerosis. The Lancet Neurology. 2015;14(4):435-42.

163. Stutzki R, Weber M, Reiter-Theil S, Simmen U, Borasio GD, Jox RJ. Attitudes towards hastened death in ALS: a prospective study of patients and family caregivers. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration. 2014;15(1-2):68-76.

164. Albert SM, Rabkin JG, Del Bene ML, Tider T, O'Sullivan I, Rowland LP, et al. Wish to die in end-stage ALS. Neurology. 2005;65(1):68-74.

165. Rabkin JG, Goetz R, Factor-Litvak P, Hupf J, McElhiney M, Singleton J, et al. Depression and wish to die in a multicenter cohort of ALS patients. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration. 2015;16(3-4):265-73.

166. Maessen M, Veldink JH, Onwuteaka-Philipsen BD, De Vries JM, Wokke JHJ, Van Der Wal G, et al. Trends and determinants of end-of-life practices in ALS in the Netherlands. Neurology. 2009;73(12):954-61.

167. Maessen M, Veldink JH, Onwuteaka-Philipsen BD, Hendricks HT, Schelhaas HJ, Grupstra HF, et al. Euthanasia and physician-assisted suicide in amyotrophic lateral sclerosis: a prospective study. Journal of neurology. 2014;261(10):1894-901.

168. Freeman S, Smith TF, Neufeld E, Fisher K, Ebihara S. The wish to die among palliative home care clients in Ontario, Canada: A cross-sectional study. BMC palliative care. 2016;15(1):24.

169. Rurup ML, Pasman HRW, Goedhart J, Deeg DJH, Kerkhof A, Onwuteaka-Philipsen BD. Understanding why older people develop a wish to die. Crisis. 2011.

170. Kim YA, Bogner HR, Brown GK, Gallo JJ. Chronic medical conditions and wishes to die among older primary care patients. The International Journal of Psychiatry in Medicine. 2006;36(2):183-98.

171. Breitbart W. Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients With Cancer. Journal of the American Medical Association. 2000;284(22):2907-11.

172. Saleem TZ, Higginson IJ, Chaudhuri KR, Martin A, Burman R, Leigh PN. Symptom prevalence, severity and palliative care needs assessment using the Palliative Outcome Scale: A cross-sectional study of patients with Parkinson's disease and related neurological conditions. Palliative Medicine. 2013;27(8):722-31.

173. Ohnsorge K, Gudat H, Rehmann-Sutter C. Intentions in wishes to die: analysis and a typology–A report of 30 qualitative case studies of terminally ill cancer patients in palliative care. Psycho-Oncology. 2014;23(9):1021-6.

174. Ohnsorge K, Gudat H, Rehmann-Sutter C. What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. Bmc Palliat Care. 2014;13(1):38.

175. Rabkin J, Goetz R, Murphy JM, Factor-Litvak P, Mitsumoto H. Cognitive impairment, behavioral impairment, depression, and wish to die in an ALS cohort. Neurology. 2016;87(13):1320-8.

176. Charmaz K. The body, identity, and self: Adapting to impairment. Sociological Quarterly. 1995;36(4):657-80.

177. Fegg MJ, Kögler M, Abright C, Hensler M, Lorenzl S. Meaning in life in patients with progressive supranuclear palsy. American Journal of Hospice and Palliative Medicine®. 2014;31(5):543-7.

178. Fegg MJ, Kögler M, Brandstätter M, Jox R, Anneser J, Haarmann-Doetkotte S, et al. Meaning in life in patients with amyotrophic lateral sclerosis. Amyotrophic Lateral Sclerosis. 2010;11(5):469-74.

179. Locock L, Brown JB. 'All in the same boat'? Patient and carer attitudes to peer support and social comparison in motor neurone disease (MND). Soc Sci Med. 2010;71(8):1498-505.

180. Care Quality C. A different ending: Addressing inequalities in end of life care. Newcastle upon Tyne: CQC. 2016.

181. Care Quality C. Cracks in the Pathway. London: CQC. 2014.

182. Hughes RA, Sinha A, Higginson I, Down K, Leigh PN. Living with motor neurone disease: lives, experiences of services and suggestions for change. Health & social care in the community. 2005;13(1):64-74.

183. Rare Disease Uk. Living with a rare condition: the effect on mental health. London; 2018.

184. Joachim G, Acorn S. Life with a rare chronic disease: the scleroderma experience. J Adv Nurs. 2003;42(6):598-606.

185. EURORDIS. Juggling care and daily life: the balancing act of the rare disease community. A rare barometer survey. . Paris; 2017.

186. Budych K, Helms TM, Schultz C. How do patients with rare diseases experience the medical encounter? Exploring role behavior and its impact on patient–physician interaction. Health policy. 2012;105(2-3):154-64.

187. Uk Rare Diseases Policy Board. Second Progress Report from the UK Rare Diseases Policy Board. London; 2018.

188. House of Commons Health Committee. 5th report - End of Life Care HC805. 2015.

189. Health Do. Our commitment to you for end of life care. The Government Response to the Review of Choice in End of Life Care. London: DH; 2016.

190. Department of Health. The Uk Stretegy for Rare Disease. 2013.

191. Muir E. The Rare Reality–An Insight Into The Patient And Family Experience Of Rare Disease. London: Genetic Alliance UK. 2016:22-6.

192. Parkinson's UK. UK Parkinson's Audit - transforming care. parkinson's uk; 2017.

193. Calvert M, Pall H, Hoppitt T, Eaton B, Savill E, Sackley C. Health-related quality of life and supportive care in patients with rare long-term neurological conditions. Quality of Life Research. 2013;22(6):1231-8.

194. NAO NAO. Investigation into NHS continuing healthcare funding. 2017.

195. Department of Health. The National Framework for NHS continuing healthcare and NHS-funded nursing care October 2018 (revised). Department of Health London; 2018.

196. Moos S. CONTINUING HEALTHCARE FOR THE ELDERLY. Community Practitioner. 2018;91(4):30-2.

197. Boland J, Johnson MJ. End-of-life care for non-cancer patients. British Medical Journal Publishing Group; 2013.

198. Dixon J, King D, Matosevic T, Clark M, Knapp M. Equity in the provision of palliative care in the UK: review of evidence. 2015.

199. The National Council for Palliative Care. National Survey of Patient Activity Data for Specialist Palliative Care Services: Minimum Data Set (MDS) Summary Report for the year 2014-15. London: NCPC; 2016.

200. Allsop MJ, Ziegler LE, Mulvey MR, Russell S, Taylor R, Bennett MI. Duration and determinants of hospice-based specialist palliative care: a national retrospective cohort study. Palliative medicine. 2018;32(8):1322-33.

201. Field D, Addington-Hall J. Extending specialist palliative care to all? Soc Sci Med. 1999;48(9):1271-80.

202. Heyland DK, Dodek P, Rocker G, Groll D, Gafni A, Pichora D, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. Cmaj. 2006;174(5):627-33.

203. Teno JM, Casey VA, Welch LC, Edgman-Levitan S. Patient-focused, family-centered end-of-life medical care: views of the guidelines and bereaved family members. J Pain Symptom Manag. 2001;22(3):738-51.

204. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. Jama. 2000;284(19):2476-82.

205. Virdun C, Luckett T, Davidson PM, Phillips J. Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. Palliative medicine. 2015;29(9):774-96.

206. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, et al. Family perspectives on end-of-life care at the last place of care. Jama. 2004;291(1):88-93.

207. The RCN's definition of dignity [press release]. 2008.

208. Traxler P. Challenges in the transfer of patients from hospice to nursing home: a model for future partnership. BMJ supportive & palliative care. 2011;1(2):261-.

209. Kübler-Ross E. On death and dying: What the dying have to teach doctors, nurses, clergy and their own families: Taylor & Francis; 2009.

210. Mamo L. Death and dying: confluences of emotion and awareness. Sociology of Health & Illness. 1999;21(1):13-36.

211. Timmermans S. Dying of awareness: the theory of awareness contexts revisited. Sociology of health & illness. 1994;16(3):322-39.

212. Richfield EW, Jones EJS, Alty JE. Palliative care for Parkinson's disease: a summary of the evidence and future directions. Palliative Med. 2013;27(9):805-10.

213. Broom A. Dying: A social perspective on the end of life: Routledge; 2016.

214. De Lau LML, Breteler MMB. Epidemiology of Parkinson's disease. The Lancet Neurology. 2006;5(6):525-35.

215. Pinter B, Diem-Zangerl A, Wenning GK, Scherfler C, Oberaigner W, Seppi K, et al. Mortality in Parkinson's disease: a 38-year follow-up study. Movement Disord. 2015;30(2):266-9.

216. michael J fox foundation. [Available from: https://www.michaeljfox.org/understanding-parkinsons/living-with-pd/topic.php?prognosis.

217. Parkinson's UK. [Available from: https://www.parkinsons.org.uk/information-and-support/how-does-parkinsons-progress.

218. Aldred H, Gott M, Gariballa S. Advanced heart failure: impact on older patients and informal carers. J Adv Nurs. 2005;49(2):116-24.

219. Barclay S, Momen N, Case-Upton S, Kuhn I, Smith E. End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis. Br J Gen Pract. 2011;61(582):e49-e62.

220. Strachan PH, Ross H, Rocker GM, Dodek PM, Heyland DK, Network CRatEoL. Mind the gap: Opportunities for improving end-of-life care for patients with advanced heart failure. Canadian Journal of Cardiology. 2009;25(11):635-40.

221. Bentley B, O'Connor M. The End-of-Life experiences of people with motor neuron disease: Family carers' perspectives. J Palliat Med. 2016;19(8):857-62.

222. Finucane TE. How gravely ill becomes dying: A key to end-of-life care. JAMA. 1999;282(17):1670-2.

223. Seymour J, Gott M, Bellamy G, Ahmedzai SH, Clark D. Planning for the end of life:: the views of older people about advance care statements. Soc Sci Med. 2004;59(1):57-68.

224. Fried TR, O'Leary JR. Using the experiences of bereaved caregivers to inform patient-and caregiver-centered advance care planning. Journal of general internal medicine. 2008;23(10):1602-7.

225. NHS England. My future wishes: Advance Care Planning (ACP) for people with dementia in all care settings. Redditch; 2018.

226. de Boer ME, Dröes R-M, Jonker C, Eefsting JA, Hertogh CM. Thoughts on the future: the perspectives of elderly people with early-stage Alzheimer's disease and the implications for advance care planning. AJOB Primary Research. 2012;3(1):14-22.

227. Dickinson C, Bamford C, Exley C, Emmett C, Hughes J, Robinson L. Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. International psychogeriatrics. 2013;25(12):2011-21.

228. Churm D. Planning for the Future: Advance Care Planning in Parkinson's Disease: Newcastle University; 2016.

229. Gott M, Seymour J, Bellamy G, Clark D, Ahmedzai S. Older people's views about home as a place of care at the end of life. Palliative Med. 2004;18(5):460-7.

230. Gomes B, Higginson IJ. Where people die (1974—2030): past trends, future projections and implications for care. Palliative Med. 2008;22(1):33-41.

231. Fund K. Transforming our health care system: Ten priorities for commissioners. Revised edition Available at: https://wwww kingsfund org uk/sites/files/kf/field/fieldpublicationfile/10PrioritiesFinal2 pdf (accessed 7 August 2017). 2015.

232. NHS England. About end of life care 2019 [Available from: https://www.england.nhs.uk/eolc/introduction/.

233. Healthwatch Norfolk. 'Thinking ahead' Advance Care Planning. Norfolk; 2016.

234. Fritz Z, Slowther A-M, Perkins GD. Resuscitation policy should focus on the patient, not the decision. Bmj. 2017;356:j813.

235. Tracey v. Cambridge Uni Hospital NHS Foundation Trust and others. EWCA Civ2014. p. 822.

236. Winspear v. City Hospitals Sunderland NHS Foundation Trust. EWHC2015. p. 3250.

237. Lee MA, Brummel-Smith K, Meyer J, Drew N, London MR. Physician orders for life-sustaining treatment (POLST): Outcomes in a PACE Program. Journal of the American Geriatrics Society. 2000;48(10):1219-25.

238. McPHERSON CJ, Wilson KG, Lobchuk MM, Brajtman S. Self-perceived burden to others: patient and family caregiver correlates. Journal of Palliative Care. 2007;23(3):135-42.

239. Seckler AB, Meier DE, Mulvihill M, Paris BEC. Substituted judgment: how accurate are proxy predictions? Annals of internal medicine. 1991;115(2):92-8.

240. Prendergast TJ. Advance care planning: pitfalls, progress, promise. Critical care medicine. 2001;29(2):N34-N9.

241. McPherson CJ, Wilson KG, Murray MA. Feeling like a burden to others: a systematic review focusing on the end of life. Palliative Med. 2007;21(2):115-28.

242. Wendler D, Rid A. Systematic review: the effect on surrogates of making treatment decisions for others. Annals of internal medicine. 2011;154(5):336-46.

243. MND association. End of life: a guide for people with motor neurone disease. Northampton: MNDA; 2017.

244. Field D, Copp G. Communication and awareness about dying in the 1990s. Palliative Med. 1999;13(6):459-68.

245. Sullivan AM, Lakoma MD, Matsuyama RK, Rosenblatt L, Arnold RM, Block SD. Diagnosing and discussing imminent death in the hospital: a secondary analysis of physician interviews. J Palliat Med. 2007;10(4):882-93.

246. Hebert RS, Dang Q, Schulz R. Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: findings from the REACH study. J Palliat Med. 2006;9(3):683-93.

247. Schulz R, Boerner K, Shear K, Zhang S, Gitlin LN. Predictors of complicated grief among dementia caregivers: a prospective study of bereavement. The American journal of geriatric psychiatry. 2006;14(8):650-8.

248. Breen LJ, Aoun SM, O'Connor M, Howting D, Halkett GK. Family caregivers' preparations for death: a qualitative analysis. Journal of pain and symptom management. 2018;55(6):1473-9.

249. Hebert RS, Schulz R, Copeland VC, Arnold RM. Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. Journal of pain and symptom management. 2009;37(1):3-12.

250. Cherlin E, Fried T, Prigerson HG, Schulman-Green D, Johnson-Hurzeler R, Bradley EH. Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said? Journal of palliative medicine. 2005;8(6):1176-85.

251. Lemke MR, Fuchs G, Gemende I, Herting B, Oehlwein C, Reichmann H, et al. Depression and Parkinson's disease. J Neurol. 2004;251(6):vi24-vi7.

252. Burn DJ. Depression in Parkinson's disease. European Journal of Neurology. 2002;9:44-54.

253. Schrag A, Jahanshahi M, Quinn N. What contributes to quality of life in patients with Parkinson's disease? Journal of Neurology, Neurosurgery & Psychiatry. 2000;69(3):308-12.

254. Bomasang-Layno E, Fadlon I, Murray AN, Himelhoch S. Antidepressive treatments for Parkinson's disease: A systematic review and meta-analysis. Parkinsonism Relat D. 2015;21(8):833-42.

255. Starkstein SE, Brockman S. Management of Depression in Parkinson's Disease: A Systematic Review. Movement Disorders Clinical Practice. 2017;4(4):470-7.

256. Mills KA, Greene MC, Dezube R, Goodson C, Karmarkar T, Pontone GM. Efficacy and tolerability of antidepressants in Parkinson's disease: A systematic review and network meta-analysis. International journal of geriatric psychiatry. 2018;33(4):642-51.

257. Benrud-Larson LM, Sandroni P, Schrag A, Low PA. Depressive symptoms and life satisfaction in patients with multiple system atrophy. Movement disorders: official journal of the Movement Disorder Society. 2005;20(8):951-7.

258. Winter Y, Spottke AE, Stamelou M, Cabanel N, Eggert K, Höglinger GU, et al. Health-related quality of life in multiple system atrophy and progressive supranuclear palsy. Neurodegenerative diseases. 2011;8(6):438-46.

259. NICE NIfHaCE. Parkinson's Disease in adults [NG71] London: NICE; 2017 [Available from: https://www.nice.org.uk/guidance/ng71.

260. Compassion in Dying. Starting the Conversation: planning ahead for your treatment and care. In: Dying Ci, editor. London2018.

261. UK Ps. Preparing for end of life. In: UK Ps, editor. London2016.

262. Oliver DJ, Borasio G, Caraceni A, de Visser M, Grisold W, Lorenzl S, et al. A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. European journal of neurology. 2016;23(1):30-8.

263. Hussain J, Adams D, Allgar V, Campbell C. Triggers in advanced neurological conditions: prediction and management of the terminal phase. BMJ supportive & palliative care. 2013:bmjspcare-2012-000389.

264. Health Do. End of Life care in Long Term Neurological Conditions: a Framework for Implementation. NEoLCP London; 2010.

265. Resuscitation Council (UK). ReSPECT 2017 [Available from: https://www.respectprocess.org.uk/.

266. National Bereavement Alliance. A guide to commissioning bereavement services in England. 2017.

267. Lobb EA, Kristjanson LJ, Aoun SM, Monterosso L, Halkett GKB, Davies A. Predictors of complicated grief: A systematic review of empirical studies. Death Studies. 2010;34(8):673-98.

268. Stroebe M, Schut H, Stroebe W. Health outcomes of bereavement. The Lancet. 2007;370(9603):1960-73.

269. Aoun SM, Breen LJ, Howting DA, Rumbold B, McNamara B, Hegney D. Who needs bereavement support? A population based survey of bereavement risk and support need. PloS one. 2015;10(3):e0121101.

270. Aoun SM, Rumbold B, Howting D, Bolleter A, Breen LJ. Bereavement support for family caregivers: The gap between guidelines and practice in palliative care. Plos One. 2017;12(10):e0184750.

271. Parkinson's UK. Peer support service [Available from: https://www.parkinsons.org.uk/information-and-support/peer-support-service.

272. Cruse. Bereaved by Dementia Project 2016-19 [Available from: https://www.cruse.org.uk/wales/dementia.

273. association M. Post bereavement support project [Available from: https://www.mndassociation.org/get-involved/volunteering/volunteer-zone/news-2/post-bereavement-support-project/.

274. Richfield EW. Palliative care in Parkinson's disease: developing a needs assessment tool: University of Hull and the University of York; 2015.

275. Higginson IJ, McCrone P, Hart SR, Burman R, Silber E, Edmonds PM. Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial. J Pain Symptom Manag. 2009;38(6):816-26.

276. Health Education England H. Care Navigation: A Competency Framework. London; 2016.

277. Hudson PL, Schofield P, Kelly B, Hudson R, O'Connor M, Kristjanson LJ, et al. Responding to desire to die statements from patients with advanced disease: recommendations for health professionals. Palliative Med. 2006;20(7):703-10.

278. Zwakhalen SM, Hamers JP, Abu-Saad HH, Berger MP. Pain in elderly people with severe dementia: a systematic review of behavioural pain assessment tools. BMC geriatrics. 2006;6(1):3.

279. Williams OE, Elghenzai S, Subbe C, Wyatt JC, Williams J. The use of telemedicine to enhance secondary care: some lessons from the front line. Future Hospital Journal. 2017;4(2):109-14.

280. Department of Health. The UK Strategy for Rare Diseases. 2013.