Quality end of life care for people with dementia: The views and experiences of family carers

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ACKNOWLEDGMENTS AND AUTHORSHIP STATEMENT

I, Nathan Mark Davies confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

I have worked on the IMPACT study leading Work Package two with Professor Steve Iliffe. The IMPACT study (2011-2015) has developed and implemented a toolkit of quality indicators in eight services that provide palliative care for people with cancer, and or people with dementia. The study has been conducted in five different European countries (England, Germany, Italy, the Netherlands and Norway).

ABSTRACT

Background

Many have reported the difficulty of defining 'quality' with several concepts emerging to characterise quality end of life care. People with dementia have been described as the 'disadvantaged dying' with poor end of life care. Towards the end of life people with dementia cannot report on the care they receive. It is therefore important to talk to carers; however, few have explored the views about end of life care from the carers' perspective.

Aim

To explore the features of 'good' and 'bad' quality end of life care for people with dementia from the perspective of family carers.

Method

1) A systematic review of qualitative studies which explored family carers' views of quality end of life care for people with dementia.

2) A qualitative study with 46 in-depth interviews with carers analysed using thematic analysis methods. Purposive sampling was used to recruit 1) family carers of someone who had recently received a diagnosis of dementia, 2) family carers currently caring for someone with dementia, and 3) bereaved family carers.

Results

Many elements to 'good' care were identified including: tailoring care, attention to the individual, respect and dignity. Participants perceived some basic principles such as compassion were lacking, particularly from nurses. The finer details of care such as clothing and appearance were important manifestations of social identity and personhood. Care for the carer was also important, with carers often being left to act as a care manager and navigate the health and social care systems.

Conclusion

At end of life not everyone with dementia will require input from specialist palliative care services; there are many basic principles to good quality end of life care. This study suggests that end of life care for someone with dementia may not be that different to dementia care in general.

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ABBREVIATIONS AND GLOSSARY

ACP	Advance care planning
EAPC	European Association for Palliative Care
EOLC	End of life care
EOL	End of life
GSF	Gold Standards Framework
IMPACT	Implementation of Quality Indicators in Palliative Care Study
INTERDEM	Early detection and timely INTERvention in DEMentia
LCP	Liverpool Care Pathway
NCPC	National Council for Palliative Care
QOC	Quality of care
QOL	Quality of life
PwD	Person with dementia or people with dementia
WHO	World Health Organisation

CHAPTER 1:QUALITY IN END OF LIFE CARE

1.1   Introduction

This chapter will set the context of quality within health care, discussing the development of the idea of quality over the decades and how quality is viewed today. It will make particular reference to quality in end of life care. It will begin by highlighting the ambiguities of terms used in this field, including palliative care and end of life care and how they relate to one another.

1.2   The construction of the term 'palliative care'

What is often referred to as palliative care is the set of practices or values that were initially developed for people with cancer through the hospice movement in the late 1960's, pioneered in the UK by Dame Cicely Saunders. For many years it has traditionally been thought of as care provided for people with cancer (Field and Addington-Hall, 1999), with both researchers and clinicians focussing on cancer (van der Steen et al., 2014). Only in recent years has it been applied to other patient groups (Addington-Hall and Higginson, 2001). This has been facilitated by the change of the World Health Organisation (WHO) definition in 2002 which declared that palliative care is relevant for all life threatening illnesses (Sepulveda et al., 2002).

1.2.1   World Health Organisation definition of palliative care

According to the WHO:

> *"palliative care is an approach that improves the quality of life of patients and their families facing the problems 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. Palliative care;

- *provides relief from pain and other distressing symptoms;*

- *affirms life and regards dying as a normal process;*

- *intends neither to hasten or postpone death;*

- *integrates the psychological and spiritual aspects of patient care;*

- *offers a support system to help patients live as actively as possible until death;*

- *offers a support system to help the family cope during the patients illness and in their own bereavement;*

- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*

- *will enhance quality of life, and may also positively influence the course of illness;*

- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications"* (Sepulveda et al., 2002)

1.3 Defining end of life care

End of life care may be considered part of palliative care and is often described in text books as the type of care someone receives when it is clear that they are in a progressive state of decline (Wilcock et al., 2008). For example, end of life care for dementia has

been described as beginning from diagnosis, as dementia is a progressive terminal illness (Small et al., 2007, Wilcock et al., 2008).

Radbruch and colleagues, on behalf of the European Association of Palliative Care define end of life care as:

> *'End of life care may be used synonymously with palliative care or hospice care, with end of life understood as an extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of their illness'* (Radbruch and Payne, 2009).

However, there are many different understandings of this term among different countries (Froggatt and Payne, 2006). The UK End of Life Care Strategy (which will be discussed in more depth later within this chapter), defines it as the last 12 months of life (Department of Health, 2008a). Within research, definitions and time periods of end of life care are often used differently (van der Steen, 2010).

1.4   Difficulties of Definitions

1.4.1   End of life care and palliative care

In the literature and in clinical practice 'palliative care' and 'end of life care' are often used interchangeably (National Council for Palliative Care, 2008). However, these are not the only two terms which have made this area complex. Terms such as supportive care, terminal care, specialist palliative care and generalist palliative care are also used in the literature and practice; see Pastrana and colleague's discourse analysis of definitions (Pastrana et al., 2008). Confusion between the terms palliative care and end

of life care is not only seen in the UK, but is a concern shared amongst many other European countries, and worldwide (Davies et al., 2013).

In a qualitative study in New Zealand and England, Gott and colleagues illustrated the terms used in this field exploring the views of professionals who were trained in palliative care. They were often self-defined or organisationally defined as palliative care specialists, and those who provided some form of palliative care but were not trained, were described as generalists, for example general practitioners (GP's) (Gott et al., 2012). They found that palliative care specialists did not "struggle" to define palliative care; however, many generalists such as GP's did have difficulties with a definition. Many generalists believed that palliative care referred to the very end part of life, but some took on board the revised WHO definition. GP's, in particular, believed the introduction of palliative care earlier in the disease trajectory was confusing. If palliative care began earlier this meant it greatly overlapped with their work, yet they did not feel palliative care was a 'core component' of their role.

This study also found 'end of life care' was not well understood by many participants from both specialist and generalist fields; one participant alluded to it as a term used for non-cancer patients instead of palliative care. Not surprisingly they also associated palliative care and cancer services. End of life care was not seen by many generalists in the way it had been defined as the last 12 months of life by the National End of Life Care Strategy (Department of Health, 2008a), but more as the last days or weeks immediately preceding death.

Pastrana and colleagues undertook a discourse analysis of the definitions of palliative care, as so many terms were being used in this area with a lack of consensus about their meanings (Pastrana et al., 2008). These included; 'hospice', 'hospice care', 'continuing care unit', 'continuing caring', 'end of life care', 'thanatology', 'comfort care', and 'supportive care'. In their view these do not represent a mix of terms to describe the same thing, but rather terms with different meanings. While they noted there is some consensus about the term palliative care, they argued that the definitions of palliative care are not shared.

Pastrana and colleagues identified four aspects (from 37 English and 26 German definitions) which they considered formed a fundamental part of the definition of the term palliative care; target group, structure, tasks and expertise (Pastrana et al., 2008). Their analysis of the literature identified that the common shared goal of different palliative care definitions is to: enhance or preserve quality of life, in the remaining time the patient has left. The target population is also often specified within the definitions, with a variety of terms to describe patients: patients with serious or severe or complex illness; patients with a terminal illness, regardless of patient age; and patients whose disease is not responsive to curative treatment. When describing structure many definitions refer to the multidisciplinary team approach that is needed in palliative care. Access to these teams help should be available 24/7 and across different settings, with an emphasis on care at home. The common tasks discussed within the definitions include control of symptoms, including but not restricted to pain. Finally, expertise was the final domain in definitions which relates to the knowledge and skills thought to be needed for specialist palliative care. They particularly mentioned competencies in the areas of communication, ethics and counselling.

The authors concluded from their discourse analysis that there is a variety of concepts, some of which contradict one another. In particular there are contradictions about when palliative care should begin for someone, in what circumstances they become a patient in need of palliative care, and the relationship with curative treatment. For example, the authors noted that in the UK palliative care is still very much 'end stage', even though 'end stage' too is ill defined. They recommended more clarity over definitions and understanding of the terms used within the definitions, for example, what is meant by 'limited prognosis' or 'active' (active treatment) and 'progressive' (progressive disease).

Subsequently Gott and colleagues concluded that there is a significant gap between what policy defines and what is actually seen in clinical practice (Gott et al., 2012). There seems a constant effort within the palliative care field to define terminology clearly to prevent the confusion of work distribution and work load (Pastrana et al., 2008, Gott et al., 2012).

1.4.2   Generalist and specialist palliative care

A key distinction is made in some circles between specialist and generalist palliative care services. As noted above, the European Association for Palliative Care (EAPC) has made efforts to reach a consensus over definitions, and this includes seeking to define specialist palliative care:

> *'provided by a specialist team or service for patients with complex needs not adequately covered by other treatment options'* (Radbruch and Payne, 2009).

In contrast, it defined general palliative care as:

> *'provided by primary care professionals and other non-palliative care specialists treating patients with life-threatening diseases who have good basic palliative care skills and knowledge'* (Radbruch and Payne, 2009).

In their discussion of specialist palliative care, Gott and colleagues debate whether palliative care is a speciality, and question if it is unique (Gott et al., 2012). In particular Fordham et al. argued that specialist palliative medicine simply took the methods and philosophy from general practice, with little being unique about palliative medicine (Fordham et al., 1998).

1.4.3   Stance for this thesis

For this thesis, based on the debates discussed above I take a view that end of life care is part of palliative care. Patients at the end of life may receive care which is palliative by nature to enhance comfort and maintain a level of quality of life for the individual. End of life care is the final phase of care which may be delivered to a person who is dying. This period of time is not limited as some would suggest the final days, hours or weeks of life. It is more as the EAPC has suggested, a period of potentially up to one or two years when the patient or family and professionals recognise the individual is dying (Radbruch and Payne, 2009). I also agree that for some, end of life care treatment options may be appropriate earlier in the course therefore nearer the time of diagnosis of the life limiting/terminal condition. These treatment options may include the decision to not use antibiotics, for example. As can be seen, end of life care definitions vary and for that reason a broad definition is being adopted for this thesis. This will be discussed further with reference to dementia in Chapter Two.

1.5   What is Quality?

Within the UK quality of care has become an increasingly important topic as recognised in Lord Darzi's report 'High Quality Care for All' (Darzi, 2008). The starting point for any study of quality in health care must be an agreed definition of *'what is quality?'* For example without this definition it would not be possible to develop and assess the current state of healthcare, develop interventions and analyse these interventions for effectiveness on health care improvement (World Health Organisation, 2006). Pfeffer and Coote said 20 years ago 'although everybody is talking about quality, the concept is slippery and meaning elusive' (Pfeffer and Coote, 1991).

Defining quality of care is difficult and there is still no unanimously agreed upon definition. Over twenty years ago, the Health Services Research Group in Toronto concluded that all definitions will be incomplete and arbitrary (Health Services Research Group, 1992).

1.5.1   World Health Organisation definition of quality

The World Health Organisation (2006) recognised that there are many definitions of quality, not only within health care but also within other related and unrelated domains. It developed a whole system approach, working definition of quality of care based on six key concepts, stating that health care needs to be:

- Effective – based on evidence, resulting in improved outcomes

- Efficient – maximising resources and reducing waste

- Accessible – healthcare which is timely and geographically reasonable

- Acceptable/patient centred – taking into account the preferences and aspirations of the service users

- Equitable – healthcare which does not vary among race, age, gender, occupation, socio-economic status, ethnicity

- Safe – minimising risk and harm to service users (World Health Organisation, 2006).

1.5.2   Donabedian's model of quality

Donabedian (1966) quotes Lee and Jones as saying that the best-known definition:

'good medical care is the kind of medicine practiced and taught by recognised leaders of the medical profession' (Lee et al., 1962).

However, definitions today such as that above from the World Health Organisation are now more patient centred, which is an important aspect lacking from Lee and Jones's definition.

The model of understanding quality from Donabedian consists of: structure, process and outcome (Donabedian, 1966, Donabedian, 1988). Structure relates to the capacity of the organisation and its ability to provide quality care. It includes the attributes of the settings which are providing care, for example facilities and equipment. It will also include the structure of the organisation and the staff numbers/ ratios etc. Process relates to activities and services that are provided; what is actually done. This includes treatment that is provided to the patient as well as diagnosis. Finally, outcome relates to results of the structures and processes. This would mean the effect of care received on the health status of the patient, to include satisfaction of the patient. There is a three way relationship amongst these domains; the structure which is in place will affect the

processes which take place and the processes will influence the final outcomes of the care.

Donabedian suggested areas of measurement (which he terms 'formulations') which will provide a more detailed view of his notion of quality of care (Donabedian, 1988). He compared these formulations as successive circles surrounding the 'bull's-eye' of a target (see Figure 1.1) with the bull's-eye representing quality of care and the circles the influencing factors. The first circle represents the practitioner level. Practitioners provide two types of care; technical care (i.e. medical tasks) and interpersonal care, mainly communication with the patient and family. This latter aspect of care is not often acknowledged in quality of care assessments. It is an important aspect as noted in the recent Francis report on the Mid Staffordshire NHS Foundation Trust (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013). It is difficult however to measure this aspect of care as it will rarely be recorded in patient notes.

Donabedian noted the next aspect of quality of care is the attributes of the settings within which care is provided, for example, amenities such as comfort and noise level. The next circle/formulation moves away from practitioner input to the contribution patients make towards their own care. Donabedian reported that previously he discussed the input of interpersonal processes from the professionals and the influence these have on care. However, he explains that the patient also has an input on this aspect of care and therefore an influence on the care they receive. Donabedian argued that they must carry some of the responsibility for the success or failure of their own care. Finally, he argued care received by the community as a whole should also form part of the

assessment, which includes access to care and the social distribution of the quality of care provided.
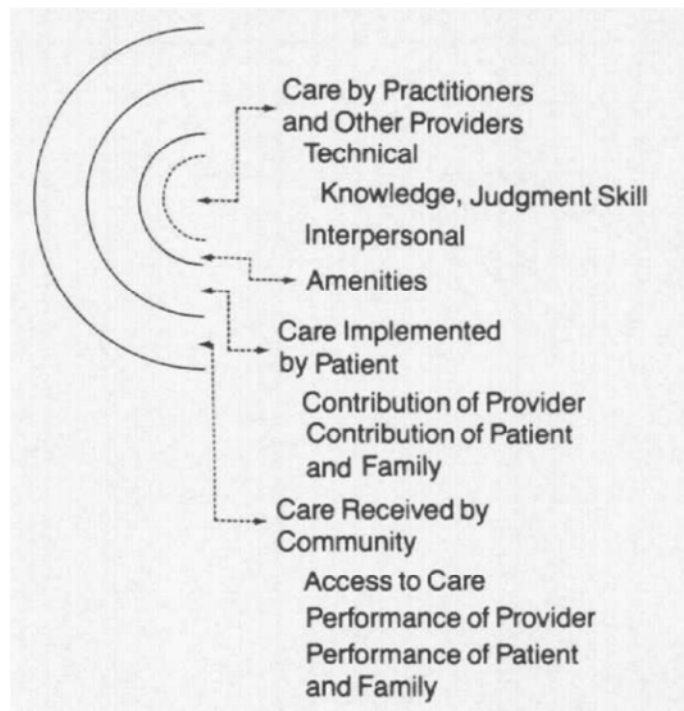
Figure 1.1 Donabedian's formulations for assessment of quality (Donabedian, 1988)

In this model patients' preference is part of the quality of care. However, he accurately observed that no two patients will be the same. Therefore assessments which measure the quality of care will all have different preferences to measure and consequently it is difficult to have standardised measures.

Donabedian emphasises that in order to make measurements or measure quality of care the following questions need to be considered: who is being assessed?, what are the activities being assessed?, how are the activities supposed to be conducted?, what are they meant to accomplish?

1.6   Quality in health and social care

1.6.1   Fordist Movement

An emphasis has developed on quality as an outcome and to define the objective of an intervention, particularly within health care provision, which is aimed at care rather than cure (Small et al., 2007). However, as discussed above, there is no consensus over the definition of quality. It has been argued that quality has derived from post-Fordist management within the private sector which was then translated into the public sector (Alaszewski and Manthorpe, 1993). There is a key difference between these sectors with the private sector driven primarily by profit, whilst the public sector (such as the National Health Service (NHS)) is theoretically at least, driven by public good (Parsons, 1995).

Originally the Fordist approach to activity meant that services developed to best fit those who provided them and not the consumer. For example, hospitals were built in a standard way, size and layout; meal times were developed to fit the running of the organisation. A market orientation however, changed this and firms began to realise that maximising output and minimising costs was not enough. Henry Ford's notion that "you can have any colour Model T car that you want as long as it is black" was no longer good enough. The emphasis turned to getting products and services right for the consumer (in this case the patients and family), and quality. It was this post-Fordist manufacturing ethos that has been replicated in health and social care provision (Small et al., 2007).

1.6.2   Quality in recent times

Quality within the NHS has taken three different approaches over time. It began with the Fordist type approach where the professionals dictated to the consumer what quality

was with no say for the 'consumer'. Next came the post-Fordist movement and the development of internal markets which brought in choice for the patients to create competition that would improve efficiency and quality. Finally, the NHS reverted to a top down approach, with set quality standards to be followed (Small et al., 2007).

Standard setting with top-down and bottom-up approaches together, with integration of local services appears to be the most widely used approach today within the UK. This can be seen in the abundance of standards produced and recommendations of integration, like the End of Life Care Strategy (Department of Health, 2008a) and the National Institute for Health and Care Excellence (NICE) quality standards for end of life care (National Institute for Health and Care Excellence (NICE), 2011). This approach to standard setting allows for the description and comparison of current practice to that of recommended best practice, also known as benchmarking. Standard setting is often associated with financial incentives or penalties, in an effort to increase quality. GP surgeries have the Quality and Outcomes Framework (QOF). This is an incentive programme awarding general practice surgeries for various accomplishments which are aimed at good practice. For example, practices receive 'points' for having a palliative care register (NHS Employers, 2014). However, this is not without problems; it is what practices do with a palliative care register and the information they hold that is important to the individual in need of palliative care, not simply having a register. For example, a register may increase the number of visits or amount of contact an individual has with their GP or practice.

Standard setting helps with problems of staffing, staff skill mix, protocols for admission, transfer and discharge (Small et al., 2007), all of which can have an

influence on the quality of care provided. However, Small and colleagues argue that despite having regulatory frameworks there are still difficulties with aspects of care. For example, it is not so easy to regulate and monitor interactions between staff and people with dementia (Small et al., 2007), as these may be done on a one to one basis.

1.6.3 Health and Social Care Act 2012

In April 2013 there were large changes to the structure of the NHS during the implementation of the Health and Social Care Act 2012 (Health and Social Care Act, 2012). The Act was designed to increase patient choice and promote greater competition within the NHS, in part by introducing competition from commercial providers. This new competition within the NHS will be regulated by the agency 'Monitor' under section 76 of the act. Importantly for this thesis, the Trust Development Authorities (TDAs) which have replaced Strategic Health Authorities (SHAs), will work with Monitor to ensure quality improvement in the NHS.

Further changes included legislative changes to commissioning, with the abolishment of Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs), and their replacement, Clinical Commissioning Groups (CCGs). This is a change of direction to more clinically led commissioning, which was initiated by previous governments. Local authorities took a more prominent role in the responsibility of budgets for public health. Members of local communities were to form Health and Wellbeing Boards to encourage integrated working of commissioners of social care, public health and children services. Clinical led commissioning means NHS professionals who know their patients and needs will be in charge. Michael Dixon, Chairman of the NHS Alliance argues this, together with core duties of CCGs such as enabling patient involvement in commissioning, will enable patients to have "better care" (Dixon, 2011).

1.7   Why focus on quality of care?

There is much written about improving quality of care, but the global question remains which quality strategies (e.g. care staff training) together with existing initiatives (i.e. QOF) would produce the best quality health care (World Health Organisation, 2006). Even in countries which are well developed and resourced there is a great concern about quality (World Health Organisation, 2006). The UK, for example, has demonstrated wide variation in access to care and standards delivered. With growing public pressure, there is a demand to improve the quality in care delivered by the health system, particularly at end of life (Torjesen, 2013).

In the current economic climate there is also increasing pressure on health care organisations, to control or reduce spending (Davies et al., 2013). Therefore patients and families are at a potentially increased risk of poorer quality care, for example, due to reduced services. It is thus important to document quality of care from the perspective of patients and the families of those who are often unable to speak for themselves, such as people with dementia.

Through examining and measuring quality of care, by direct conversation with patients, relatives or professionals we should be able to compare care provided by different services, and within different settings.

There are both pragmatic and systemic concerns as to whether we should actually be concerned to measure quality (Small et al., 2007). Pragmatic sceptics would question whether there is enough time to make quality improvements and initiatives before the next reorganisation of the service. Constant change makes it difficult to implement

change and subsequently measure quality. Systemically, how do we measure quality? Organisations and their aims are multifaceted and therefore it can be hard to measure the quality of services provided by such organisations. Additionally, quality can be fluid and subjective; what one may view as quality in one situation or at one point in time may be different to how they view this at another point in time.

The next section focusses on understanding quality of end of life care. This is particularly important as it will allow for comparisons of care across settings to identify where the best possible care can be achieved (Stewart et al., 1999).

1.8   Quality in end of life care

1.8.1   End of life care: differences in measuring quality

When clinicians can no longer cure or extend the life of an individual, then that person should have the reassurance that the hospital or other place of care provides them with 'good' quality care that will prevent discomfort and distress. Traditionally quality is measured and discussed in terms of medical care. However, as seen in the World Health Organisation's definition (Sepulveda et al., 2002) palliative and end of life care may be conceptualised as holistic care from a multidisciplinary team, not just medical care. Steele and colleagues recognised the importance of including family, social support and the community surrounding the patient in the assessment of quality of care (Steele et al., 2002). Quality of care is typically measured in terms of recovery, but in end of life care this is not appropriate, as we know the patient will die relatively soon (Aspinal et al., 2003). Therefore in measuring the quality of end of life care we cannot use all types of outcome measures as a basis.

1.8.2 What is quality end of life care?

Many have tried to answer the question of *'what is quality end of life care?'* The Institute of Medicine is an American organisation which advises the US government and the private sector about the use of evidence in decision making. They identified six elements to quality end of life care: overall quality of life, physical well-being and functioning, psychosocial well-being and functioning, spiritual well-being, patient perception of care, and finally family well-being and perceptions (Field and Cassel, 1997). Other groups have similarly tried to identify the components of quality end of life care, with all producing similar elements (Lynn, 1997, Emanuel and Emanuel, 1998).

The National Consensus Programme reviewed over 2000 citations to determine the elements of end of life care. The National Consensus Programme is a group of American palliative care specialists including doctors, nurses and researchers from the five main palliative care membership and leadership organisations in America. They split quality of care for end of life into eight elements; structure and process of care, physical aspects of care, psychological and psychiatric aspects of care, social aspects of care, spiritual religious and existential aspects of care, cultural aspects of care, care of the imminently dying patient, ethical and legal aspects of care (National Consensus Project for Quality Palliative, 2004).

Many of these taxonomies of end of life care have been developed by professionals and therefore may differ from families' and patients' views of quality (Bowman et al., 2000). Bowman argued that quality end of life care is most appropriately viewed from the perspective of the patients (Bowman et al., 2000). The domains of quality of care are described in more detail in this chapter with reference to a conceptual model below.

1.9   Quality of life at end of life

1.9.1   What is quality of life at end of life?

As seen in the discussion about definitions of palliative care above, attention to quality of life is a component of palliative care (Sepulveda et al., 2002, Pastrana et al., 2008). The EAPC in its attempt to define quality of life stated that quality of life appears to be representative of a gap between expectations and actual experiences, rather than impairment of functioning (Radbruch and Payne, 2009). They explain that care is guided by quality of life considerations, which would be judged by each individual patient. However they do not discuss those who do not have capacity to make decisions and are not able to communicative their judgement themselves. Stewart argues that quality of life should be defined in terms of subjective evaluations as opposed to meanings that others may attribute to experiences of that individual (Stewart et al., 1999). Hence, it is difficult for family carers to provide an accurate account of their relative's quality of life in dementia, for only the individual can tell us about their quality of life (Higginson and Romer, 2000). The focus of this thesis is on quality of care and not quality of life, the distinction between these terms will be discussed in more detail below.

1.9.2   Domains of quality of life

Many elements or domains of quality of life have been constructed, including physical comfort; psychological well-being; social functioning and well-being; spiritual functioning well-being, meaningfulness of life; physical functioning; cognitive functioning; overall perceived quality of life and quality of dying (see Table 1.1 for an example). Some have argued that quality of life as defined by people who are dying or by a member of their family may be different from people who do not have a life-limiting condition or are not imminently dying (Patrick and Erickson, 1993, Addington-

Hall and McPherson, 2001). For example, a person who is dying may place more value on their personal dignity, spiritual well-being, and their family (Addington-Hall and Kalra, 2001, Waldron et al., 1999).

Table 1.1 Domains of quality of life constructed by Stewart and colleagues (Stewart et al., 1999).

Domain of Quality of Life	Definition/example
Physical comfort	It can be described by a range of different symptoms from pain or dyspnea (shortness of breath) to fatigue or malaise and other symptoms common at the end of life. Some argue that pain is the most important aspect of physical comfort and should be assessed as a separate symptom.
Psychological well-being	Conceptualised into four main parts: *Emotional well-being:* to include depression, anxiety, fear and worry. *Dignity/esteem:* This is difficult to conceptualise for dying patients and as with quality of life as a whole will depend on the individual. This could range from physical appearance such as wearing a hospital gown, to a death which honours and protects those who are dying. *Sense of control:* At end of life it is important for patients and families to feel that they have some control of the situation. This can be as simple as control over visiting times, or can be referring more

	generally to control over the way they die such as the type of treatment they receive.
	Resilience: Ones ability to cope with stress and maintain an emotional equilibrium.
Social functioning and well-being	*Communication:* The ability to communicate to others and the quality of this communication.
	Social Connection and Sense of Closure: An environment where it is possible to communicate and have those close to the person dying, allowing an opportunity to say goodbye. Closure refers to the sense of having said and done all important things, and making contact with all significant others.
Spiritual functioning well-being, meaningfulness of life	Often referred to as the most important aspect of quality of life at end of life. It is the ability to feel at peace whilst finding the meaning in life, transcend physical discomfort and accept death.
Physical functioning	This alters substantially for someone who is dying. For example, the ability to perform self-care such as bathing, and not being confined to bed, may matter. However, many people with dementia do not reach the advanced stages and do not lose their physical functioning, so their quality of life may not be affected by a loss of physical functioning.
Cognitive functioning	Cognitive functions are important to maintain communication with family members, such as thinking, being mentally alert, comprehending and paying attention.
Overall perceived quality of life	Many outcome measures include an overall rating for quality of life.
Quality of dying	A perception of the overall quality of the dying phase (discussed below).

1.10 Quality of death and dying

1.10.1 What is a good death?

This is the subjective personal experience of the dying process and may contain many of the same concepts as quality of life (Small et al., 2007). There are many different definitions of and ideas about the notion of a 'good death' which is generally portrayed as varying for each individual. Their definition of what this may mean may change as death approaches. According to Kehl (2006) the most cited definition is that produced by the 1997 Institute of Medicine report on end of life care:

> *'A decent or good death is one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards'* (Field and Cassel, 1997).

It is argued, however, that this definition is confusing (Kehl, 2006). For example, Kehl noted that the terms 'decent' and 'good' are used interchangeably. Furthermore, she maintained that it was still unclear how one would measure or evaluate a good death. Neither is it clear she argued how to structure care in order to ensure a good death beyond meeting the patient's wishes, following standards and avoiding distress.

Kehl completed an analysis of the concept of a good death, analysing 42 articles. She found that the main components of a good death consisted of being in control, being comfortable, having a sense of closure, affirmation[1], trust in care providers, recognition of impeding death, honouring of beliefs and values, burdens minimised, relationships

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[1] Value of the dying person recognised

optimised, accepting the appropriateness of death, leaving a legacy, and care for the family (Kehl, 2006).

1.10.2 Quality of dying

Stewart and colleagues, as discussed below, identified a separate domain which they called the quality of dying, defined as:

> *'A personal evaluation of the dying experience as a whole, including a subjective evaluation of concepts according to expectations and values'* (Stewart et al., 1999).

Quality of life is an evaluation of experiences while living with a terminal illness, whilst quality of dying focuses on the experience of death itself. Patrick and colleagues believed that differentiating quality of life, quality of medical care, quality of dying and death, and measuring them independently, are needed to understand a good dying experience (Patrick et al., 2001).

1.11 Conceptual framework of quality of care

As the above concepts of quality of care, quality of life and quality of death and dying have many similarities, this chapter now moves to discuss a framework which potentially helps simplify their distinction. This framework, for the purpose of this thesis, is simply used to discuss and simplify the key concepts in quality. It will not be used for any subsequent analysis of results derived from the thesis. Stewart and colleagues' conceptual framework (see figure 1.2) allows for differentiation between indicators of 'good' quality of care and indicators of 'good' quality of life (Stewart et al., 1999). Although this framework is developed to focus on quality of life, Stewart

and colleagues acknowledged it is a framework that defines all relevant domains for describing and evaluating end of life care. This chapter will attempt to simplify the relationship between the two terms. The quality of care that is provided in the final months, days or hours of life can strongly affect the quality of life of the patient according to Stewart and colleagues (Stewart et al., 1999). To be useful however, Stewart and colleagues agree with Patrick and colleagues that quality of care and quality of life must be distinguished (Patrick et al., 2001).

PATIENT FACTORS AFFECTING HEALTH CARE AND OUTCOMES OF CARE	STRUCTURE AND PROCESS OF CARE		OUTCOMES OF CARE	
PERSONAL AND SOCIAL ENVIRONMENT Patient and family situation Clinical status, case-mix Social support for patient Social support for family	STRUCTURE OF CARE Access to care within systems Organisation of care Formal support services available Physical environment(s) of care	PROCESS OF CARE WITH PHYSICIANS, NURSES, SOCIAL WORKERS Technical process with patients Decision-making process with patient and family Information, counselling of patient and family Interpersonal and communication style with patient and family	SATISFACTION WITH HEALTHCARE Patient satisfaction with care Family satisfaction with care	QUALITY AND LENGTH OF LIFE Quality of life of patient Quality of life of family and loved ones Quality of dying of patient Length of life

Figure. 1.2 Conceptual framework of factors affecting quality and the length of life of patients dying and their families (Stewart et al., 1999).

There are three main categories within this framework, 1) the patient and family factors affecting health care and its outcomes; 2) The structure and process of care which Stewart and colleagues argue equates to quality of care; and finally 3) patient and family outcomes of care including satisfaction with care and the quality and length of life (see figure 1.2).

1.11.1 Patient factors affecting health care and outcomes of care

As can be seen in figure 1.2, personal and social environment is the only component of patient and family factors affecting health care. This encompasses factors such as financial situation, social support for both the family and the patient, and details of the clinical condition. The model is not very clear exactly how they define social support in this context. The category would suggest it is not support derived from professionals as this is listed within structure of care. However, Stewart and colleagues noted that if social support is lacking this could reflect an unmet need that should be provided by the healthcare system; however, they do not note that it may also be provided by the social care system. In the UK this is a need which could be met by the social care system and not the health system. This indicates that the framework may relate to the US health care system like much of the literature used by Stewart and colleagues to develop this framework.

1.11.2 Structure and process of care

Structure of care is comprised of many different components including access to care within the system, such as a palliative care team; organisation of care, referring to management and leadership and availability of providers of end of life care; availability of formal support services, to include counselling for both patient and family, and both home and respite care; and finally the site of care and of death, including descriptions of

the environment. The latter has been described as particularly important for people with dementia (Sampson, 2010).

The process of care has four parts: 1) technical processes with patient (e.g. timely diagnosis, appropriate use of medication and treatment); 2) decision-making processes with both patient and family; 3) information for and counselling of the patient and their family; and finally 4) interpersonal and communication style with patient and family. Stewart and colleagues argued that structure is where the majority of indicators are derived from for assessing quality of care at end of life. The technical process refers to more medical-based processes, including accurate prognosis and use of medication. The former may be problematic within dementia as the trajectory itself is different to other terminal diseases and it can be difficult to provide an accurate prognosis (Hanrahan and Luchins, 1995, Sachs et al., 2004, Volicer et al., 1993, Luchins et al., 1997, Mitchell et al., 2004b, Schonwetter et al., 2003). Coordination and continuity are also key aspects of the technical process; however, this framework accepts that these may also be affected by the structure of care. Within the process of care Stewart and colleagues looked to previous research from Kristjanson (Kristjanson, 1989) to identify the most important processes of care as perceived by family members of dying patients. The importance of shared decision making among the triad of patient, family and professionals has also been emphasised by Fortinsky (Fortinsky, 2001). Current policy in the UK promotes early decision making and discussions around end of life care through advance care planning for dementia (Department of Health, 2009). However, research has also acknowledged the difficulties and magnitude of decisions families have to make at the end of life, sometimes leading to feelings of guilt and anxiety (Peacock and Forbes, 2003).

This framework illustrates the importance of information and keeping both the patient and family informed and allowing them both to have a 'voice'. This is not always possible for people with dementia as the disease progresses and they lose the ability to communicate and so the onus is on the family to communicate. As with all care it is argued that it is important for professionals to act with respect and compassion at all times to both the patient and family (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013).

It is important to note within this framework that not all processes will affect everyone. For example not all patients or families will be concerned with the amount of information which they receive. Therefore Stewart and colleagues acknowledged the need for care to be tailored to the individual and their carer.

1.11.3 Outcomes of care

The final part of the framework is concerned with two outcomes of care; satisfaction with health care, and quality and length of life. Satisfaction is further categorised into satisfaction for patients and satisfaction for family. As Stewart et al. acknowledged, patients and families receive different services and therefore measurement of satisfaction may be of different aspects or processes. Quality and length of life complete the outcome section and the framework as a whole. This is separated into family and patient related as well as quality of dying, and a final outcome of length of life. Quality of care may have a small impact on the quality of life, but in end of life care this impact may be much stronger (Stewart et al., 1999).

In discussing their framework Stewart and colleagues acknowledged that there is still some work to do with the validation of concepts. They note that some studies which have compared outcomes across settings often do not find a difference in quality of life, but there are differences in satisfaction with care (Dawson, 1991). This suggests problems with the outcomes being measured or the constructs of terms in general.

1.11.4 Support for Stewart et al's framework

Throughout the framework the categories and domains were grounded in previous research. Various studies have utilised Stewart and colleague's work to interpret their results and shape their discussions. Kramer and Yonker (2011) found substantial support for Stewart and colleagues' framework as a heuristic device when addressing end of life care needs of patients and family (Kramer and Yonker, 2011). They argued that there has been little research on the variables within process and structure of care which are listed in the framework. Identifying the variables which are the most important aspects of process and structure of care, they considered, will help with improving quality of care and the development of strategies to improve care. Morita et al. (2004) agreed with Stewart et al's splitting of quality of health care into the domains; quality of life and quality of death, and satisfaction as outcomes. Finally they agreed targeting the structure and process of care for improvements in the quality of care, Morita and colleagues judged that measurement of the process and structure are the most important aspects to focus on when attempting to improve end of life care (Morita et al., 2004).

1.11.5 Alternative conceptual models/frameworks

There are several alternative conceptual models or frameworks available within the quality of care literature, with some focussing on end of life care (Yabroff et al., 2004b,

Byock et al., 2001, Glass, 1991). In this section I will briefly discuss the limitations of these other alternative models.

Yabroff and colleagues provided an alternative model that is based primarily on cancer with an understanding that it could be used with other terminal disease (Yabroff et al., 2004a). Some research has recognised that models of care cannot simply be transferred from one disease to another (Sampson et al., 2011a), this would disregard the complexities of the conditions. The framework from Stewart and colleagues was developed for seriously ill patients at end of life, not limited to or designed for those with cancer (Stewart et al., 1999). The Yabroff et al. model was also developed to consider the barriers to providing optimal palliative care.

Some other alternative models developed have focussed on particular aspects or domains of care for example spiritual care (Nolan and Mock, 2004) or are for specific settings such as nursing homes (Glass, 1991).

Nolan and Mock (2004) did not discuss their model in terms of structure and processes of care or make reference to the Donabeidan's quality of care model (Donabedian, 1966, Donabedian, 1988). Nolan and Mock (2004) posed a model which is organised around preserving the integrity of the individual at the end of life. They argued that the spiritual domain should be given greater emphasis because people at the end of life identify spiritual issues as being of 'paramount importance'. This therefore plays a central role in their model, with it influencing physical, functional, and psychological domains as outcomes of care. It is important to note that spiritual care is important for some even for those who were not previously spiritual. However, despite this potential

importance, a conceptual model which focuses on and places such high importance on spiritual care will not be valid for all people at the end of life.

The model from Glass (1991) was produced from literature which focussed on quality in nursing homes. The focus on nursing homes restricts the view of quality, for example, it focusses on the nutrition and food services, and physical environment. They used the term 'nursing home quality' as a way of including both quality of care and quality of life. However, this blurs the two ideas and therefore is not appropriate as a means of discriminating between confusing terms.

Finally, some models have focussed solely on quality of life and how these can inform the development of measurements (Round et al., 2014). Round and colleague's model does not discuss the aspect of quality of care or quality of dying.

None of these alternative models have considered the differences between quality of care, life and death (Nolan and Mock, 2004, Yabroff et al., 2004a, Glass, 1991, Round et al., 2014), which is why the Stewart model was chosen for this section of the thesis.

1.11.6 Summary

The Stewart framework offers a way to conceptualise quality of care and the outcomes associated with it, such as quality of life. The framework by Stewart and colleagues however provided a more comprehensive and holistic approach to describing quality end of life care than these alternative models (Stewart et al., 1999). It is not restricted to a specific setting of care on focus on one domain of quality such as spirituality. As the WHO (2006) definition states palliative care should be holistic. It incorporates the

family environment, the staff and management, practical processes such as prognosis, as well as communication and information for the patient and family. Stewart's framework places strong emphasis on the importance of the family in palliative and end of life care, as the definition of palliative care suggests (Stewart et al., 1999). This corresponds with the emphasis of family carers that this thesis will consider and illustrate. The framework recognises the importance of families at the end of life, which is particularly important for those who no longer have the ability to communicate easily such as people with moderate to severe dementia. However, the Stewart framework failed to acknowledge that not all dying patients are loved by their family, and that some professionals wrongly refer to patients as 'loved ones' (Sanders and Power, 2009). Finally, all categories and domains of the framework were grounded in evidence.

1.12   Measuring quality of care

This section briefly discusses some of the common methods of evaluating quality of care, commenting on the use of outcome measures and quality indicators. As discussed above, methods to measure quality of care in palliative care have long been problematic (Hanks, 1993, Volicer et al., 2001).

1.12.1 Measures/instruments in end of life care/palliative care

Measurements may provide valuable information for commissioners, clinicians and researchers about the effectiveness of an evaluation or an intervention. They can also be used for audit, to carry out research, monitor care and provide information about which model of care to provide for a patient.

1.12.2 Difficulties of traditional measures

It can be difficult to simply translate or transfer measures usually used in evaluating quality of care generally into palliative or end of life care (Aspinal et al., 2003). Measures may not be sensitive to the changes in priorities of someone who is dying or the aspects of care which may become more important, for example, spirituality. Many of the measures developed in healthcare which relate to outcomes, are not appropriate for use in palliative or end of life care because the outcomes refer to mortality rates or recovery rates (Stiel et al., 2012, Aspinal et al., 2003). It is therefore important to develop instruments for outcomes which are relevant to palliative and end of life care.

1.12.3 Limitations of instruments

Despite difficulties with measures developed for quality of care, some specific instruments are available for end of life care and palliative care. However, a review by Lorenz and colleagues declared a need for more measures (Lorenz et al., 2008). A decade ago there were calls by many researchers for measures which would be widely applicable and generalizable to evaluate end of life care (Tilden et al., 2002, Steinhauser et al., 2000). As others have commented, when developing or utilising these measures, they need to be particularly clear about which elements of care the measures are examining. For example, one needs to be clear if they measure quality of life, quality of care or quality of death and dying (Stewart et al., 1999, Patrick et al., 2001).

Over the past decade measures for evaluating end of life care and palliative care have been developed but have sometimes been subject to criticism for a variety of reasons, including questionnaire length and inappropriate content (Echteld et al., 2006, Hughes et al., 2004). There is limited consensus within the field about which outcome domains and instruments should be used (Seow et al., 2009a, Seow et al., 2009b). Stiel and

colleagues believed it is debatable whether adequate instruments for evaluation of quality of care in palliative and hospice care can be constructed, if a uniform set of measurement instruments cannot be agreed upon (Stiel et al., 2012).

Many reviews report an abundance of measures being used, but many seem not to be used more than once (Mularski et al., 2007). There is often difficulty in obtaining information about the reliability[2] and validity[3] of measures, and where these data are available many of the measures are only tested in one setting. Often samples have been found to be unrepresentative of the dying population (Mularski et al., 2007). Finally, many measures may be affected by culture, as would be expected when following the Stewart and colleagues framework but many measures are not sensitive to the effects of ethnicity or race (Mularski et al., 2007).

1.12.4 Toolkit of Instruments to Measure End of life care (TIME)

Teno and colleagues aimed to develop a toolkit (TIME) of instruments to measure quality improvement (Teno et al., 1999b, Teno et al., 2001). Their intention was that the toolkit would include measurement tools for purposes of clinical assessment, quality comparison or accountability, and research. In a life threatening illness, seeking the views of patients' family members is often the only way professionals are able to understand the meaning of quality of care to the individual, and this is even more important in diseases where prognosis is hard to predict. Teno and colleagues recognised that the patients' and families' voices in determining quality of care were missing from research and views of quality of care (Teno et al., 1999a). This is

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[2] The reliability of a measuring instrument is defined as the ability of the instrument to measure consistently the phenomenon it is designed to measure (Black and Champion, 1976, p.234)
[3] The validity of a measuring instrument is defined as the property of a measure that allows the researcher to say that the instrument measures what he says it measure (Black and Champion, 1976, p.222)

discussed further in chapter three of this thesis. For the toolkit they developed a prospective patient interview and an after-death bereaved family member interview.

The family interview developed by Teno et al aimed to explore end of life care retrospectively and whether it met the expectations and needs of those dying, and their families. This interview was explored in a validation study (Teno et al., 2001) shortly after development with 156 bereaved family members across different settings and diseases. The interview covered eight domains of care; informing and decision making, advance care planning, closure (see table 1.1 for closure), coordination, achieving control and respect, family emotional support, self-efficacy and, rating of patient focussed, family centred care (PFFC). These were all represented by scales or problem scores. Problem scores were the sum of the negative responses received. This gave an indication of where quality could be improved.

They conducted a factor analysis and correlation with overall satisfaction measures. All except advance care planning and closure reported moderate correlation with satisfaction. They concluded that seven of the eight (with the exception of closure) warrant further investigation and this interview provides a useful insight into quality of end of life care. The numbers used to test this interview were low (at 156), compared to the 36 items of the interview.

The interview also has sensitivity limitations in that it is not specific[4] to different disease groups and therefore is not sensitive[5] to the differences among different life threatening conditions. Despite this, it has been used successfully in studies providing information from families about end of life care. There are disagreements about the use of closure which as Teno has indicated it needs further investigation. Curtis and colleagues (Curtis et al., 2002) also found that in their questions they developed for the Quality of Death and Dying scale (QODD), items about "being at peace with dying" and "finding meaning purpose in life" had missing responses for almost one in five respondents. Steinhauser and colleagues however found patients, families, and health care professionals believed that 'life completion' is an important domain for a good death (Steinhauser et al., 2002). This will require further investigation and research to clarify this domain of care.

1.12.5 Instruments used with people with dementia

Although there are a many measures of quality of care, there are very few for quality of palliative care. In particular, instruments for palliative/end of life care and dementia are few, offering a potential explanation as to why there is limited research in this field (Munn et al., 2007). Outcome measures within end of life care for people with dementia are methodologically problematic, partly because outcomes such as survival or prognosis are simply not applicable (Sampson et al., 2005). To address this Volicer and colleagues developed three scales (see table 1.2) for use in end of life dementia care, to be completed by family members. These included: satisfaction with care at end of life in

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[4] Specificity refers to the measure of probability of correctly identifying a non-affected person with the measure, and the discriminative ability of the measure; and the ability of the gradation in the scales scores adequately to reflect actual change (Bowling, 1997, p.134)

[5] Sensitivity refers to the proportion of actual cases who score as positive cases (e.g. people who have dementia) on a measurement tool; and the ability of the gradations in the scale's scores adequately to reflect actual changes (Bowling, 1997, p.134).

dementia (SWC-EOLD), symptom management (SM-EOLD) and comfort during the last 7 days of life (CAD-EOLD) (Volicer et al., 2001). The authors argued that as many of the items included in the instruments were recommended from previous instruments and experts, that these scales have good content validity. They claimed that good care being received by patients would be reflected by higher scores on all of the three scales. The validity of the scales was supported by results demonstrating good correlations between the three scales (Volicer et al., 2001).

The scoring for the SWC-EOLD ranges from 10-40, with a higher score indicating more satisfaction with care. The scale has ten items measuring the level of agreement on statements including; "I felt fully involved in all decision making", "All measures were taken to keep my care recipient comfortable", "I always knew which doctor or nurse was in charge of my care recipient's care". The majority of the topics within this measure are concerned with treatment the patient received, and the inclusion of the family member in their treatment and the information they had about this treatment.

The SM-EOLD has nine items/symptoms which it measures with family caregivers; pain, shortness of breath, skin breakdown, calm, depression, fear, anxiety, agitation, resistiveness to care. Carers are asked how many times in the last 90 days of life their relative had these symptoms (i.e. never, once a month, two or three days a month, once a week, several days a week or every day). This produces a score between 0-45.

The CAD-EOLD consists of 14 items measuring comfort which have been separated into four subscales following a factor analysis. The subscales consist of physical distress, emotional distress, well-being, and dying symptoms. Physical distress incudes

the items discomfort, pain, shortness of breath and restlessness. Emotional distress includes anxiety, fear, moaning, and crying. Well-being includes serenity, peace, and calm. Finally, dying symptoms includes choking, gurgling, difficulty swallowing, and shortness of breath.

The three scales were evaluated by Kiely and colleagues using another cohort to establish the validity and reliability of the scales (Kiely et al., 2006). There was satisfactory to good reliability for all scales, with good convergent validity compared to other established instruments measuring similar constructs (Barry et al., 1996). They further explored two of these scales, the SM-EOLD and the SWC-EOLD, demonstrating their sensitivity to clinically meaningful changes (Kiely et al., 2012) in a population of nursing home residents. More testing is needed to see if the results can be generalised to other populations.

There are some further limitations with these scales, for example, it is not clear if they can be used for patients who are currently dying or only for patients who have already died. Additionally, the scales do include a scale measuring satisfaction with care provided. The section below discusses the problem with using satisfaction outcomes for measuring the quality of care.

Van Soest Poortvliet and colleagues reported on instruments which had been developed for or tested with people with dementia in long term care settings in the Netherlands, where many residents also have dementia (van Soest-Poortvliet et al., 2012). They discussed ten instruments identified from a review of literature (see table 1.2). They stressed the importance distinguishing between quality of care and quality of dying.

As all these measures are relatively new, we know relatively little about their psychometric properties. To address this van Soest Poortvliet and colleagues completed a study with professionals and bereaved family members of people with dementia. Of the quality of care instruments they concluded that SWC-EOLD and FPCS showed better validity and internal consistency than the FPPFC and this was better than the FATE-S and the TIME. The most valid instruments used in quality of dying were the CAD-EOLD and MSSE, and finally SM-EOLD. Details of these instruments are summarised in table 1.2.

Table 1.2 Dementia measures at end of life for quality of care van Soest-Poortvliet et al. (2012) (van Soest-Poortvliet et al., 2012)

Instrument	Author	Focus	Description	Developed for dementia
SWC-EOLD	Volicer et al. (2001) (Volicer et al., 2001)	Quality of care – satisfaction	Developed for satisfaction with end of life care from the bereaved families' perspective.	Yes
SM-EOLD	Volicer et al. (2001) (Volicer et al., 2001)	Quality of dying	Assess the extent to which patients experienced symptoms.	Yes
CAD-EOLD	Volicer et al. (2001) (Volicer et al., 2001)	Quality of dying	Measures physical distress, dying symptoms, emotional symptoms and wellbeing.	Yes
Family assessment of	Casarett et al. (2008) (Casarett	Quality of care	Developed to measure perceptions about	No

treatment at the end-of-life short version (FATE-S)	et al., 2008)		outcomes of care and how well care met their needs.	
The family perception of care scale (FPCS)	Vohra et al. (2004) (Vohra et al., 2004)	Quality of care	Allows for the evaluation of families perceptions about quality of resident care, family support, communication and rooming.	No
The family perception of physician-family caregiver communication (FPPFC)	Biola et al. (2007) (Biola et al., 2007)	Quality of care	This was developed to investigate the families' perceptions of physician communication during the dying process.	No
After death bereaved family member interview (TIME)	Teno et al. (2000; 2001) (Teno et al., 2001, Teno, 2000)	Quality of care	The interview aims to investigate end of life care received and whether it meets the expectations and needs of those dying and their families.	No
Mini-Suffering State Examination (MSSE)	Aminoff et al. (2004) (Aminoff et al., 2004)	Quality of dying	Developed for patients with dementia prospectively to examine their suffering but can also be used retrospectively.	Yes
POS	Hearn and Higginson	Quality of dying	Developed for cancer patients but can be	No

			used on cognitively impaired patients, covering various domains of palliative care.	
QOD-LTC	Munn et al. (2007) (Munn et al., 2007)	Quality of dying and quality of care	Assesses quality perspectives of personhood, closure and preparatory tasks.	Yes

1.12.6 Satisfaction for use in palliative care

Satisfaction is a popular outcome measurement of quality not just in health care but across industries (Lohr, 1988). However, caution needs to be taken when adopting some of the measurement tools developed, because some tools are not measuring satisfaction. A systematic review of the literature using satisfaction as an outcome measure in end of life care by Dy and colleagues, identified eight common domains used when measuring satisfaction amongst studies (Dy et al., 2008). These included: accessibility, coordination, competence, communication and relationships, education, emotional support, personalisation, support of patients' decision making. These domains of care closely match those proposed within the Stewart and colleagues' framework (figure 1.2) and domains which are proposed for other studies (Ferrell, 2005). However it does not include some important aspects of end of life care such as religion and spirituality, indicating that studies measuring satisfaction are not covering all aspects of end of life care. This is also reflected in some disagreement in the major domains and themes to measure satisfaction in end of life care (Dy et al., 2008). Dy and colleagues in their review reported that although the major themes were similar across studies, they were sometimes defined differently. For example, emotional support in some studies had compassion as a theme; however, in other studies this was themed as physical touch.

Despite the widespread use of satisfaction as an outcome for quality of care, Dy and colleagues found few studies that use satisfaction in palliative care outcomes. An earlier review of existing instruments for satisfaction concluded that none were suitable for use in end of life care (Teno, 1999). This was for several reasons, including the measures not having items applicable to a dying population, and criticism of scales using 'very satisfied' to 'very dissatisfied'. Ware had previously argued that there is an effect that patients or caregivers will respond to questions with a tendency to agree with statements regardless of their content (Ware, 1978). They found an upward bias in satisfaction scores for items which were worded positively and a downward bias for those which were worded negatively. However, Kutner also argued that satisfaction is an important outcome to be used in end of life care research (Kutner, 2008), but caution was needed when interpreting the results of satisfaction. Several empirical studies have revealed a disadvantage of satisfaction as an indicator of care quality. Satisfaction is significantly influenced by patient/family expectations, depression, and social desirability (Morita et al., 2004).

Theoretical understanding of satisfaction

Over the past decades the lack of theoretical underpinning for the use of satisfaction in measuring quality in health care has been highlighted by several authors (La Monica et al., 1986, Staniszewska and Ahmed, 1999, Rogers et al., 2000). Some authors have attempted to theorise satisfaction, for example, using discrepancy theory which states the difference between expectation and perceptions determines satisfaction levels. However, this fails to account for much of the variance in levels of satisfaction (Medigovich et al., 1999). Some argue a definition must be agreed upon before,

determining a theoretical basis for satisfaction, because this is often not clear (Aspinal et al., 2003). Despite this, many studies do not address definitions (Detering et al., 2010). Some three decades ago, associations were identified between satisfaction and fulfilment of needs and of expectations (Fox and Storms, 1981, Linder-Pelz, 1982). Many however have subsequently argued that research findings dispute the link of expectations and satisfaction (Medigovich et al., 1999, Sanchez-Menegay et al., 1992). This argument continues to be complicated by the difficulties of defining expectations which may have many dimensions. If satisfaction and expectation levels are linked then it brings into question whether satisfaction levels do provide information about quality of care. Alternatively, satisfaction could be measuring how well expectations are met. Expectations will vary among differing groups of people, for example, age has been shown to have an effect on them (Fakhoury et al., 1997, Lecouturier et al., 1999). Aspinal and colleagues argued that until a definition and conceptual grounding is made for satisfaction it is difficult to say exactly what measures of satisfaction are actually measuring (Aspinal et al., 2003). In their review, Aspinal and colleagues concluded that satisfaction measures are 'seriously flawed', that they should not be used to make informed decisions about palliative care and make changes. Others agreed that measuring satisfaction at end of life is complex and difficult (Higginson and Romer, 2000).

1.12.7 Quality Indicators

What are quality indicators?

'Quality indicators are explicitly defined and measurable items referring to outcomes, process, or structure of care' (Campbell et al., 2002), allowing for the measurement of the standards of care. Quality indicators usually consist of a numerator and

denominator, with a standard performance (ideal situation) explained. This allows for the identification of not only 'good' quality care but also the opportunity to identify potential problems (Campbell et al., 2002).

Quality indicators in palliative and end-of-life care

There has been little research on the use of quality indicators in end of life care (Davies and Higginson, 2004, Lunney et al., 2003a).The past decade has however seen an increase in their development with the Council of Europe encouraging this (Council of Europe, 2003). Currently, many of these indicators developed thus far refer to cancer or are setting-specific (Peruselli et al., 1997).

Pasman and colleagues conducted a systematic review of quality indicators developed and used in palliative care for all conditions (Pasman et al., 2009). They identified 142 quality indicators, some of which overlapped. Most were concentrated in the domains of process and structure, and physical aspects of care, respectively.

The majority of quality indicators within palliative care focus on physical domains and miss out domains of social and spiritual care (Claessen et al., 2011). However, these authors acknowledged that there is debate about which domain some indicators fit within, which may explain why some domains appear to be more heavily concentrated than others. When separating the indicators into outcome, process and structure, the majority of indicators identified by Classen and colleagues (2011) fell into the category of process of care.

Pasman and colleagues' (2009) review did identify some problems with quality indicators. As highlighted in the discussion of measurement instruments of this chapter, not all information is readily available. Pasman and colleagues note that some studies do not provide very detailed definitions of the quality indicators. Their review however only scrutinised peer reviewed publications, which will not capture all the quality indicators that are available. In England, the Department of Health, NICE, and SCIE constructed their own set of quality indicators which were not published within the timeframe of Pasman and colleagues review (National Institute for Health and Care Excellence (NICE), 2010).

Following the review by Pasman and colleagues (2009) several other quality indicator sets have been developed (Ostgathe and Voltz, 2010, Pastrana et al., 2010, Claessen et al., 2011). Claessen and colleagues (2011) were part of the team which conducted the original Pasman and colleagues (2009) review. They developed a further 33 quality indicators which attempted to cover all palliative care aspects including spiritual care (Claessen et al., 2011). A more recent literature search from Van Riet Paap and colleagues identified over 600 available quality indicators (Van Riet Paap et al., 2014).

This section highlights the abundance of quality indicators which appear to overlap in many areas. This suggests that less work is needed in developing new quality indicators, but more work in utilising the ones currently available; however, this may be challenging with the limited information available about indicators reported here.

1.13 End of life care Guidelines/Frameworks

The next section provides an overview of palliative and end of life care guidelines. In the English context many different sets of guidelines have been produced by various NHS Trusts. This section will only focus on national guidelines which shape the working landscape. Many of these palliative care guidelines are directed solely at cancer care and for this reason will not be discussed within this thesis. Several third sector organisations, particularly the National Council for Palliative Care (NCPC), published numerous reports designed to influence and inform policy and guidelines, and so these will not be discussed within this section individually, as their contents appear to be reflected in national documents, for example, the National End of Life Care Strategy (Department of Health, 2008a).

1.13.1 The National End of Life Care Strategy

The National End of Life Care Strategy was devised in 2008 to provide guidance and specify 'good' quality end of life care for adults in England (Department of Health, 2008a), with the aim of improving end of life care and enabling people to die where they would like. The Strategy covers 12 key areas and provides recommendations for service improvement. These areas include: raising the profile of end of life care; strategic commissioning; identifying people approaching the end of life; care planning; coordination of care; rapid access to care; delivery of high quality services in all locations; last days of life and care after death; involving and supporting carers; education and training and continuing professional development; measurement of process, structure and outcome and research; and increased funding and better use for existing funding within health and social care sector.

The National End of Life Care Strategy provided quality indicators to aid its implementation (Department of Health, 2008a). These apply to a range of different settings including: primary care, acute hospital, community hospitals, care homes, ambulance services, out of hours services, specialist palliative care inpatient units, specialist of end of life care in the community, district nurses/community services. Table 1.3 contains the top 10 quality indicators/markers which the Strategy recommended. These quality indicators were not mandatory but were designed to improve end of life care in accordance with the strategy (Department of Health, 2008a, p.2).

The National End of Life Care Strategy does not cover dementia specifically, and the specific challenges this condition presents. Neither does it fit well for those who will die with multiple pathologies, which can be common among people with dementia.

Table 1.3 Top ten quality makers for providers of end of life care from the National End of Life Care Strategy (Department of Health, 2008a)

Number	Strategy
1	Have an action plan for the delivery of high quality end of life care, which encompasses patients with all diagnoses, and is reviewed for impact and progress.
2	Institute effective mechanisms to identify those who are approaching the end of life.
3	Ensure that people approaching the end of life are offered a care plan.
4	Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.
5	Ensure that the needs of carers are appropriately assessed and

	recorded through a carers' assessment.
6	Have mechanisms in place to ensure that care for individuals is co-ordinated across organisational boundaries 24/7.
7	Have essential services available and accessible 24/7 to all those approaching the end of life who need them.
8	Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs.
9	Adopt a standardised approach (the Liverpool Care Pathway or equivalent) to care for people in the last days of life.
10	Monitor the quality and outputs of end of life care and submit relevant information for local and national audits.

1.13.2 The National Institute for Health and Care Excellence (NICE)

The National Institute for Health and Care Excellence (NICE) was set up in 1999 to provide evidence based guidance on which medication, treatment and procedures provide the best quality of care and value for money for the NHS (www.nice.org.uk). It also provides quality standards for a range of diseases/conditions or clinical areas. Previously, NICE only provided guidance to the NHS but from 1st April 2013, guidance is also being provided to social care sectors. As of 2014 the only specific NICE guidance for palliative care is aimed at cancer and not for other conditions (National Institute for Health and Care Excellence (NICE), 2004).

NICE has devised a library of quality markers/standards for a range of conditions/disease and clinical areas. They recently produced a set for end of life care for adults over 18 years of age with a life threatening or advance progressive, incurable conditions (National Institute for Health and Care Excellence, 2013). It has recognised that not all markers will apply to all groups, but they are meant to cover all settings and

services where one may be treated or die. They provided 16 standards (see table 1.4) which professionals are advised to use in conjunction with other quality standards produced for specific diseases/conditions.

Table 1.4 NICE quality standards for end of life care for adults (National Institute for Health and Care Excellence, 2013)

Number	Statement
Statement 1	People approaching the end of life are identified in a timely way.
Statement 2	People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
Statement 3	People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
Statement 4	People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
Statement 5	People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social

	participation for as long as possible.
Statement 6	People approaching the end of life are offered spiritual and religious support appropriate to their preferences.
Statement 7	Families and carers of people approaching the end of life are offered comprehensive and holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
Statement 8	People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the persons current medical condition, care plan and preferences.
Statement 9	People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
Statement 10	People approaching the end of life that may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.
Statement 11	People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.

Statement 12	The body of a person who has died is cared for in a culturally sensitive and dignified manner.
Statement 13	Families and carers of people who have died receive timely verification and certification of the death.
Statement 14	People closely affected by a death are communicated with in a sensitive way and are offered immediate and on-going bereavement, emotional and spiritual support appropriate to their needs and preferences.
Statement 15	Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high quality care and support for people approaching the end of life and their families and carers.
Statement 16	Generalist and specialist services providing care for people approaching the end of life and their families and carers have multidisciplinary workforce sufficient in number and skill mix to provide high quality care and support.

These statements employ a holistic approach to end of life care as advised by the World Health Organisation (Sepulveda et al., 2002). This encapsulates a continuous on-going approach to care, including spiritual, social, psychological and physical aspects. What is important within these quality statements is the specific inclusion of family carers and their needs, both during the dying process and during bereavement.

1.13.3 The Gold Standards Framework

The Gold Standards Framework was developed in the UK in 2000 (http://www.goldstandardsframework.org.uk). It is a non-condition specific systematic evidence based approach aimed to improve/optimise the care delivered at the end of life by generalists. The approach was originally developed for use in primary care but has been rolled out across different settings including care homes and the acute hospitals. It is used for a variety of terminal conditions. The Gold Standards Framework offers ideas about training, support and resources for the development of end of life care in various settings. Its care home training programme was developed in 2004 and comprises of a structured curriculum and formal accreditation programme. This is the most widely used training programme for end of life care. Care homes who have received the training have reported (using after-death analyses) improved quality of care, greater staff confidence and reduced admissions to hospital (Hall et al., 2011, Kinley et al., 2014, Hockley et al., 2010).

The Gold Standards Framework is based on the premise that clinical practice would be improved by the following of three 'simple' steps: firstly to identify patients in the last year of life, secondly assess their current and future clinical and personal needs, and finally, development of a plan of care. The framework includes a toolkit to provide practitioners with a range of aids to deliver these three simple steps. The identification is described as being aided by the surprise question *'would you be surprised if this person were to die in the next year?'* This, it is suggested, encourages clinicians to think about the prognosis of their patients. The framework also provides needs-based coding using a colour spectrum. The spectrum ranges from blue, meaning, of 'a year plus' prognosis through to red, meaning final days and finally navy, meaning after care.

Assessments are supported with an abundance of assessment tools such as the 'PEPSI COLA'[6] aide memoir which is an acronym for a holistic checklist. There are guidance and support documents/templates for advance care planning and finally, an action plan of care is developed using the principles of the 7Cs which underpin the Gold Standards Framework. These consist of communication, co-ordination, control of symptoms, continuity of care, continued learning, carer support, and care of the dying pathway.

The Gold Standards Framework is constantly being developed. A trial of a dementia-specific training programme within the Gold Standards Framework has been funded by the Department of Health (Stobbart-Rowlands, 2014). Interestingly, there has been little research evaluating the Gold Standards Framework effectiveness, but it is grounded in a firm base of evidence. The Gold Standards Framework allows for a systematised care approach in an area which can at times be un-systematised, particularly in conditions such as dementia.

1.13.4 The Liverpool Care Pathway

The Liverpool Care Pathway was originally developed by Marie Curie Cancer Care (http://www.mariecurie.org.uk) for people with cancer for use in hospitals during the last hours and days of a patient's life. The aim was to improve the care during their final hours of life. It evolved to be used across end of life including for people with dementia, in a variety of settings. It was intended to transfer the design of best quality care from the hospice movement to other clinical areas of care. The pathway consisted of three phases: an initial assessment, on-going assessment and care after death for the relatives. The pathway advised withdrawal of unnecessary medication and interventions. Attention was to be provided to the personal circumstances of the patient such as

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[6] P – physical, E – emotional, P – personal, S – social support, I – information communication, C – control and autonomy, O – out of hours, L – living with your illness, A – after care

spiritual and psychological needs. However, Sampson acknowledged that the Liverpool Care Pathway was not without problems for people with dementia (Sampson, 2010). This was because people with dementia do not always die suddenly but over a prolonged period of time, with their final hours difficult to recognise. The Liverpool Care Pathway accounted for this by allowing people to join the pathway with the option to be removed if their condition changed. They would then be placed back on the pathway if and when the time is right. The pathway was a recognised quality approach to end of life care and was recommended by NICE (National Institute for Health and Care Excellence (NICE), 2011, National Institute for Health and Care Excellence (NICE), 2004) and previously by the National End of Life Strategy (Department of Health, 2008a). Like the Gold Standards Framework, the Liverpool Care Pathway offered a systematic approach to end of life care, guiding professionals in their approach.

Media attention in 2012 highlighted concern about the ways in which end of life care was being implemented within the UK using the Liverpool Care Pathway. In particular reports from family members of elderly relatives who felt their relatives were abandoned, leading to an independent review of the Liverpool Care Pathway (Neuberger, 2013). As a consequence of the review, the UK government announced it would gradually phase out the Liverpool Care Pathway over a 6-12 month period. This was despite pleas from some practitioners disputing the criticisms (McCartney, 2012, O'Dowd, 2012). The Neuberger review concluded that the failings of the Liverpool Care Pathway were attributable to an over-emphasis on paper work and therefore a lack of attention to care. This was made worse, in Neurberger's view, by the misinterpretation of many of the features of the Liverpool Care Pathway namely

nutrition, and hydration, together with a lack of appropriate training in its implementation (Chinthapalli, 2013b, Chinthapalli, 2013a, Neuberger, 2013). There was already feeling among some practitioners that care for people with dementia at the end of life lacked a clear pathway (Harrison-Dening et al., 2012a). The Liverpool Care Pathway provided some support and a set of procedures for practitioners to follow, and some have predicted a 'guidance gap' as well as a potential decline in confidence among practitioners (McCartney, 2012, Torjesen, 2013).

1.13.5 Preferred Priorities for Care

The Preferred Priorities for Care is a tool which is used to enable discussion about end of life care (National End of life Care Programme, 2007). It may enable people to remain in their preferred place for end of life care and ultimately death. The Preferred Priorities of Care can be thought of as part of care planning. It is useful if a person should lose capacity, with their previous wishes in their Preferred Priorities of Care document acting as an advance statement. However, statements about refusing treatment cannot be made within the Preferred Priorities of Care, and would need to be done as an advance decision. Advance care planning and advance statements are discussed in more detail in chapter two.

1.14 Conclusion

This chapter has introduced and outlined several key areas and concepts which are important for this thesis. It is apparent from the literature that many of these concepts are difficult to define, including; quality, palliative care and end of life care. These problems of definition are reflected in the difficulties encountered when seeking to find common sets of quality indicators and instruments to measure quality. Despite such

difficulties, research in and recommendations for quality and end of life care have become more prominent in recent years in England. These subjects have been recognised as a priority within both the health and social care sectors with the introduction of the End of Life Care Strategy (Department of Health, 2008a) and National End of Life Care Programme which has now come to an end (http://www.nhsiq.nhs.uk/).

The next chapter will explore quality in end of life care for people with dementia. It will discuss what is conceived of as the state of the art in practice and policy and will explore if dementia end of life care is different from end of life care for people with other conditions such as cancer.

CHAPTER 2:QUALITY END OF LIFE CARE FOR PEOPLE WITH DEMENTIA

2.1   Introduction

The first chapter discussed the difficulty of conceptualising quality and made specific reference to quality in end of life care, but not explicitly dementia. The first chapter argued that there are many ways to measure quality, but all have problems attached to these. This chapter will explore the meaning of quality in end of life care for people with dementia, highlighting the challenges this idea may bring to researchers, and health and social care professionals. It will begin with an in-depth discussion of the construction of dementia and the common symptoms, concerns and treatment associated with dementia at the end of life. These will be discussed alongside the barriers to providing 'good' end of life care. The chapter will conclude with a summary of guidelines that are available for end of life care and dementia.

2.2   The construction of dementia

2.2.1   Defining 'Dementia'

The World Health Organisation (WHO) defines dementia as:

> '*A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in*

other conditions primarily or secondarily affecting the brain' (World Health Organization, 1992).

This WHO definition of dementia is used as an umbrella term for a range of different diseases, such as Alzheimer's disease and vascular dementia, the two most common (Ladislas, 2000, Draper, 2013). However, there are many other diseases which cause the symptoms of dementia. For example, dementia with Lewy Bodies, and fronto-temporal dementia are two other less common causes. There are over 200 subtypes of dementia all of which have their own distinct courses and variations in both their pattern of expression and their neuropathology (Stephan and Brayne, 2008).

2.2.2   Symptoms of dementia

Memory problems are most commonly associated with dementia and are the most common reason for people seeking help (Samsi et al., 2014). However, the first signs or indications of dementia may include a change in personality of the individual, such as becoming suspicious or anxious (Small et al., 2007). People close to the person with dementia may report behavioural changes becoming socially withdrawn and or mood changes for example (Jacques, 1992). Other common first indications that there is something amiss include errors in driving, errors in managing finances or errors made in the workplace. Early identification of these initial signs and symptoms has become a priority for the Department of Health, as outlined in the National Dementia Strategy (Department of Health, 2009). This Strategy encourages earlier recognition to provide individuals with more opportunities to plan for future care and to access services, including access to services for early diagnosis. McCarthy and colleagues emphasise

that identifying patients with future palliative care needs early will improve care at the end of their life (McCarthy et al., 1997).

2.2.3 Prevalence and incidence

Due to improved health care people are living healthier and for longer, leading to an ageing population in the developed world. The United Nations estimates that in 2000 there were over 600 million people aged 60 years or over, worldwide. In 2009 this figure had risen to over 700 million and is estimated to be 2 billion by 2050 (United Nations Population Fund, 2012). The older population worldwide is growing at a rate of 2.6 per cent annually which is markedly higher than the general populations rate of 1.2 per cent (United Nations, 2009). With this ageing population age related conditions such as dementia are expected to rise. Approximately 800 000 people in the UK are thought to have dementia (Lakey et al., 2012), and this number is expected to rise to over 1 million by 2025 (Knapp and Prince, 2007). There are estimated to be 80 million people with dementia worldwide by 2040 (Ferri et al., 2005) and 115 million worldwide by 2050 (Alzheimer's Disease International, 2009). However, a recent study by Matthews and colleagues suggests that the prevalence may have previously been overestimated (Matthews et al., 2013). They suggest it is closer to 6.5% in the older population rather than the 8.3% often quoted.

2.3 End of life care for people with dementia

With an increase in dementia worldwide, dementia is becoming one of the leading health and social concerns. With many dementias characterised by a progressive neuro-degeneration, with as yet no known disease modifying treatment, end of life care is rapidly becoming a major priority for dementia services, evidenced by the increase in

research in this field and call for the prioritisation of this work (Mitchell et al., 2012). It has been reported that end of life care for people with dementia is not optimal, with improvement needed in many areas of care (Ballard et al., 2001). In particular there is poor access to end of life care (Department of Health, 2008a, Sampson, 2010, Department of Health, 2009). The remainder of this chapter will focus on quality in end of life care for people with dementia.

Sampson and colleagues, using a rapid participatory appraisal technique, developed a typical end of life pathway for people with dementia in the final 6 months of life (Figure 2.1) (Sampson et al., 2012). This demonstrates the complexity that surrounds end of life care for people with dementia, and the diversity of professionals potentially involved in care during this period.
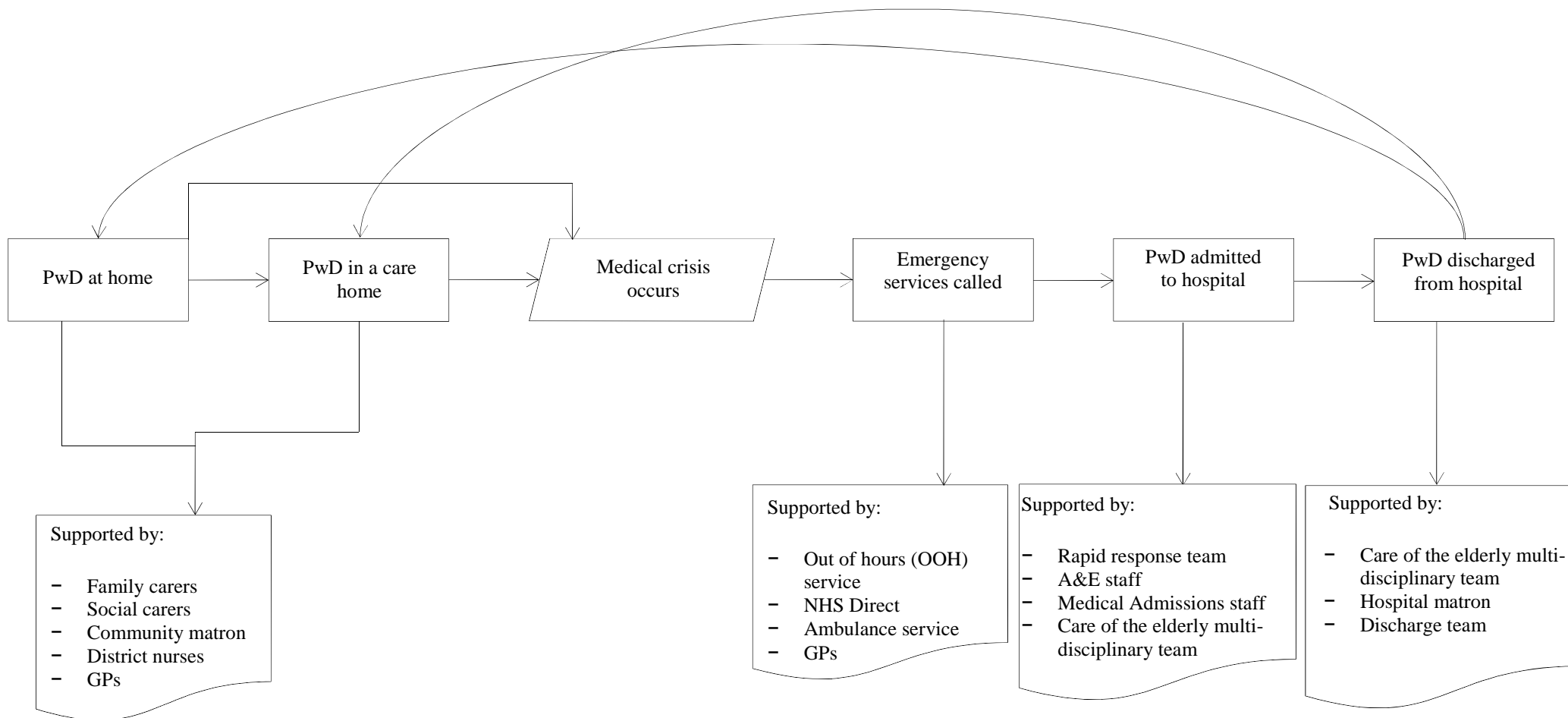
Figure 2.1 Typical end of life pathway for person with dementia in the final 6 months of life (Sampson et al., 2012)

2.4 Symptoms at the end of life

2.4.1 Common symptoms

Common symptoms associated with dementia at end of life are described as similar to symptoms associated with other life threatening illnesses, such as cancer (Davies et al., 2014b, McCarthy et al., 1997, McCarthy et al., 2000) . In end stage or advanced dementia common problems reported by Mitchell and colleagues include difficulties in swallowing, pain, shortness of breath, skin breakdown, poor nutrition, fever, poor sleep, infections, urinary incontinence and constipation (Mitchell et al., 2009). It is important to note however that not everyone with dementia will survive to the advanced stages (De Roo et al., 2014) as they may die of other conditions. Although not the focus of their study, De Roo and colleagues reported that only 46.4% of the people they studied had advanced dementia when they died.

Although similarities exist between symptoms experienced by people with dementia and people with cancer, a study by McCarthy and colleagues found people with dementia experienced symptoms for a more prolonged period of time (McCarthy et al., 1997), although they did not specify for how much longer. As described later in this chapter, the trajectory and prognosis for dementia are uncertain and therefore people with dementia may receive end of life care for a longer period of time than those with cancer.

Mitchell and colleagues described the importance of family in the initial stages (i.e. in spotting early signs of dementia), but also recognised the importance of families at the end of life. Residents of nursing homes whose family understood more than others about the prognosis and clinical complications of dementia were found to be less likely to seek

aggressive treatment or burdensome interventions for their relative (Mitchell et al., 2009). Mitchell and colleagues suggested that the occurrence of infections and eating difficulties can be used to indicate to both professionals and the families that the end of life is near (Mitchell et al., 2009).

2.4.2 Pain

Although dementia itself may not cause pain, disease progression in existing comorbidities can cause pain. There is a growing literature examining pain in dementia. A retrospective study of pain in people with dementia and with cancer found significantly more people with dementia were thought to have experienced pain in the final six months of life compared to those with cancer (75% versus 60%) (McCarthy et al., 1997). In a review of studies van der Steen (2010) found studies reported pain in 12-76% of people with dementia, with pain thought to increase as the dementia progressed. The same review found that shortness of breath was reported between 8% and 80% of people near death (van der Steen, 2010). The wide variation in the reporting of symptoms in this paper seems to illustrate the unpredictable and individual nature of the course of dementia, although it could be an indication of poor data collection. The implications for care and practice of a diagnosis of dementia and pain management are discussed below.

2.4.3 Behavioural and psychological symptoms of dementia

Not only do many people with dementia experience physical symptoms but as Steinberg and colleagues have shown, 97% of people with dementia also exhibit at least one of what is termed behavioural and psychological symptoms (BPSD) (Steinberg et al., 2008). Such symptoms can include agitation, psychotic symptoms (hallucinations and delusions) and

mood disorders (i.e. depression) (Ballard and Corbett, 2013). These symptoms may appear at different stages of dementia, for example, mood disorders are said to be less common in the end stages and more associated with early to mid-stages. In the advanced stages, agitation and distress appear more common (Mitchell et al., 2009). Families appear to be less concerned about these psychological symptoms compared to more physical symptoms such as pain (Shega et al., 2008), and professionals are less confident in treating BPSD (Robinson et al., 2005).

2.5   Symptom management

2.5.1   Treatment of pain

Management and treatment of symptoms in dementia have been criticised in recent years (Sampson et al., 2005) and a conclusion of many reports is that pain is undertreated in dementia (Scherder et al., 2005, Sampson et al., 2006). A review by Scherder and colleagues identified differences in receipt of pain management between people with dementia and people without dementia in nursing homes and hospital settings (Scherder et al., 2005). A study included within this review (from Bernabei and colleagues) demonstrated that fewer older people with cancer in US nursing homes were reported as receiving analgesics compared to younger cancer patients (Bernabei et al., 1998). They reported that cognitive performance was an influential determinant of analgesic use. Morrison and colleagues found that patients in hospital with advanced dementia received a third fewer opioid analgesics compared to cognitively intact patients when admitted to hospital for a fractured hip (Morrison and Siu, 2000a). However, overall there was under treatment of pain for elderly patients with a fractured hip regardless of their cognitive abilities, with 76% of dementia patients and 83% of cognitively intact patients not having a

standing order (PRN or medication already prescribed in advance for when needed) for an analgesic agent.

Schreder and colleagues found that different sub types of dementia were associated with differences in pain relief provided (Scherder et al., 2005). For example, people with Alzheimer's disease received less pain medication compared to those with vascular dementia (Semla et al., 1993). Reasons for this discrepancy are unknown, however, explanations include possible differences in the ability to communicate between people with Alzheimer's and people with vascular dementia (Lindeboom and Weinstein, 2004).

However, a recent study from Jensen-Dahm and colleagues (2014) compared opioid use in elderly people with dementia and elderly people without dementia in Denmark. They found frequent and higher use of opioids in people with dementia in both nursing homes and at home than people without dementia (Jensen-Dahm et al., 2014). They reported that the use of opioids rose with age. This contrasts with earlier studies such as Bernabei and colleagues (1998). Many of the previous studies of pain in dementia are dated and Jensen-Dahm et al note that opioid use has increased over the past 15 years. However, the increase in opioid use is not just for people with dementia (Schubert et al., 2013, Jensen-Dahm et al., 2014).

Despite this recent evidence, Davies and colleagues have found that treatment of pain can be suboptimal for people with dementia because some professionals fail to recognise that people with dementia can experience pain (Davies et al., 2013). Other studies have also

found limited understanding of the aetiology of pain and dementia associated neuropathology of pain among people with dementia (Corbett et al., 2012).

2.5.2 Assessment of pain

Because of communication disabilities many people with dementia may express pain in ways which are not recognised by others (Regnard et al., 2007). These expressions may be experienced as aggression, depression or agitation (Raymond et al., 2013, Small et al., 2007). Some assessment tools have been devised to better recognise pain such as the Pain assessment in advanced dementia (PAINAD) scale (Warden et al., 2003). Over the past 30 years 35 pain assessment tools have been developed for people with dementia (Corbett et al., 2012). At end of life a series of observational assessments have been designed to be used with people who have diminished cognitive capabilities. Commonly used assessments in the UK include the Doloplus-2 scale (Wary and Collectif, 1999, Wary et al., 2001), Abbey Pain Scale (Abbey et al., 2004), and the Pain assessment in advanced dementia (PAINAD) scale (Warden et al., 2003); several other scales are available see Herr (2011). These scales have been described as important to use in place of 'normal' pain assessments as they allow for the consideration of other symptoms in dementia that may otherwise be associated with signs of pain. Such symptoms which these assessments look for include body language, facial expression, and activity. Despite the availability of pain assessment tools for dementia, many are not used allegedly due to time constraints (Davies et al., 2013).

Some have argued that it is not currently possible to recommend a particular tool based on their psychometric properties, and recommend more work is needed within this area

(Zwakhalen et al., 2006). The cross European 'COST' project is currently seeking to develop a consensus on which tools to use in pain assessment of older adults focussing on the various subtypes of dementia (Corbett et al., 2014).

2.5.3   Guidance on pain management

This lack of specific guidance for pain management in dementia is reported to increase risk of under-treatment of pain in dementia, with professionals simply using their knowledge and current general guidance for pain management. Current general guidance recommends the use of non-opioids in the first instance working progressively towards the use of opioids until the pain is under control, following the WHO's pain relief ladder (see figure 2.2) (World Health Organization, 1996).
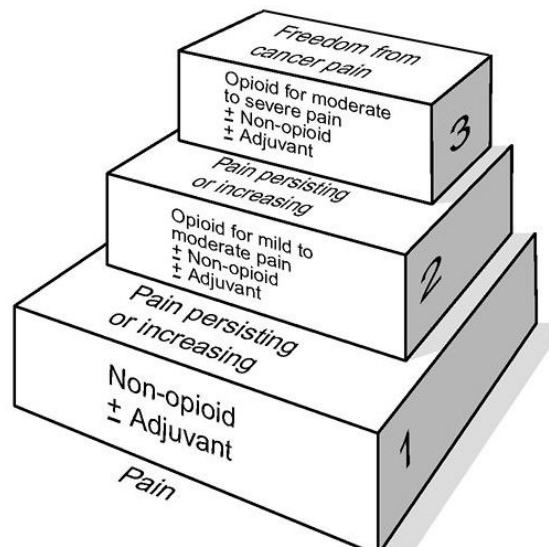
Figure 2.2 WHO pain relief ladder (World Health Organization, 1996)

Additional treatment with antidepressants (known as adjuvant treatment) may be needed in some cases (World Health Organization, 1996). Robinson and colleagues in their review argued that non-pharmacological interventions, such as massage and aromatherapy, should be available for the treatment of pain (Robinson et al., 2005) despite the lack of evidence to support them. Availability of these treatments remains limited (Robinson et al., 2005, Cameron et al., 2003).

2.5.4   Suffering

It is not only pain which is said to be ill managed at the end of life for people with dementia. Aminoff and Adunsky investigated suffering in people with dementia during their final stay in a long term geriatric ward in Israel using the Mini Suffering State Examination (MSSE) (Aminoff and Adunsky, 2004). See box 2.1 for the ten MSSE prompts used to assess suffering. They defined suffering as:

> *"Patient suffering is a pathological syndrome traditionally viewed as encompassing psychological distress, spiritual concerns, and various aspects of physical pain".*
> (Aminoff and Adunsky, 2004)

However, many in the field of dementia, including the Alzheimer's Society, would argue against the use of the word 'suffering'. Not all who have dementia may be 'suffering', which stands in contrast to the campaign for "living well with dementia".

1. Not calm

2. Screams

3. Pain

4. Decubitus ulcers

5. Malnutrition (e.g. protein levels, haemoglobin etc.)

6. Eating disorders (e.g. refusal to eat)

7. Invasive action (e.g. blood tests)

8. Unstable medical condition (e.g. pneumonia)

9. Suffering according to medical opinion

10. Suffering according to family opinion

Box 2.1 Mini Suffering State Examination (MMSE) prompts (Aminoff et al., 2004)

Aminoff and Adunsky (2004) found most patients died with a high MSSE score (63%), with only 7% in the low range. Compared to admission to a long term geriatric ward, a significantly greater proportion of people were in the mid-higher score range on the MSSE in the last week of their life. During their final week 72% of patients were agitated and 70% had pressure sores. Suffering, as measured by the MSSE, increased in this sample despite an increase in pain medication being prescribed. The authors conclude that other methods may be needed to ease suffering in this population. They suggested there could be more aggressive palliative medical and nursing care, to prevent some of the symptoms which equate to high levels of suffering, such as decubitus ulcers and mal-nutrition. Although the authors did not explicitly state what they mean by more aggressive palliative care, it may be

possible to assume they meant artificial nutrition and other such approaches. However, as will be discussed in the next section, this would be criticised by many others and seen as prolonging unnecessary 'suffering' or replacing one form of suffering by another. The authors concluded that a substantial number of people with dementia die whilst experiencing high levels of suffering, entitling their research 'dying dementia patients: too much suffering, too little palliation".

2.5.5 Behavioural and psychological symptoms of dementia – their treatment

Robinson and colleagues argue that it is important not only to focus on the physical symptoms but also on behavioural and psychological symptoms of dementia (BPSD), as these may cause burden for carers and risk to other residents in a nursing home for example (Robinson et al., 2005). BPSD treatment may vary throughout the course of dementia, depending on the specific symptoms (Howard et al., 2001). Depression is more common in the earlier stages of the disease and may or may not be responsive to antidepressants, while hallucinations and delusions are more common in the later stages (Sampson, 2010). Sampson argued that in end of life care the management of BPSD is complex and requires a structured approach, with a full assessment of BPSD (Sampson, 2010). She emphasised the importance of the environment in end of life care, proposing that noisy environments increase agitation. Roger suggested that improved communication and strong social relationships may help with agitation and possible resulting aggression, which may also become a problem within end of life care (Roger, 2006).

Treatment of BPSD remains controversial, and the use of non-pharmacological treatments is recommended before the use of neuroleptic (antipsychotic) drugs (National Institute for

Health and Care Excellence, 2006). The evidence base for the use of non-pharmacological interventions such as exercise or music therapy is limited (Robinson et al., 2005). Evidence however is growing, for example, short term benefit of music therapy has been demonstrated but evidence remains limited for long term benefit and an understanding of how and why music therapy works (McDermott et al., 2013) not to mention the fact they require a large amount of resources such as staff availability (Robinson et al., 2005). However, a recent Cochrane review from Oregata and colleagues found evidence of a benefit of psychological interventions such as cognitive behavioural therapy (CBT), interpersonal therapy and counselling, compared to usual care (Orgeta et al., 2014). Staff turnover within care homes is high, complicating the consistent use of such therapies (Margallo-Lana et al., 2001).

The use of neuroleptic drugs such as Risperidone has been studied extensively, with benefits reported for 6-12 weeks (Ballard and Howard, 2006, Schneider et al., 2006a). There is also concern over their long term use, as the median duration of use for these drugs is greater than one year (Margallo-Lana et al., 2001). Evidence of a benefit for prolonged use is lacking, with only three trials which go beyond 14 weeks follow up (Ballard and Corbett, 2013, Ballard et al., 2011). The AGIT-AD trial compared Quetiapine, Rivastigmine and placebo over 6 months (Ballard et al., 2005); the CATIE trial compared Risperidone, Olanzapine, Quetiapine and placebo over 9 months (Schneider et al., 2006b); and finally the DART-AD trial compared Risperidone, Chlorpromazine, Haloperidol, Trifluoperazine and placebo over 12 months (Ballard et al., 2009). Risks with long term use of these drugs have been reported in several studies, including an increased risk of stroke

(Committiee on safety of medicines (CSM), 2004), falls (Robinson et al., 2005) and mortality (Schneider et al., 2005). In light of this evidence, Risperidone is currently the only drug licenced for treatment of BPSD in dementia, for a period of up to six weeks (Medicines and Healthcare Products Regulatory Agency, 2009).

2.6   The Concepts of Unnecessary and Invasive Treatment

2.6.1   Hospital admission

In the process of attempting to manage symptoms and maintain quality of life, many people at the end of life often experience what are termed as unnecessary hospital admissions (van der Steen, 2010). This description of 'unnecessary' may be for a number of reasons including the nature and consequences of the condition, such as infection (Lamberg et al., 2005, Mitchell et al., 2009). These admissions often cause more pain and distress to both the patient and family (Sachs et al., 2004) than remaining in their normal place of care. Patients can go to hospitals which have a focus on cure as opposed to care, and may receive what is described as unnecessary tests or aggressive and invasive procedures. For example, Sampson and colleagues completed a study to examine the quality of end of life care of people with dementia admitted to hospital compared to those without dementia (Sampson et al., 2006). They found those who had dementia received different end of life care, with fewer having central lines (an intravenous line placed into a large vein, normally in the neck or close to the heart) and mechanical ventilation but higher rates of blood gas measurements, which is both intrusive and painful. People with dementia also received less palliative medication and fewer referrals to specialist palliative care teams than those without dementia.

2.6.2   Antimicrobial treatment

Typical burdensome interventions in end stage dementia are described in the international literature as including the use of antimicrobial treatment and enteral tube feeding. Both of these interventions have been shown to have limited benefit for the person with dementia at the end of life (Candy et al., 2009, van der Steen et al., 2012b). D'Agata and colleagues completed a prospective study of antibiotic use in people with advanced dementia describing the quantity, type and pattern of antimicrobials used. They found a respiratory tract infection was the most common indication for antimicrobial treatment (46.7%) followed by urinary tract infections (35.6%) and skin infections (13.1%). The two most common groups of antibiotics administered for these infections were Quinolones and third generation Cephalosporins, administered by the parenteral route. The use of these increased as the patients approached death, with 20% of the sample receiving antimicrobials in last 6-8 weeks, 26.3% in the last 4-6 weeks, 28% in the last 2-4 weeks and finally, increasing to 41% in the final two weeks of life (D'Agata and Mitchell, 2008).

The ability of antimicrobial treatment for recurrent infections in people with dementia to extend life or improve comfort is not well understood (Mitchell et al., 2012). Hurley and colleagues found the use of antibiotics for fever actually hastened deterioration, however, the cause of fever was not identified in these patients (Hurley et al., 1996). It has been suggested that effectiveness of antibiotics could depend on the diagnosis (van der Steen et al., 2012b). However, others have demonstrated increased survival following antimicrobial treatment compared to no treatment or a palliative approach (Givens et al., 2010, Fabiszewski et al., 1990, van der Steen et al., 2012b). Givens and colleagues investigated the use of antimicrobials including oral, intramuscular, and intravenous for pneumonia, in

323 residents from 22 nursing homes in the US. They found the use of antimicrobials increased survival but were associated with increased discomfort in a care home population with advanced dementia (Givens et al., 2010). Similarly, Van der Steen and others found increased survival when using antibiotics to treat pneumonia, but only for a few days in some cases (van der Steen et al., 2012b).

Antimicrobial use appears more beneficial for people in the earlier stages of dementia compared to the later stages, with no difference in mortality at this later point between those receiving antimicrobial treatment and palliation and those not (Fabiszewski et al., 1990). Nearly 25 years on the effectiveness of antimicrobial treatment is still unclear (Mitchell et al., 2014). Treatment increasing survival for just a few days, is described as simply prolonging the dying process (van der Steen et al., 2012b). Antimicrobial treatment is associated with renal failure, diarrhoea, use of intravenous lines, and skin rashes. Hurley and colleagues found no difference in discomfort between those treated with a palliative approach or antibiotics (Hurley et al., 1996). Some have argued that patients who have pneumonia would be less comfortable than patients with some other sources of infection and therefore it is important to identify the source of infection when commenting on the difference in comfort levels (van der Steen et al., 2012b). More research into the use of antimicrobial treatment is needed to ascertain the risks and benefits of their use, and if antimicrobials are more effective for certain types of infections.

Despite the lack of evidence, Van der Steen and colleagues reported that antibiotic treatment was used in more than 40% of people dying with dementia in the UK, US,

Switzerland and Italy (van der Steen, 2010). In the Netherlands antibiotic treatment for pneumonia is commonly withheld for people with advanced dementia (van der Steen et al., 2002), however, there has been an increase in use of antibiotics for symptom relief (van der Steen, 2010). The use of antimicrobials for treatment of infections increases with the proximity to death in the US (Mitchell et al., 2012, D'Agata and Mitchell, 2008) despite results showing that these drugs are less effective in more advanced dementia (Fabiszewski et al., 1990).

2.6.3   Artificial nutrition and hydration

An additional medical decision, and arguably one of the most distressing decisions for families to make with dementia in the later stages, is the introduction of artificial feeding. Some carers believe that they cannot allow their relative to 'starve to death'; they feel that the use of artificial feeding will extend life and prevent discomfort or further complications such as aspiration (Thuné-Boyle et al., 2010), potentially leading to an improvement in quality of life (Mitchell and Lawson, 1999). In the UK the adoption of artificial nutrition and hydration has been a controversial topic for some time and is not recommended in the NICE-SCIE guidelines (National Institute for Health and Care Excellence, 2006). Artificial nutrition can be provided for patients who have difficulty eating or swallowing, through two methods: percutaneous endoscopic gastrostomy (PEG) feeding tube via the abdominal wall, or a nasogastric tube (NG) feeding tube, which enters via the nasal passage.

Studies (all of which have been conducted in the US) of the prevalence of artificial feeding vary, with the amount of tube feeding being used in people with dementia varying from 4 - 39% (Hanson et al., 2008, Munn et al., 2007, Sloane et al., 2003, Gessert et al., 2006b,

Ahronheim et al., 1996). Currently there is no evidence that feeding tubes offer any benefit to the individual (Mitchell et al., 2004a, Candy et al., 2009). On the contrary they increase the chance of infection, aspiration and further complications (Mitchell et al., 2004a, Gillick, 2000, Petersen and Kruse, 1997, Evers et al., 2002). This has led to the EAPC recommendation that permanent artificial feeding should be avoided (van der Steen et al., 2014). As with the limited understanding of pain in dementia we similarly have a limited understanding around feelings of hunger and thirst in people with dementia. Work undertaken with stroke and cancer patients to help understand these sensations, suggests they only feel transient hunger, whilst thirst can be easily quenched with the use of mouth swabs (McCann Rm, 1994).

2.7   Cause of death

Common causes of death among community and hospital settings for people with dementia are reported to be pneumonia, cardiovascular events and pulmonary embolism, a pattern which does not differ greatly from that of people dying without dementia (Kammoun et al., 2000, Beard et al., 1996, Lloyd-Williams, 1996). There are, however, many other dementia related complications which can occur at the end related to dementia such as dehydration and cachexia (difficulties in swallowing) (Koopmans et al., 2007), which also illustrate the difficulty of determining a cause of death. A person with dementia may not die from dementia, but they will die with dementia (Cox and Cook, 2002). A report from the National End of Life Care Intelligence Network found that between 2001 and 2009, 631,078 deaths were reported in England with Alzheimer's disease, dementia, or 'senility' noted on the death certificate (National End of Life Care Intelligence Network, 2010). However, Romero and colleagues have argued that dementia is still under reported on death

certificates (Romero et al., 2014). This may be because people still do not accept people can die from dementia nor recognise it as a terminal illness (Davies et al., 2013, McCarty and Volicer, 2009). Dementia has only been accepted as a cause of death on death certificates in the US since 1994 (Sachs et al., 2004), making international comparisons difficult.

Cox and Cook proposed that people with dementia die in one of three ways. They can have dementia, but die from another cause other than dementia. They live with dementia and a mix of other conditions which together cause death. Or finally people may have advanced dementia and subsequently die from the complications that this brings (Cox and Cook, 2002).

2.8   Barriers

As this chapter has demonstrated, researchers perceive high quality care as being provided for people with dementia at the end of life, either through correction of under treatment of pain or avoidance of overtreatment of other symptoms. Some research has focussed on why quality has not been implemented in end of life care in dementia (Harrison-Dening et al., 2012a, Sachs et al., 2004, Kupper and Hughes, 2011, Ryan et al., 2011, Gardiner et al., 2011). Within the literature this implementation problem has been described as a matter of overcoming one or several barriers. The following section synthesises the conceptualisation of barriers as categorised and discussed in the research literature.

2.8.1   Trajectory and prognosis

People with dementia at the end of life generally experience a gradual decline in mobility. In general terms, most become increasingly frail, and will experience a further decline in the final few months of life (Lunney et al., 2003b). However, the trajectory of dementia can be very uncertain and this limits the ability of professionals to provide an accurate prognosis for a person with dementia (Hanrahan and Luchins, 1995, Sachs et al., 2004, Volicer et al., 1993, Luchins et al., 1997, Mitchell et al., 2004b, Schonwetter et al., 2003). The course of dementia is unlike that of cancer, for example, where it can be easier to predict the course and trajectory of the disease. This can be seen in the disease trajectory of chronic conditions (Figure 2.3) which also reflects the trajectory of dementia, compared to cancer (Figure 2.4) (Sachs et al., 2004). In cancer the patient will reach an advanced stage then follow a general decline over the coming weeks or months. The dementia trajectory is punctuated by declines induced by acute illness, with many incidents such as infection or falls which can become the final incident and result in death. Other chronic diseases such as congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD) have a similar trajectory to that of dementia; however, the slope is slightly steeper for dementia. A person with 'only' COPD and no cognitive impairment may regain baseline activities of daily living after an acute illness, but a person with dementia is less likely to return to baseline (Murray et al., 2005).
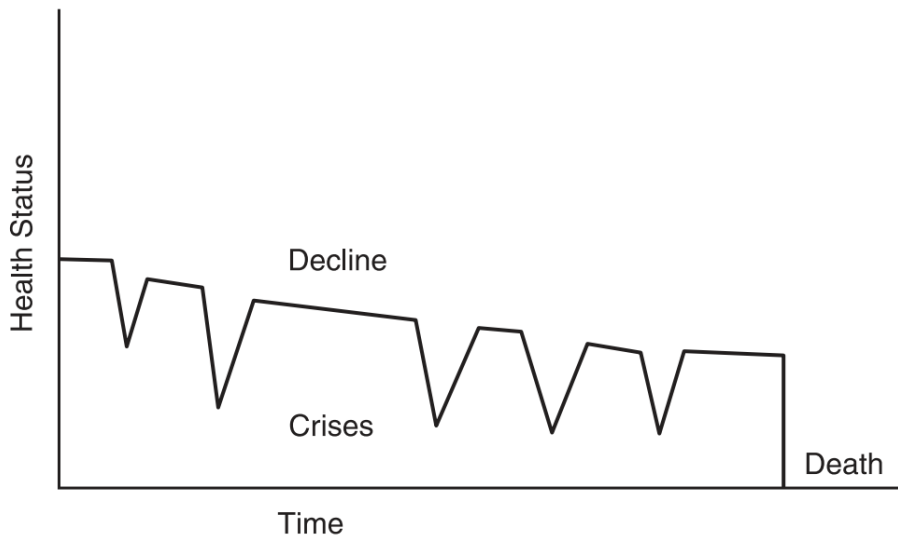
Figure 2.3 Death trajectory in chronic conditions (including dementia)
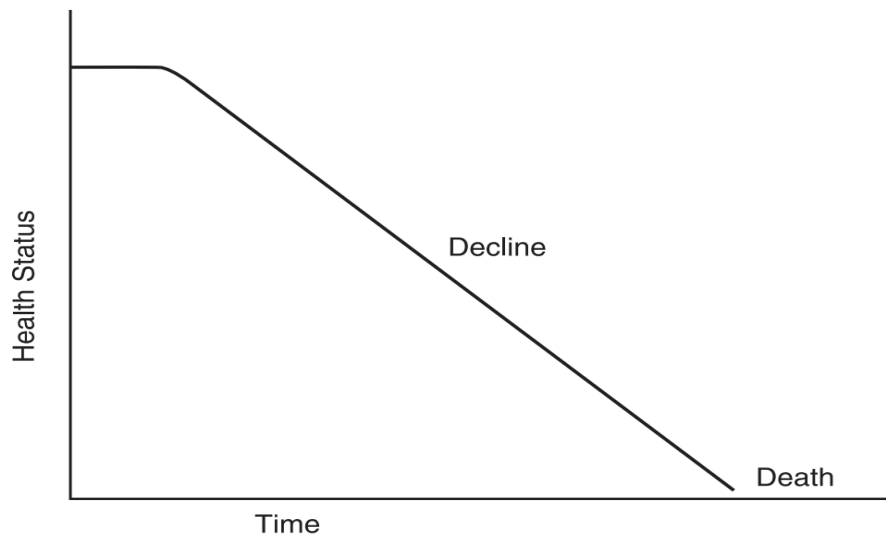
Figure 2.4 Death trajectory in cancer

No two people with dementia have the exact same symptoms, progression or trajectory, complicating prognosis and the development of treatment further (Alzheimer's Society, 2014). Moreover, not all patients will live long enough to develop advanced dementia, as people can die throughout the course of dementia (van der Steen et al., 2012a). According to van der Steen the majority of research into end of life care for dementia has focussed on advanced dementia (van der Steen, 2010), and more work needs to focus on other points in the trajectory and end of life care.

Prognostication can be particularly problematic for people in the US healthcare system, with a six month or less prognosis required to be eligible for hospice care (Brickner et al., 2004). Although the dementia trajectory makes prognostication difficult, increasing numbers of people with dementia are receiving hospice care in the US (Miller et al., 2010).

Many studies have attempted to estimate survival within dementia (Rait et al., 2010, Larson et al., 2004, Koopmans et al., 2003, Walsh et al., 1990, Williams et al., 2006). Rait and colleagues found median survival after a diagnosis of dementia in primary care was 6.7 years for those aged 60-69, falling to just 1.9 years for those diagnosed at age 90 or over (Rait et al., 2010). This does not provide an estimate of survival from onset of symptoms or consider time taken to establish a diagnosis. What is more interesting, however, is the high mortality rate in the first year after diagnosis of dementia, with a rate three times greater than people without a diagnosis of dementia. This rate dropped in subsequent years, but suggests diagnoses are made at times of crises or late in the course of dementia. Xie and colleagues conducted an analysis on data with a 14 year follow up of people with dementia,

to determine estimates of survival after onset (Xie et al., 2008). Similar to Rait and colleagues' findings, they found age was a significant factor in predicting mortality. They reported a median survival time from symptom onset for men of 4.1 years and 4.6 years for women. When broken down into age groups these survival times after onset were 10.7 years for the age group 65-69; 5.4 for 70-79; 4.3 for 80-89 and 3.8 years for people aged 90 years and over.

Often close family members will notice the first signs of dementia, but they are often unsure as to whether these are signs of dementia or simply signs of the normal ageing process (Social Care Institute for Excellence (SCIE), 2013). Those who lack close family may not have someone to notice early signs, and may therefore live with dementia for quite some time before they receive a diagnosis. The timing of diagnosis of dementia within the UK has been a concern for some time. The National Dementia Strategy published in 2009 identified diagnosis as one of its key priorities within the UK (Department of Health, 2009) although early diagnosis was later replaced by an aim of 'timely' diagnosis (Burns et al., 2014).

Some tools have been developed to help professionals with prognosis, generally known as prognostic indicator guides. These include guides produced by the Gold Standards Framework (GSF) (Thomas, 2005) and Supportive and Palliative Care Indicators Tool (SPICT) (Boyd and Murray, 2010), both of which were recommended in the National End of Life Care Strategy (Department of Health, 2008a). Neither of these guides are dementia specific, however, an alternative is; the Functional Assessment Staging Test (FAST)

(Reisberg, 1987). A study of the predictions of nursing home staff and medical professionals in the US found that they estimated 1.1% of their residents would have a life expectancy of less than 6 months, but 71% died within this period (Mitchell et al., 2004a). More recently a review from Brown and colleagues found 6 month prognoses made using the FAST scale were unreliable, as they only identified studies from the US and Israel, the reliability of other guides (such as the GSF and SPICT) were not discussed (Brown et al., 2012). Until recently the GSF prognosticator guide had not been studied prospectively. O'Callaghan and colleagues however have reported that the tool is highly specific (92%) and moderately sensitive (63%) at identifying people in their last year of life (O'Callaghan et al., 2014). This was limited however to an acute hospital setting and was not specific to people with dementia, only including 4 people with dementia out of 99 participants.

2.8.2   Poor understanding of dementia

People with dementia do not have equal access to palliative care services as people with other conditions such as cancer (Sampson et al., 2006). However, the WHO has stated that 'every person with a progressive illness has a right to palliative care' (World Health Organisation, 2004). Sampson and colleagues demonstrated that professionals fail to refer people with dementia to specialist palliative care services because dementia was often not recognised as a terminal condition (Sampson et al., 2006). Families and some professionals have acknowledged that palliation is the best option for people with advanced dementia (Teno et al., 2004), however, professionals appear to have difficulties with this in practice. The research previously discussed on survival times indicates clearly that dementia is a terminal illness (Rait et al., 2010, Xie et al., 2008). It has survival times similar to other end of life conditions such as metastatic breast cancer (Mitchell et al., 2009) and new

recommendations from the EAPC state it should be regarded as a terminal condition (van der Steen et al., 2014). Some have suggested that care for people with dementia should be palliative from the point of diagnosis (Shega et al., 2003), as it is a terminal illness with no disease-modifying treatment available.

Since the development of the modern hospice movement, palliative care services have focussed on cancer (van der Steen et al., 2014). However, in recent times within the UK (as discussed in chapter one) this has begun to change, with its services branching out in response to other diseases which may require specialist palliative care (Addington-Hall and Higginson, 2001). Despite this, the IMPACT study found that there is still inequitable access to palliative care across Europe for people with dementia compared with cancer (Davies et al., 2013).

There are several potential explanations for this inequitable access. Sampson suggested that the lack of recognition of dementia as a terminal illness occurs because of the poor understanding of the pathophysiology of dementia among healthcare providers (Sampson, 2010, Thuné-Boyle et al., 2010). They argued that knowledge and understanding of both dementia and palliative care need to be combined when caring for persons with dementia at the end of life. Davies and colleagues found that many palliative care services do not recognise dementia (Davies et al., 2013). Robinson et al. suggested that a multidisciplinary approach is required, incorporating a range of different services from old age psychiatrists to palliative care specialists (Robinson et al., 2005). The multidisciplinary approach proposed can be seen in the typical pathway of end of life care (Figure 2.1).

Harrison-Dening and colleagues have highlighted that many professionals, including hospital staff, district nurses and ambulance staff, believed they had little training in dementia and needed more knowledge and skills (Harrison-Dening et al., 2012a). Possible misunderstandings about dementia may have ramifications for the skills that these professionals bring to bear on people with dementia. Concerns about knowledge and skills are twofold; they encompass concerns from professionals with dementia knowledge knowing little about palliative care and palliative care specialists knowing little about dementia. It is becoming apparent that there needs to be a multidisciplinary approach for end of life dementia care with an increased skills and knowledge base about both dementia and palliative care. All members of the health and social care team involved should be trained and have adequate skills to provide end of life care to people with dementia (van der Steen et al., 2014).

2.8.3   Lack of ability to communicate

As noted, in the latter stages of dementia there is a reduced ability to communicate (Mitchell et al., 2009). This appears to be particularly problematic when concerning the relief of symptoms such as pain (Regnard et al., 2007), with consequences for the quality of care. In care homes there is much reliance on the nursing and care staff providing information and observations about the patients or residents as they develop a relationship with them (Robinson et al., 2005). However, many care homes have a high staff turnover (Hitchen, 2008, Hussein and Manthorpe, 2011), often because of high work load, poor pay and limited acknowledgment of the work they do (Hussein, 2010, Hussein and Manthorpe, 2011). Robinson and colleagues argued that impaired communication in people with dementia makes information provided by staff about residents, such as their ability to

recognise facial expressions and pain, invaluable (Robinson et al., 2005). Unfortunately, a high turnover of staff may make this harder as staff do not know the patient or resident well enough (Hughes and Robinson, 2004).

The National End of Life Care Strategy in England recommends, and the NCPC is campaigning for, advanced care planning (ACP) to be completed by people in the earlier stages of dementia, while the person still has cognitive capacity (Department of Health, 2008a, National Council for Palliative Care (NCPC), 2009). The EAPC has furthermore recommended support for people with mild dementia to begin such planning (van der Steen et al., 2014). Advance care planning (ACP) can be defined as:

> *'process of discussion that usually takes place in anticipation of a future deterioration of a person's condition, between that person and a care worker'* (Henry and Seymour, 2007).

It potentially gives patients and families an opportunity to think about what is important for them and plan to ensure these wishes are met (Harrison-Dening et al., 2011). In the context of England and Wales it may consist of a statement of wishes (with no legal validity) about what an individual would like to happen at the end of life. This may include the wish to remain at home or even the type of music they would like to have played when they are in their final days or hours. While this is not a legally binding document upon professionals, it should be taken into consideration by professionals when making decisions about an individual's treatment.

ACP may be confused with advance decisions (under the Mental Capacity Act (MCA) 2005, applicable in England and Wales). An advance decision is a document which details what an individual does not want to happen to them at the end of life or should they be unable to make a decision. It is a decision to refuse treatment. This could include a 'do not attempt resuscitation' (DNAR) type instruction, or forbid the use of artificial means of nutrition and hydration. Advance decisions can only be made by a person who has capacity and therefore need to be considered and if desired completed early for people who are diagnosed with dementia. An advance decision is legally binding, if signed and witnessed.

In England such planning and decision making for end of life care is still a relatively new concept with little understanding by some professionals (e.g. GPs, old age psychiatrists), not helped by the complexities of the varying terms such as 'advance care planning', 'advance decision', 'living will' and the powers of attorney roles (Robinson et al., 2013). It is still relatively rare within the UK for a person with dementia to have an advanced care plan or advance decision (Sampson, 2010, Harrison-Dening et al., 2011). Many health and social professionals are reported to lack the confidence, feel inexperienced and need additional training and support in this area (Sampson et al., 2012). One study of a range of health and social care staff found that they believed that if they did not call emergency services in a crisis there would be repercussions for them (Harrison-Dening et al., 2012a).

As noted, introducing planning and decision making as early as possible is encouraged in the National End of Life Care Strategy and by the NCPC (National Council for Palliative Care (NCPC), 2009, Department of Health, 2008a). Decisions and discussions may include

artificial nutrition and hydration and cardio-pulmonary resuscitation. Where advance planning has not been completed professionals often rely on families to aid the decision making process, although this can also occur when planning and decisions have already been made. There is a growing amount of literature surrounding planning with some placing high importance on what they regard as the necessity for people with dementia to complete advanced care plans (McCarthy et al., 1997).

2.8.4   The extent of an integrated approach

It is argued that a multidisciplinary approach is required to deliver 'good' quality end of life care for people with dementia (Robinson et al., 2005). However, this can be problematic on many levels for many countries, not just the UK. Integration might be seen as a term that refers not only to the integration of specialist palliative care services with other services, or the health and social care systems, but also how services and systems should work with each other. It has been argued that for successful and quality end of life care there needs to be good organisation and integration of all services, however, this appears to be lacking (Hughes and Robinson, 2004, Davies et al., 2013, Davies et al., 2014b), with the National Dementia Strategy expressing concerns over the lack of clear integrated dementia pathways (Department of Health, 2009). A range of disciplines are involved in end of life care for people with dementia (see Figure 2.1), but research with a wide variety of professionals has showed that many have little knowledge of each other's work and remit (Harrison-Dening et al., 2012a).

Dementia is neither solely a medical nor a social condition and therefore both health and social care systems need to cooperate and work with one another; however many countries

do not experience this (Davies et al., 2013). Many professionals feel there needs to be better and earlier integration of general and specialist palliative care services and have expressed their concerns about how people move through the health and social care systems, with little to guide them and several potential breaches of continuity of care (Davies et al., 2013). Harrison-Dening and colleagues found that pathways of care were lacking and that this impacted on the coordination of care provided, particularly at times of crises, when out of hours services were called to respond (Harrison-Dening et al., 2012a). A simple pathway of care is thought to be one improvement which can be made to improve the integration of professionals and services, to provide a holistic and multidisciplinary approach but such an approach has not been proven at proof of concept level still less in practice (Davies et al., 2014b). However, as Samsi and Manthorpe suggested the term pathway has multiple and overlapping meanings (Samsi and Manthorpe, 2014). They propose four: 1) a mechanism for the management of confusion and uncertainty; 2) a manual for sequencing events; 3) a guide to consumers, indicating eligibility for care activities or self-management for dementia dyads; 4) a manual for walking with the person. Sami and Manthorpe advised caution when assuming a shared understanding of the term 'care pathway'.

2.9   Place of care

Most people with dementia in the UK are cared for at home. Those receiving social care largely receive this from the private sector, predominantly in care homes (Ballard et al., 2001), with the majority of deaths in 2010 in people with dementia occurring in care homes (63%) or hospitals (30%) (Kane, 2012).

2.9.1   Preferred place of care

Within England through the End of Life Care Strategy, it is policy to ensure that an individual's wishes as to where they would like to die are adhered to as much as possible (Department of Health, 2008a). According to Gomes and colleagues, the majority of people would prefer to die within their own home, although for some a care home is regarded as a home (Gomes et al., 2012). However, this has not been explored with people with dementia (Badrakalimuthu and Barclay, 2014). They may have different preferences arising from the nature of the disease and potential burden on family members. A possible desire among those with dementia to die at home is further complicated by increased risk of infections, difficulties swallowing and emergency admissions to hospital as previously discussed (Kane, 2012, van der Steen, 2010, Mitchell et al., 2009).

2.9.2   Care at home

A retrospective survey with families of people with dementia showed that those who remained at home had fewer symptoms at the end of life, compared to those who spent all or some of the time in other settings including nursing homes and hospitals (Volicer et al., 2003). Families also reported fewer physical signs of distress in people who died at home compared to in hospital. Moves to nursing homes were often caused by confusion and lead to behavioural problems. Like much of the literature on end of life care and dementia, this study was conducted in the US, therefore caution needs to be taken when applying these findings to a UK setting, because home care in the US may differ to that in the UK. For example, hospice care in the US is usually at home and there are fewer building based hospices, whereas in the UK hospices exist more as bed-based facilities and are less home-

based. However, in the UK there are growing numbers of community-based hospice or palliative care teams, with 337 home palliative care teams in 2012 (Bolognesi et al., 2014).

2.9.3 Care homes

Mitchell and colleagues studied care received by people with advanced dementia in nursing homes in the US (Mitchell et al., 2004a). They found that it was common for invasive treatments to be offered to residents with dementia, including feeding tubes, laboratory tests and intravenous therapy. Restraints were more commonly applied to people with advanced dementia compared to residents with cancer. Finally, they found pressure ulcers and the use of anti-psychotics were more prevalent in residents with advanced dementia compared to people with cancer. The authors concluded that more needs to be done in nursing homes to understand the terminal nature of dementia and the palliative approach that should be taken in end of life care.

Many residents of care homes in the UK have dementia, either with or without a formal diagnosis. This is suggested by the fact that half of all deaths in 2012 in care homes in England and Wales were from dementia (Office for National Statistics, 2013). Barclay and colleagues noted that care homes are increasingly becoming acknowledged as 'important providers' of palliative care for older people (Barclay et al., 2014) and hence providers of palliative care for people with dementia.

A case study report of two nursing homes and a survey of 180 managers of nursing homes from Seymour and colleagues demonstrated how end of life care for older people in England requires improvement (Seymour et al., 2011). They identified several key factors

which influenced their conclusion of 'poor' care, including: 1) the relationship with the GP, in particular the support from the GP and willingness to prescribe; 2) lack of support from out-of-hours services; 3) lack of support from other agencies including district nursing teams; 3) the cost of syringe drivers; and 4) lack of access to training for staff. Access to syringe drivers is particularly important at the end of life, with potential implications for pain management. Others have shown poor pain management in care homes is an international problem (Torvik et al., 2008, Miller et al., 2004).

Seymour et al. highlighted the importance of the multidisciplinary approach and how the limited availability of it can have a negative influence on the care received. However, caution to the interpretation of these results should be advised due to the limited cases involved in the study (two) and results from the survey data.

Handley and colleagues, however, have similarly identified issues of working relationships between primary healthcare staff and care home staff which did not have onsite nursing facilities (Handley et al., 2014). They reported that although GPs and district nurses visited the care home residents, rarely was there documentation to discuss end of life care or signs of deterioration, with ambiguity about roles. This is despite primary healthcare staff acknowledging it was their responsibility to have discussions about end of life care and future care planning. Handley et al. call for better working relationships between health care and care home staff from entry to a care home up to and including end of life.

2.9.4 Hospital

Efforts that have been made to reduce deaths in hospital across all conditions (Andrew, 2012), may be viewed as positive, given that hospitals are not the best place for people with dementia. It is argued that most treatment which is undertaken in a hospital among people with dementia could be undertaken at home or in care homes (Givens et al., 2010, Loeb et al., 2006), with the exception of some treatments such as treatment of fractures. Morrison and colleagues found that following an acute illness there was an increased risk of mortality at 6 months after hospitalisation from a hip fracture or pneumonia amongst people with dementia compared to people who were cognitively intact (Morrison and Siu, 2000b). They recommended that treatment following such incidents or illnesses should be focussed on increasing comfort as opposed to aggressive or invasive life prolonging efforts. However, this study was only completed in one hospital in the US, limiting its generalizability. It is also not clear if relatives of the patients opted for a palliative approach to their care, as opposed to life-prolonging treatment.

Gozalo and colleagues in the US demonstrated that transition to hospital at the end of life in nursing home residents with cognitive impairment (as defined by a cognitive performance score of 5 or 6 on the MDS cognitive performance scale) was associated with 'poor' quality care. They found those having more transitions to hospital were more likely to have feeding tubes and stage IV decubitus ulcers (Gozalo et al., 2011). Harrison-Dening and colleagues interviewed carers of people with dementia in London and found people with dementia were often discharged from hospital in a worse state than when admitted to hospital (Harrison-Dening et al., 2012a). They were discharged with infections, bed sores and worse behavioural problems than they were experiencing on admission. It is now asserted that a

hospital is not the best setting for people with dementia to receive care and everything should be done to prevent transfer between settings when people with dementia are at the end of life.

2.9.5   Hospice care

Many in the palliative care world for example, van der Steen have recommended a palliative care approach at the end of life for people with dementia (van der Steen et al., 2014); and have observed that care provided by a hospice is rarely available to people with dementia (Hughes et al., 2005). Similarly, poor access to specialist palliative care has been documented in the literature (Davies et al., 2013, Sampson et al., 2006). More needs to be done to ensure that there are equitable end of life care services for people with dementia that enable people to die in their preferred place of care, and receive 'good' quality end of life care in the UK.

2.10   Dementia end of life policies, guidelines and strategies

As described above, many debates surround treatment for people with dementia at the end of life. Subsequently this means that the development of guidelines can be quite challenging, with only few guidelines existing, often based on consensus (van der Steen, 2010). In contrast to cancer, there are relatively few guidelines available to professionals for end of life care in dementia. Policy documents developed within England, such as the National Dementia Strategy contain minimal information about end of life care (Department of Health, 2009) while palliative care guidelines do not acknowledge end of life care for people with dementia (Mast et al., 2004, National Institute for Health and Care Excellence (NICE), 2004).

The number of guidelines worldwide has increased in recent years, but the evidence base for these guidelines is weak, with research lacking in this field (Sampson et al., 2011a). In the absence of guidelines, recommendations have been made within the academic literature, particularly from Volicer (Volicer et al., 2002, Volicer, 2005, Volicer et al., 1986) and organisations such as Alzheimer's Europe (Alzheimer's Europe, 2008) and the EAPC (van der Steen et al., 2014), whilst others have tried to create guidelines (Lloyd-Williams and Payne, 2002).

Guidelines relevant to dementia relate to specific issues such as the use of antibiotic treatment (van der Steen et al., 2000). There are also guidelines which provide guidance on advanced dementia but do not advise on end of life care (Holmes et al., 2008). It is important to note that many people may not reach advanced dementia and they may die before this stage and therefore advanced dementia guidelines cannot always be used to guide end of life care in dementia (van der Steen et al., 2012a). Due to a lack of overlap between the National Dementia Strategy (Banerjee, 2009) and the National End of Life Care Strategy (Department of Health, 2008a), the NCPC and the Alzheimer's Society has been working to amalgamate both of these two guidelines (National Institute for Health and Clinical Excellence, 2011); however a direct government approach would be welcomed.

At the time of writing, the EAPC has produced a white paper which has defined optimal palliative care for people with dementia (van der Steen et al., 2014). This was developed as a project using consensus methods and it produced 11 core domains and 57 recommendations for optimal palliative care for people with dementia (see box 2.2). This is

currently the most detailed guidance and framework available to researchers and practitioners on delivering palliative care for people with dementia.

- applicability of palliative care

- Person-centred care, communication and shared decision making

- setting care goals and advance planning

- continuity of care

- prognostication and timely recognition of dying

- avoiding overly aggressive burdensome or futile treatment

- optimal treatment of symptoms and providing comfort

- psychosocial and spiritual support

- family care and involvement

- education of the health care team

- societal and ethical issues

Box 2.2 EAPC 11 core domains of optimal palliative care (van der steen, 2014)

2.10.1 The English National Dementia Strategy

The English National End of Life Care Strategy as introduced in the previous chapter contained little information about the care that should be provided for people with dementia (Department of Health, 2008a). Shortly after the publication of this Strategy, the Department of Health released the English National Dementia Strategy (Department of Health, 2009). Like the End of Life Care Strategy, there has been criticism that it does not integrate both end of life care and dementia well. The aim of the National Dementia Strategy is described as enabling everyone with dementia to live well with dementia, rather than a focus on dying well (although Objective 12 is explicit in its focus).

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Objective 12 focuses on end of life care and covers planning for people with dementia using the range of planning tools which are available, ensuring individuals' preferences are taken into consideration. Other aspects of the objective aim to enhance the structure of end of life care for dementia through the development of local pathways and frameworks using the GSF. Finally, it aims to improve the spread of best practice for end of life care in dementia through the palliative care networks. The networks are groups of palliative care researchers and clinicians whose aim is to improve palliative care, such as the European Association of Palliative Care (EAPC), or the Palliative Care Research Society (PCRS). The objective refers to the End of Life Care Strategy, expressing the need to link dementia services with those listed in the National Dementia Strategy.

2.10.2 The National Institute for Health and Care Excellence (NICE)

Working in collaboration with the Social Care Institute for Excellence (SCIE), the National Institute for Health and Care Excellence (NICE) devised guidelines for dementia practice (National Institute for Health and Care Excellence, 2006). The guidelines emphasise the use of a palliative care approach, with an emphasis on quality of life, focussing on physical, psychological, social and spiritual needs from diagnosis until death. The guidelines state it is important for palliative care professionals to ensure that people with dementia have the same access to palliative care as those who do not have dementia. Specifically it recommends that primary care teams should ensure palliative care assessments are completed and communicated throughout the team. The guidelines acknowledged the management of complexities which arise in dementia, including nutrition, infection and cardiopulmonary arrest. They recommended that there should be encouragement to eat by mouth for as long as possible, with artificial feeding used solely if dysphagia is a transient

phenomenon and not if it is a part of the decline of the disease. They specified that antibiotics in the end stages should be considered on an individual basis. Cardiopulmonary resuscitation is unlikely to succeed, they acknowledged and this should be reflected in organisational policies while decisions should reflect the patients and families wishes. Finally, in terms of pain management, an observational pain assessment tool should be used such as those already discussed in this thesis (e.g. PAINAD (Warden et al., 2003), or DOLO-PLUS 2 (Wary and Collectif, 1999, Wary et al., 2001)). Treatment following these assessments should use both pharmacological and non-pharmacological approaches.

The dementia quality standards later produced by NICE/SCIE have limited information on end of life care (National Institute for Health and Care Excellence (NICE), 2010). Of the ten quality standards, one of these refers to end of life care, recommending assessments for people with dementia which will assist in identifying and planning their palliative care needs.

This and the previous chapter have pointed to the significance of NICE guidelines and quality standards for both end of life care in general and specifically for people with dementia. Current guidelines for dementia refer to end of life care, and other areas covered may be applicable to end of life care (National Institute for Health and Care Excellence, 2006). The dementia quality standards however are lacking an end of life care focus and professionals have been encouraged to utilise the general end of life care quality standards (National Institute for Health and Care Excellence (NICE), 2010). The palliative care clinical guidance is of less use for dementia as these are based on palliative care for cancer

(National Institute for Health and Care Excellence (NICE), 2004). Despite this, until such end of life care guidance for dementia is developed, professionals have been advised to utilise both the NICE guidance for dementia and palliative care, in conjunction with information from the National Dementia Strategy (Department of Health, 2009), EAPC (van der Steen et al., 2014) and information from third sector organisations such as the Alzheimer's Society or the NCPC.

2.11   Conclusion

End of life care for dementia may require an increase in research and clearer findings to establish firmer evidence on which to base comprehensive guidelines to encourage better quality of care; however, the implementation of good practice is a further challenge. As noted throughout this chapter, much of the dementia research discussed has been completed in the US. This research, although beneficial, has variable transferability to UK settings, with differing health, social and financial systems. At present the evidence supports the description of people with dementia as 'the disadvantaged dying' (Robinson et al., 2005).

CHAPTER 3:QUALITY END OF LIFE CARE FOR PEOPLE WITH DEMENTIA: WHAT HAVE FAMILY CARERS TOLD US SO FAR? A NARRATIVE SYNTHESIS

3.1 Background

3.1.1 Conceptualising carers?

With the increasing number of people with dementia (see chapter two), health and social care systems are facing an increasing demand for care (Knapp and Prince, 2007, Ferri et al., 2005, Alzheimer's Disease International, 2009). The symptoms of end stage dementia leave individuals unable to care for themselves and dependent on the care of others. The majority of this care is provided by the relatives or friends of the person with dementia (Brodaty and Donkin, 2009). These carers are often spouses, middle aged adult children, or children-in-law of the person with dementia and are more likely to be female than male (Alzheimer's Association and National Alliance for Caregiving, 2004, Australian Institute of Health and Welfare, 2007, Prince, 2004, Schneider et al., 1999). However, the number of male carers is increasing and their contribution to caring may not be fully acknowledged (Arber and Gilbert, 1989). Population predictions suggest a larger subgroup of older males as spouses caring for their wives will emerge (Ribeiro et al., 2007) and male carers generally may increase in numbers (Robinson et al., 2014). It is estimated that carers 'save' the UK economy approximately £12 billion every year and are therefore a component within health and social care in the UK (Luengo-Fernandez et al., 2010). Together it is estimated that carers provide 1.3 billion hours of care per year to people with dementia (Alzheimer's Society, 2014).

3.1.2 The term 'Carer'

There are currently around 670,000 family and friends acting as primary carers (i.e. provide the majority of care) of people with dementia in the UK (Lakey et al., 2012). They have a range of different titles or labels such as lay carers, untrained carers, informal carers, or family carers (Thomas et al., 2002). However, some have suggested that the term "carer" or "caregiver" is now redundant and should not be used (Molyneaux et al., 2011, Pilgrim, 1999). The term distracts from the relationship which existed before they became a 'carer' for the person, for example as wife, husband, daughter or son and which they still retain. For many the realm of responsibility and duty is encompassed within this traditional role and does not need to re-defined as 'carer'(Cleary et al., 2006). Traditionally there are distinct boundaries between carers and the cared for. Caring in palliative care however may differ from caring for someone with physical or intellectual impairment. The boundary between the 'carer' and the 'cared for' is said to be somewhat blurred, because of the increasing need for the carer in palliative care (Molyneaux et al., 2011). Molyneaux and colleagues agreed with Pilgrim and suggested a description of the relationship and what the relationship was before 'caring', would be more acceptable (Molyneaux et al., 2011, Pilgrim, 1999).

3.1.3 Career of a Carer

Some have suggested that caring is a 'career' with many people having to devote a substantial proportion of their time to their relative (Lindgren, 1993). In respect to dementia, there has been a discourse by some of caring for a "living dead person" (Albinsson and Strang, 2003), and some portray the person with dementia as the 'already dead' (Small et al., 2007, p.3). The caring career involves a variety of tasks in addition to

meeting the physical and mental needs of the person with dementia. These include: interaction with health and social care professionals, doing daily house hold chores, and escorting the person with dementia to various medical, dental, optical and hairdressing appointments.

Lindgren interviewed spouses of people with dementia and concluded the caring career can be split into three stages (Lindgren, 1993), beginning with the 'encounter stage'. This is the point at which the person is diagnosed and is characterised by a period of adjustment to and understanding of the diagnosis. A relative may learn the new skills to care for someone with dementia and may change their life style to fit these perceived demands. Often families are the ones who have 'pushed' for the diagnosis, however their willingness and readiness to receive a diagnosis varies (Bunn et al., 2012). The 'enduring stage' is the middle phase of the caregiver career in which the workload and the intensity of the caring reaches its peak. This is followed by the final stage, the 'exit stage'. This stage is associated with the death of the person with dementia, the loss of the carer role and adjustment to a new life (Lindgren, 1993). Lindgren stated that the exit stage is the stage we know least about. In 2006 Zarit and Gaugler agreed with this (Zarit and Gaugler, 2006) and 20 years on from Lindgren (as discussed below) this appears to still be the case.

3.1.4   Caring for someone with dementia

Despite carers being seen as having a caring 'career', the experience is not the same for all. Something which is often neglected in the caregiving literature is that not all carers are loved by their relatives, and can be mistakenly labelled as "loved ones". Sanders and colleagues explored the experiences of family carers of people with dementia at the end of

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life (Sanders et al., 2009). Sanders and much of the literature from the US talk about caregivers. When referring to American literature and Sanders for example, I will use the term caregiver, but throughout this thesis the term carer will be used. They described four 'portraits' or typologies of caregivers, disengaged, questioning, all-consumed, and reconciled. Disengaged caregivers were caregivers who had either physically or emotionally removed themselves from the person with dementia. They had often had poor relationships with their relative before dementia was diagnosed, and the diagnosis of dementia generated more strain on this relationship. Questioning caregivers were those who were anxious about the diagnosis and struggled to understand the disease and its trajectory. Such caregivers often had lower levels of education and tended to not accept or believe the diagnosis or the terminal nature of the disease. 'All consumed' caregivers, were individuals wanting to know, and be involved in every detail of their relatives' care. Many of these kept their relative at home for as long as possible. Finally, reconciled caregivers accepted that their relative was dying and were prepared for their death.

It is well known that caring in general can be a stressful role and that the burden placed on the individual carer is often great, with limited opportunity to have breaks, socialise and have whatever one may classify as a 'normal' life (Twigg and Atkin, 1994). However, caring for an older person or a relative with dementia is thought to be one of the most stressful and difficult forms of caring (Kneebone and Martin, 2003). Carers as described in the portraits by Sanders and colleagues, face the difficulty of coming to terms with the diagnosis and the loss of the person they once knew (Sanders et al., 2009). They may find

difficulties with the individual's behavioural and cognitive decline, the loss of their own 'normal' life, the role of caring, and finally the eventual death of the person.

With this difficulty in adapting to the carers new role, there has come a large body of literature exploring the burden of caring for someone with dementia, the guilt felt by carers (Adams and Sanders, 2004), pre-death grief (Kiely et al., 2008, Chan et al., 2013), physical and mental health including stress (Diwan et al., 2004) and depression (Haley et al., 2003), coping (Mausbach et al., 2007, Rudd et al., 1999) and unmet need (Gaugler et al., 2004). Most of this work above on carers has surrounded the diagnosis and middle stages of caring (Peacock, 2012).

At the time of writing only four reviews had explored the experiences of family carers of people with dementia at the end of life. The first review, from Ryan and colleagues, focussed on the beliefs around decision making at end of life and families' involvement from ten papers (Ryan, 2009).

The second review, by Hennings and colleagues focussed solely on dying in care homes from 12 papers (Hennings et al., 2010). They noted that 'rarely have the views and experiences of family caregivers in their own right been elicited'. They identified similar themes to those by Peacock (2012) in her review, with carers finding themselves in unfamiliar territory, unaware of the disease and its trajectory, and often not helped by the lack of communication with professionals. Having a relative with dementia in a care home at the end of life entailed numerous decisions for carers. Hennings and colleagues discussed

the difficulty some carers had in making these decisions and the tools they used to help with this. The authors' final theme encompassed the grieving carer, who had to make decisions about care and treatment whilst still grieving for their relative, again often ill-supported by professionals.

The third review by Peacock only found 10 papers that had been published relating to carers' experiences of end of life care in dementia (Peacock, 2012). Half of these studies were quantitative and two had mixed methods, leaving three which used qualitative methods. Peacock believed this is a weakness of research in this field as experiences require in-depth discussion and understanding which are best achieved in one-to-one in-depth interviews. She felt that even with semi-structured interviews some understanding may be missed. In her review Peacock summarised the findings of the ten papers into five themes: grief and loss; burden and guilt; depression; response to end stage; and expressed needs of family caregivers. She concluded that there were lingering feelings of guilt, burden, grief and depression among many family carers. These could be made worse either by placement of the person with dementia into long term care or by the death of the individual. However, one of the most important findings of this review is the abundance of knowledge gaps it identifies in the literature, a reflection of the lack of work in this field. Such gaps included potential differences of experiences related to place of death and the positive and negative aspects of caring.

The final review by Raymond and colleagues included 12 papers and was a rapid appraisal of both the family and professional carer literature, focussing on narratives (Raymond et al.,

2014b). This review identified themes around the wishes and rights of the person with dementia, medical management and symptom control, elder abuse and neglect, spirituality, being a family member or carer, and grief. The authors note in this review there were a range of perspectives around these issues. Notably, there were contrasting views between professionals and carers.

The small number of reviews, and the limited number of studies within them are a measure of the shortage of research into the carers' experiences of end of life care for people with dementia. Carer research still appears to be most prominent in the cancer literature (Payne and Grande, 2013). However, attention to carers of people with dementia has been identified as a priority for future research and policy initiatives worldwide (van der Steen et al., 2014). The VOICES (views of informal carers for the evaluation of services) survey which was developed in the 1990's by Julia Addington-Hall, is a questionnaire of the experiences of end of life care of carers (non-professional carers). The National End of Life Care Strategy made an objective to develop VOICES and carry out a national survey (Department of Health, 2008a).The survey which the Department of Health commissioned as the 'National Survey of Bereaved People' was carried out in 2011 and 2012 by the Office for National Statistics (Office for National Statistics, 2014). The results demonstrated varied quality of care across the country and that between 48% and 58% died in the preferred place of death. However, again this survey did not focus on bereaved relatives of people with dementia.

The reviews above have several limitations. Ryan's review offers a detailed view into the process of decision making, but lacks many of the other aspects of end of life care (Ryan, 2009). Hennings and colleagues focussed only on care homes and excludes papers related to other settings (Hennings et al., 2010). People with dementia are often moved across different settings at the end of their life, including unnecessary hospital admissions (van der Steen, 2010). The review from Peacock was much broader view of carers' experiences than others but thereby lacked focus. However, it did give useful commentary on the current gaps in the literature (Peacock, 2012). The review from Raymond and colleagues was a rapid review which focussed on narratives rather than original research (Raymond et al., 2014b). The results were also based on a combination of professionals' and family carers' views. None of the reviews discussed incorporated quality of care either within their search strategies or within their discussions.

3.1.5   Aim of the current review

The development of the research question is discussed below as part of the methodology. It was previously said by Eakin and Mykhalovskiy that the research question should be seen more as a compass as opposed to an anchor within qualitative research (Eakin and Mykhalovskiy, 2003). The research question as a compass suggests the questions should be developed over time, taking an iterative approach to identifying and analysing qualitative research, similar to the iterative approach in primary qualitative research (Dixon-Woods et al., 2006).

None of the reviews discussed above appear to have used search terms to identify the available literature on the quality of care seen from the perspective of family carers. For

example, some simply used the word 'experience' (Peacock, 2012). However, for the purpose of this thesis they have been used as good scoping reviews for the field in general. The current review therefore aimed to be more systematic in its approach to searching and synthesising papers. This review explored carer's views, focusing on their experiences and opinions of the quality of end of life care for dementia.

3.2   Method

3.2.1   Design

This is a qualitative review which took a systematic approach to both the search strategy and the selection of studies, following the guidelines of the Centre for Reviews and Dissemination (Centre for Reviews and Dissemination, 2009). The review adopted a narrative synthesis approach which followed the guidelines of the Economic and Social Research Council (ESRC), using thematic analysis and tabulation as tools for analysis (Popay et al., 2004).

3.2.2   Approach to search strategy

Systematic reviews are traditionally used for identifying and synthesising quantitative studies, but there is increasing work to include qualitative studies in systematic reviews (Dixon-Woods et al., 2006). Applying systematic review methods to qualitative research has created debates as to whether they should be used for this type of research. Some argue systematic reviews de-contextualise studies and it is not possible to synthesise literature from authors with varying philosophical stances (Dixon-Woods et al., 2006). Philosophical stance is discussed in more detail in chapter five.

Traditional search strategies for quantitative systematic reviews aim to be exhaustive and identify all relevant studies (Doyle, 2003). However, some take the position that qualitative reviews should not encompass an exhaustive search for all papers which are relevant. There should be more of an approach akin to primary research, to purposively sample research papers and find a range of concepts (Thomas and Harden, 2008, Doyle, 2003).

Qualitative research is notoriously difficult to locate (Dixon-Woods et al., 2006, Barroso et al., 2003, Walters et al., 2006, Wong et al., 2004). Grey literature and electronic databases should also be searched together with hand searching of journals if necessary to identify studies. For the current review, grey literature was searched, but hand searches were not performed as relevant journals were included in the electronic database searches. Searches of the reference lists of included studies and citation tracking were conducted. In addition to these techniques, relevant experts were contacted to identify any additional articles which may not have already been found through searching.

Scoping

An initial scope of the literature revealed only two reviews of carers and end of life care in dementia (Hennings et al., 2010, Ryan, 2009). Subsequently, a broader review was published at the end of 2012 as part of a PhD thesis (Peacock, 2012). As part of the IMPACT project (discussed on page two) a review was conducted which explored the views of carers in palliative care, both professionals and families (Raymond et al., 2014b). These were discussed in more detail previously in this chapter. These reviews and

identified papers helped with the development of search terms for the main search of this review.

Initial search

After this initial scope and review from IMPACT, a search of the literature based on the initial research question for this PhD *'What are the experiences and expectations of family carers for palliative care in dementia?'* was performed in 2012. After completing the literature search however, it became apparent that the resulting papers were very broad focussing on a very diverse range of topics in end of life care for people with dementia. The main problem appeared to be the term 'experience'. The term is too ambiguous and ill-defined for the purpose of this PhD. Within the literature there was a lack of shared meaning and understanding among the various authors of studies about 'experience'.

The main categories which I identified from the papers appeared to be: caregivers' individual experiences and feelings such as pre and prolonged grief, stress, strain and burden; and the experience of decision making. It could be argued that all these constitute an experience or in some way affect one's experience. However, the question remained what is an experience? This made organisation of the studies and determining the exact focus of the literature review difficult.

It was concluded that the research question *'What are the experiences and expectations of family carers for palliative care in dementia?'* was ambiguous. The research question needed redefinition and operationalizing of the key words in this question. The term

"experience" was too broad. It could be argued that an individual's experience can be affected by many different factors.

It was therefore important to go back to the original research question and develop clearer, well defined aims and objectives, and a fresh research question. In order to develop a better understanding of the field, the research question was narrowed to focus on a particular aspect within the area of end of life care and dementia, whilst still utilising the experiences of carers.

The angle of the research was changed to explore the family carers' perspectives of the quality of end of life care for their relatives with dementia. The needs of carers or the psychological experiences, including grief and stress, would not be the focus of this thesis or systematic review.

Revised Search

The revised search strategy drew on guidance from the Centre for Reviews and Dissemination guidance for undertaking systematic reviews in health care (Centre for Reviews and Dissemination, 2009). The search began by identifying a clear research question:

'What do we understand about quality end of life care for dementia from the perspective of families?'

The principle of PICO (Centre for Reviews and Dissemination, 2009) was applied to guide the selection of search terms (see table 3.1). A selection of key words were identified and used to scope the literature to develop an idea of publications in this area. Synonyms, or abbreviations that were felt appropriate were added to the search terms.

As research which is similar can be described in various ways both a selection of free text words were used and subject headings also known as MESH terms, index terms, or thesaurus terms. Papers from the scoping and previous searches were read to check on common subject headings and keywords used. From this the draft search strategy of free text words and subject headings identified in MEDLINE were tested in this database. The papers were checked for relevance and papers identified which were not used to develop the search strategy were viewed for additional keywords and subject headings. The search was amended appropriately and rerun.

Table 3.1 Application of PICO (Centre for Reviews and Dissemination, 2009)

P (patient/population)	dementia
I (intervention/treatment)	palliative care/end of life care
C (comparators)	not applicable
O (outcome)	carer perspectives

3.2.3   Databases and search terms

The search was run in April 2012 and updated in May 2013 and September 2014. The search was performed in MEDLINE, EMBASE, CINAHL SCIE, and PSYCH INFO. The following search strategy of keywords was used in all databases:

("quality" or "quality of care") and ("dementia" or "alzheimer*" or "neurodegenerative*" or "vascular") and ("palliat*" or "end of life*" or "end of life care" or "eolc") and ("carer" or "family" or "proxy" or "caregiver" or "relative" or "next of kin" or "nok") and ("perspective" or "perception" or "perceive*" or "view" or "opinion")

Subject headings for keywords were used where possible, and adjusted for different databases, however not all databases use subject headings for all keywords identified. The same key words were used across all databases. Grey literature was searched using Sigle (INIST-CNRS). The search was aided by a search filter and pre tested strategy from the Scottish intercollegiate guidelines network for dementia (Scottish Intercollegiate Guidelines Network, 2002)

This review focussed on the perceptions of quality of care and not on the satisfaction with care. For this reason some papers which may have discussed quality of care may have been missed in the search strategy. During the preliminary search it was realised that "quality of life" produced results that were relevant but did not come up without searching for quality of life. Quality of life was included therefore as a search term (subject heading only) but it is not of primary interest. Both "end of life care" and "palliative care" were used as key

terms within the search strategy as it was hoped this would allow for the discrepancies of definitions.

The search in April 2012 originally found 403 papers and this was updated in May 2013 shortly before publication of the review (Davies et al., 2014a) which found an additional 53 papers, one of which was eligible for inclusion. The search was re-run in September 2014 before submission of this PhD thesis. An additional 59 papers were found however none were eligible for inclusion.

3.2.4   Inclusion/exclusion criteria

Papers were included if they met all of the following criteria:

- About dementia

- Including family carer of a person with dementia

- Referring to end of life care or palliative care

- Including perceptions on the quality of care received by the person with dementia

Papers were excluded if they were not about an aspect of palliative care or end of life care in dementia from the perspective of the family carers. Perspectives reported by professionals were not included. Papers which were not specifically about or did not focus on dementia were excluded. Only original peer reviewed articles were included and not reviews.

3.2.5   Selection procedure

Titles and abstracts of articles were screened and excluded by myself if they did not meet the inclusion criteria. A rapid appraisal of non-English language articles, using their English abstracts was performed to ensure that any important articles were not excluded. Articles considered relevant but where not enough information was supplied to make a decision about inclusion in the abstract and title, were read in full. A fifth of excluded full text articles and all included articles were read and checked by a second reviewer (LM). This enhanced the validity and reliability of the selection procedure (Centre for Reviews and Dissemination, 2009). Any disagreements among reviewers or uncertainty about inclusion of papers were decided by a third reviewer (SI). See figure 3.1 for an overview of the selection procedure.

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┌─────────────────────────────┐
│ Number of records identified │
│ through database search:     │
│        N = 515               │
│     Medline = 163            │
│     Embase = 293             │
│     CINAHL = 32              │
│     Psychonfo = 25           │
│     SCIE = 2                 │
└─────────────────────────────┘
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Number of records identified through database search:

N = 515

Medline = 163

Embase = 293

CINAHL = 32

Psychonfo = 25

SCIE = 2

Number of records identified from other sources:

N = 2

Number of records after duplicates removed:

N = 425

Number of records screened:

N = 425

Number of records excluded:

N = 309

Number of full-text articles accessed for eligibility:

N = 116

Number of full-text articles excluded:

N=108

Reasons:

1. Reviews (n=1)

2. Protocol or no results (n=3)

3. Poster of published paper (n=1)

3. Language (n=19)*

4. Quantitative (n=26)

5. Did not meet the inclusion criteria (n= 58)

Number of studies included in the qualitative synthesis:

Research articles: N= 8

Figure 3.1. PRISMA flowchart describing the search process of finding articles for quality

end of life care for people with dementia from the perspective of family carers

*None of these abstracts met the inclusion criteria

3.2.6 Data extraction and analysis

A variety of synthesis methods can be used for qualitative research (Barnett-Page and Thomas, 2009), but there are debates about the appropriateness of these synthesis methods. There are arguments that by synthesising different qualitative studies the author is decontextualizing the data (Campbell et al., 2003). However, as in other research in this review there is a short description of each study for the reader to understand the context of each and think about how it should be applied (Thomas and Harden, 2008).

A method of synthesis which was considered for this thesis was meta-ethnography as a method of meta-synthesis. Meta-ethnography was first introduced in the education sector by Noblit and Hare as a method to synthesise qualitative research (Noblit and Hare, 1988), and the method has developed many times since then (Barnett-Page and Thomas, 2009). However, it remains poorly described and understood, and some argue plagued with methodological flaws (Atkins et al., 2008).

The evidence for this review was initially synthesised using a thematic synthesis. Thematic synthesis allows the authors to remain close to the original primary data included within the systematic review, whilst being transparent and developing new concepts and potentially hypotheses (Thomas and Harden, 2008). Systematic reviews have been widely used and developed as preparation for randomised controlled trials.

Thematic synthesis has been developed for work in health promotion and public health (Harden et al., 2004, Thomas and Harden, 2008, Harden et al., 2006). Many newly developed synthesis methods, including thematic synthesis, draw on methods from meta-ethnography (Noblit and Hare, 1988). Fundamentally, they involve the process of

translating, which is taking concepts from one piece of work and finding these concepts in another study. Following on from this a line of argument is developed based on the theories and evidence presented within these concepts.

Thematic synthesis was trialled with one paper (Gessert et al., 2006a). Both direct quotations from participants and the discussion from the original authors were transferred into Atlas.ti version 6.2.15 (Muhr, 2010) and coded line by line. However, it became apparent that there were many codes being produced and these did not seem transferable or applicable to other papers included in the review. On reflection, it was decided that the coding would become unmanageable and ultimately it would not be possible to synthesise the results of the papers in a meaningful manner. The line by line coding was delving too deep into the data which was not needed at this stage of the thesis. It was unduly time consuming. Thematic synthesis has also previously been shown to be best used for the development of hypotheses (Lucas et al., 2007); however this was not required for the current review. This review would be used to assist a further qualitative study and not for the purpose to develop a hypothesis for a quantitative study. Similarly, thematic synthesis is helpful for discovering commonalities between studies, by grouping similar studies and results into themes, but this method struggles to discover heterogeneity between studies (Lucas et al., 2007).

Narrative synthesis was considered as an alternative method to see if it would be better suited to the type of review being conducted and the identified primary papers. Narrative synthesis is useful when there is a diversity of studies to be synthesised, for example a range of different settings, types of participants, or methods used. This makes narrative synthesis ideal for synthesising qualitative data.

The method of performing a narrative synthesis has been unclear and it can be difficult to make it transparent. In response to this criticism the Economic and Social Research Council (ESRC) produced detailed guidance for conducting a narrative synthesis (Popay et al., 2004). The guidance makes it easier for both reviewers to perform narrative synthesis and readers to understand the methods. Although the authors recognise that narrative synthesis can be used in a variety of research questions, the ESRC guidance focusses on the use of narrative synthesis for two types of reviews. It focusses on questions of effects of interventions and questions of implementation of interventions. These may not be applicable to all reviews, as is the case in the current review. The ESRC guidance recognise this and therefore some of the recommended stages and tools listed may not be applicable for some review questions. To answer the current review question in this thesis the ESRC guidance was only used as guidance with deviation at points which are detailed and explained below.

The ESRC guidance describes four elements to the narrative synthesis process. The four stages are not necessarily linear in approach.

    a. Developing a theoretical model of how the interventions work, why and for whom. This is a way of devising the review question and finding the appropriate papers to include in the review. This step is not included in the current review as this is specific for interventions and an interventions 'theory of change'.

    b. Developing a preliminary synthesis which works to organise all the data from the papers. The report both suggests and offers a variety of methods and tools to help with the preliminary synthesis. Tools include: tabulation, thematic analysis,

textual description of studies, content analysis, vote counting as a descriptive tool, and groupings and clustering. For the purpose of the current review, all studies have been tabulated with relevant data extracted from the included studies using a standardized form (see table 3.2, on page 145). Data included author, year, country, participants, type of analysis, and main themes identified in the papers.

In addition to this there is a short discussion of the included studies preceding the thematic analysis. Thematic analysis was chosen as a technique for synthesising the data from the included studies as it allows the reviewer to identify commonalities and group the key findings of all studies. The reader can identify the current gaps in the literature. The included papers were coded using a coding strategy based on the principles of Strauss and Corbin (Strauss and Corbin, 2008), and overarching themes identified from these codes. Coding was conducted using Atlas.ti 6.2.15 computer software (Muhr, 2010).

As part of the analysis in this study charting was used in Excel, initially this was completed by one reviewer (ND) and then was checked by a second reviewer (LM). The second reviewer attempted to replicate the charting of quotations in Excel to check for agreement between reviewers about the meaning of quotations. Once a high level of agreement was reached, the charting and themes were discussed with a third reviewer (SI). This was to further enhance the rigour of results (Mays and Pope, 1995) and resolve any disagreements about the meaning of quotations and themes. These meetings among reviewers continued until there was agreement about the themes. As part of the discussions

alternative explanations and positions were searched for within the data, which enhanced the rigour and robustness of the results (Mays and Pope, 1995, Mays and Pope, 2000). This also allowed for the identification of any heterogeneity of the studies.

c. Exploring relationships between and within studies formed the third stage. The ESRC guidance provides a series of different approaches to begin to explore these relationships which, moves a step further than the simple description of studies provided in the preliminary synthesis. These included conceptual modelling and conceptual mapping. For this thesis the level of data available from the included studies was too limited and therefore the review did not proceed with conceptual modelling and mapping. However, diagrams were used as a method of exploring the data further, an example of this can be seen in figure 3.2.

d. The final element from the ESRC guidance is the assessment of the robustness of the synthesis. The guidance defines the robustness of the study as based on the quality of the included papers as well as the trustworthiness of the product of synthesising of these. This may be completed using the Critical Appraisal Skills Programme tool (CASP) (Critical Appraisal Skills Programme (CASP), 2006). The CASP tool allows for critical reflection on the included studies and therefore the quality of the synthesis. Critical reflection of the synthesis during peer debrief with all reviewers may also be used as a method of ensuring the robustness of the synthesis (Mays and Pope, 1995, Mays and Pope, 2000).

Treatment purely aimed at symptom modification

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  Accept  ─────────────────┼───────────────── Deny death
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Active/invasive/

aggressive treatment
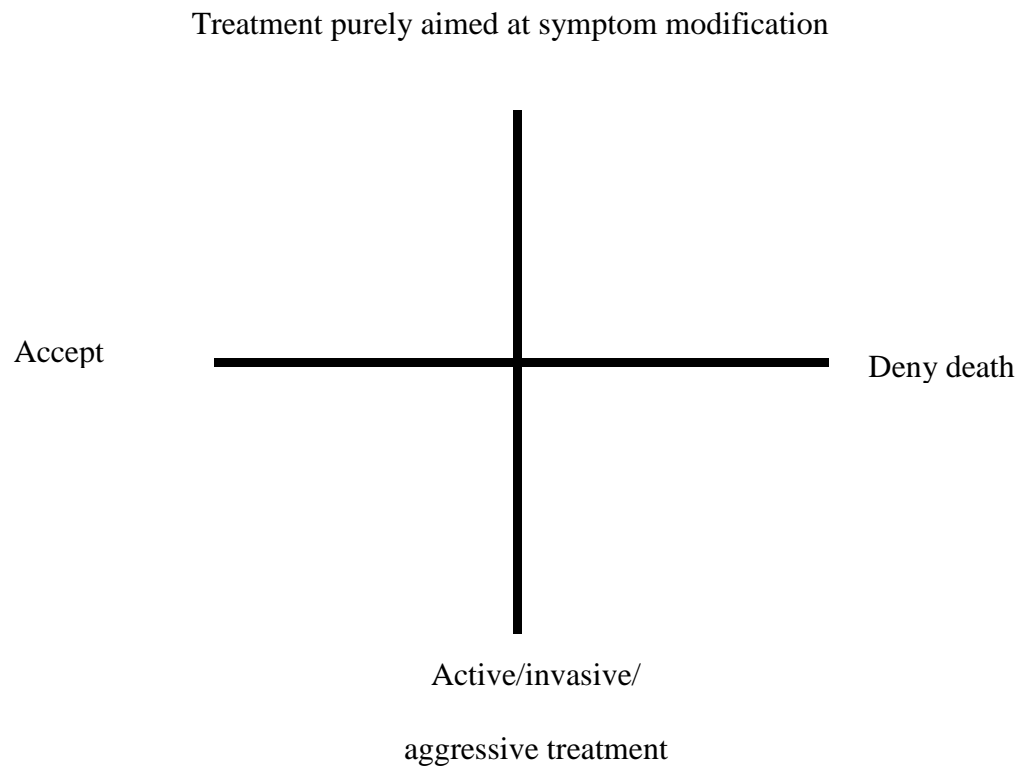
Figure 3.2 Family carer variations of beliefs of death and the approach of treatment for end of life care

It is difficult when synthesising qualitative research to determine what constitute findings. Many previous reviews have used quotations from original data within the studies plus the discussion around these quotes, as their data (Thomas and Harden, 2008). This solves the difficulty of trying to identify what qualifies as data, and also the difficulty with different reporting styles. Some of the papers within this review are discursive and do not contain direct quotes from participants. For this reason this review adopted the same position as Thomas and Haden (2008) and classified study findings as all text labelled 'results' or 'findings'.

3.3 RESULTS

3.3.1 Quality appraisal

The importance and relevance of critical appraisal to the content and methodology of qualitative studies in reviews is debated. The debate developed from the use of traditional methods used in quantitative research and systematic reviews (Mays and Pope, 2000) such as using checklists (Lincoln, 1985, Seale, 2002, Popay et al., 1998, Schwandt, 1996, Henwood and Pidgeon, 1992, Barbour and Barbour, 2003, Barbour, 2003). These are important questions and topics of debate, however the answer is not clear and there is not yet a consensus (Mays and Pope, 2000). For the current review the literature was appraised for quality using the CASP tool (Critical Appraisal Skills Programme (CASP), 2006), developed for the appraisal of qualitative literature. However, no studies from the current review were excluded based on the results of their quality appraisal. The tool was used to develop discussion of the included studies.

The CASP tool does have some limitations and misses some points which should be considered when appraising the literature. There is some repetition with questions prompting thought around the design and questions pertaining to the methods used. The CASP was only used as a guide and is not intended to be exhaustive. In particular some studies had a mixture of participants (families and professionals), however, this level of detail and prompts to consider study quality was not in the CASP tool. Neither does the tool suggest to think about the limitations of the primary study and if these have been discussed.

Several alternative tools were available for critically appraising qualitative research. These included: PROMPTS (Dixon-Woods et al., 2004), CORE-Q (Tong et al., 2007),

and the National Centre for Social Research Quality Framework for assessing the quality of qualitative evaluations (Spencer et al., 2003).

PROMPTS provide a series of statements about the literature which 'prompt' the reviewer to reflect on the quality of the methodology used (Dixon-Woods et al., 2004). It has been added to with a 'traffic light' system to aid this reflection, as many researchers felt unsure based on the prompt about the quality of the research. The traffic light system of green, orange and red, identify; papers, satisfactory papers as green and to be included; unsure as orange; and fatally flawed and irrelevant as red to be excluded. Although, these appear to add only further complications and ambiguities about inclusion and exclusion and therefore 'PROMPTS' was not used in the review for this thesis.

The CORE-Q offers a more comprehensive list of questions than PROMPTS which reviewers should consider, and it is very similar to the CASP tool (Tong et al., 2007). However, it is less well known and used, and has been developed only for the use of appraising studies that have used interviews and focus group methods, and therefore was not selected in this review.

Finally, the National Centre for Social Research Quality Framework for assessing the quality of qualitative evaluations is very large and cumbersome (Spencer et al., 2003). This was not required for the review when a tool was simply needed to describe and reflect critically on the literature and not exclude solely on quality.

Using the CASP tool to assess the quality of the studies included in this review, it was concluded that the studies were of mixed quality. As with much qualitative research some of the studies did not describe the methodology of the study very well (Treloar et al., 2009). Some studies failed to explain why they had chosen certain methods, for example, focus groups as opposed to interviews (Gessert et al., 2006a). It could be argued that focus groups are unsuitable when discussing end of life care, because this is a sensitive area and could need a more sensitive approach through one to one interaction/interviews. Payne suggests it may be more suitable to have smaller groups when researching sensitive and personal topics which are likely to elicit strong emotions (Payne, 2007). Yet an interesting explanation was provided by Harrison-Dening and colleagues as to why they chose to use a nominal group technique (structured group process to identify problems and generate solutions (Van de Ven and Delbecq, 1972)) (Harrison-Dening et al., 2012b). They suggested that nominal group has been used in health research for those with impaired language, understanding and capacity. They therefore argue it was appropriate to use with people with dementia. The lack of detail and clarity of some papers may have been due to the restrictions on word limits when writing for publication (Blignault and Ritchie, 2009).

The description of the data analysis was often not described in great detail in the included papers. The reader may be left guessing as to how the analysis was performed and the thought process behind it (Treloar et al., 2009, Kaldjian et al., 2010). A mixture of approaches to analysis was used in the included papers, with thematic and content analysis the most commonly used (Harrison-Dening et al., 2012b, Forbes et al., 2000, Gessert et al., 2006a, Holley et al., 2009). Two papers failed to state the type of analysis used (Gessert et al., 2006a, Treloar et al., 2009), but, based on the analysis description

by both sets of authors the reader could assume they both used thematic analysis. Only one paper discussed the possible influence of the researchers on the data collection and subsequent analysis (Lawrence et al., 2011). They used regular discussions to explore their personal beliefs and values which may have influenced these processes. However, many other studies have used a peer debriefing or group process to analyse the data, enhancing the rigour of their findings (Harrison-Dening et al., 2012b, Caron et al., 2005a, Forbes et al., 2000, Gessert et al., 2006a, Holley et al., 2009, Thuné-Boyle et al., 2010). These discussions may have included discussions about their personal influences on the data, however this was not stated. Similarly, no paper discussed qualitative theory or the theoretical stance adopted. This made it difficult when comparing studies, as it is not possible to ascertain if the various authors were looking at the data from similar or different viewpoints and beliefs.

The results sections of the papers were of mixed quality, many were supported by interesting and relevant quotes. However, two of the papers contained a mixture of professionals and family carers' views (Lawrence et al., 2011, Thuné-Boyle et al., 2010), which sometimes made it difficult to understand if the discussions were directly applicable to family carers or based on family carers' views. Despite this, both of these papers labelled quotes to indicate if the participant was a family member or a professional. Some of the included papers did however, lack some support (quotations) for the results they presented. For example, some studies provided themes with a discussion, supported by very few quotes (Lawrence et al., 2011, Holley et al., 2009, Forbes et al., 2000). In others, quotes did not address the entirety of the topic being discussed (Holley et al., 2009). Holley and colleagues suggest carers expressed a concern about access to practitioners whom were trained in geriatrics, palliation and end

of life. However, the quote they chose to support this statement only mentions experts in geriatrics.

3.3.2 Description of included studies

Five of the studies focussed on family carers as participants (Forbes et al., 2000, Gessert et al., 2006a, Treloar et al., 2009, Holley et al., 2009, Caron et al., 2005a). One recruited both family carers and people with dementia as participants (Harrison-Dening et al., 2012b). Finally, two of the studies interviewed family carers and professionals including, community, hospital, and care home staff. (Lawrence et al., 2011, Thuné-Boyle et al., 2010).

The studies spanned a variety of settings. Two focussed on the person with dementia in their own home (Treloar et al., 2009, Holley et al., 2009). Both of these studies were evaluations through interviews with carers about programmes designed to both encourage care at home for people with dementia at the end of their life. Holley and colleagues explored the Palliative Access through Care at Home (PATCH) programme (Holley et al., 2009) based in the US. Treloar and colleagues explored the work undertaken by Psychiatrists in the UK (Treloar et al., 2009). In this study Psychiatrists had been providing holistic home-based and palliative care until death. Treloar et al. explored the carers' views of people whom the psychiatrists had cared for at home until death as part of their psychiatric service.

Two of the studies explored care in nursing homes (Gessert et al., 2006a, Forbes et al., 2000). Only one study examined care in hospitals, which was conducted to inform an intervention to improve hospital care for dementia in the UK (Thuné-Boyle et al., 2010). A further study explored relationships between health care providers and carers

in long term care facilities (a university geriatric institute and a group of publicly funded long-term-care centres) in the US (Caron et al., 2005a). This was part of a much larger study on decision making among carers of people with dementia (Caron et al., 2005b). The remaining two studies were spread across different settings. Harrison-Dening and colleagues recruited from memory clinics whose client group were from a variety of settings, predominantly community (own home) and care homes (Harrison-Dening et al., 2012b). They focussed on exploring people with dementia's and carers' preferences about end of life care. Lawrence and colleagues recruited participants (carers and professionals) from a range of settings including: hospital, care homes, and continuing care units (Lawrence et al., 2011). They explored the definition of good end of life care for dementia across these settings.

Table 3.2 Description of included studies

Author	Year and Country	Study Design	Number/type Participants	Type of Analysis	Main Themes
Holley et al. (Holley et al., 2009)	2009, USA	Mixed methods – chart review, telephone/ face-face interviews	13 'caregivers' in the face-face interview	Content analysis	Preferences about the location of care; ease of access to a geriatrics and palliative Care experts; transitions of care
Gessert et al. (Gessert et al., 2006a)	2006, USA	Focus groups	38 'Family members'	Thematic analysis (but not stated)	attitudes toward death; attitudes toward prolonging life; drawing the line
Lawrence et al. (Lawrence et al., 2011)	2011, UK	In-depth interviews	27 'bereaved family members' and 23 'care professionals' from the community, care homes, general hospitals and continuing care units	Constant comparison method	Meeting physical care needs; beyond task-focussed care; planning and communication with family

Thuné-Boyle et al. (Thuné-Boyle et al., 2010)	2010, UK	Semi-structured interviews	20 'relatives' of people with advanced dementia and 21 hospital and nursing home staff	Framework analysis	Illness awareness; communication; pain awareness; attitudes towards end of life treatments and quality of life; hospitalization
Caron et al. (Caron et al., 2005a)	2005a, Canada	In-depth interviews	24 'caregivers', current and bereaved	Grounded theory: constant comparison and dimensional analysis	Quality of the relationship; frequency of contact; values and beliefs; level of trust
Harrison-Dening et al. (Harrison-Dening et al., 2012b)	2012, UK	Nominal group technique	6 people with dementia, 5 'carers', and 6 dyads of 'people with dementia and carers'	Content analysis	Good quality care; independence and control; perceptions of burden and caring
Forbes et al. (Forbes et al., 2000)	2000, USA	Focus groups	28 'family members' of people with dementia	Content analysis	Emotional effect, insult-to-life story, two faces of death, values and goals regarding end of life treatments and the unrecognised trajectory of dying

| Treloar et al. (Treloar et al., 2009) | 2009, UK | Mixed method of semi-structured questionnaire and interviews | 14 'carers' of people with dementia | Thematic analysis (but not stated) | Bereavement, essential carer's characteristics, required resources (professional expertise, and necessary equipment), funding and financial control, feeding, medication, availability of support services and end of life care and place of death. |

3.4   Findings of the synthesis

Two themes were identified as common to the papers included in this review; a carer's acceptance that their relative with dementia was dying, and a carer's idea of the appropriate level and purpose of treatment for their relative. These two themes are heavily related and together construct the theme 'a carer's belief of death and their preference of treatment'.

This section will begin by discussing this overarching theme and move on to explain the possible reasons for these beliefs and choices which emerged as themes from the papers. The reasons included: the professional as a core component of care quality, emotional and commitment pressures of caring, and finally carers' ability to think about death and dying.

3.4.1   A carer's belief of death and their preference of treatment

The included studies indicated variation among carers about what they perceived to be 'good' quality end of life care for dementia. They had different preferences about the level of treatment which should be provided. As noted research has attempted to classify carers, for example: 'disengaged'; 'questioning'; 'all consumed'; and 'reconciled' (Sanders et al., 2009). Similarly, Twigg developed three models of carers to describe orientation of agencies towards carers: carers as co-workers; carers as resources; and carers as co-clients (Twigg, 1989), later adding the superseded carer (Twigg and Atkin, 1994).

The two themes (a carer's acceptance that their relative with dementia was dying, and a carer's idea of the appropriate level and purpose of treatment for their relative) both reflect the variation in opinions of family carers. Within the first theme, it appeared

there were three constructs: carers who accepted death and that their relative was dying; carers who denied death and that their relative was dying; and finally carers who were ambivalent about the death and dying of their relative. It should be emphasised at this point that these are constructs and are not intended to be a simple categorisation of carers. They reflect a spectrum of carers' acceptance about their relative dying. It is not possible to place individual carers into one category or another. This would be an over-analysis of the available data. Most importantly it would be too simplistic and unrealistic to place carers into category A, B, or C.

The second theme (a carer's idea of the appropriate level and purpose of treatment for their relative) appeared to be discussing similar constructs related to acceptance of their relative as dying, however this was reflected as preferences of treatment or care. The reader may infer these preferences as the carers' opinions of 'good' quality care. Again views spanned a spectrum from no treatment or minimal, aimed only at symptom modification or relief, to active treatment aimed at cure.

To understand these two themes and the overarching theme being developed, a matrix of four quadrants was devised, incorporating the two spectrums (see figure 3.2, page 138). Further details and examples of quotes with the quadrants are given in figure 3.3 at the end of this chapter. The horizontal line represents the first theme of acceptance of their relative as dying. At the one end is complete acceptance that their relative is dying, and at the other end are those that have a sense of denial that their relative is dying or has a terminal illness. As the findings below will reveal many carers appear to fall somewhere along this spectrum, not clustering at either end of the spectrum. At the centre of the spectrum are those who are unsure about the idea and reality of death.

The vertical line represents the second theme of a carer's idea of the appropriate level and purpose of treatment for their relative along a spectrum. This spectrum ranges from treatment aimed at symptom relief or modification, through to treatment aimed at cure using more aggressive and invasive procedures. These procedures may include mechanical ventilation, cardiopulmonary resuscitation and artificial nutrition with the use of percutaneous endoscopic gastrostomy (PEG) tubes.

One study explored the attitudes of carers towards the death of their relative with dementia and end of life, focussing on the differences between rural and urban families (Gessert et al., 2006a). Many of the rural respondents were clear that they accepted death and they believed it was natural for their relative to die. Their preferences of treatment were for rather minimal and non-invasive treatments:

> *Rural respondents uniformly rejected medical interventions that they saw as "taking over for the patient" such as feeding tubes and "breathing machines."* (Gessert et al., 2006, 7:24)

> *Rural focus group participants discussed dying as a natural and appropriate process and revealed no interest in interfering with the process of dying.* (Gessert et al., 2006, 7:12)

> *Most rural focus group participants voiced unqualified acceptance of death. Death was characterized as natural, often with references to " going to sleep," or using language that described death as the accepted and expected " next step" in the life of the elder* (Gessert et al., 2006, 7:1)

However, their urban counterparts differed in opinion. They were less accepting of death and to some extent some even denied death and that their relative was dying. They opted for treatment which was more active or curative as opposed to palliative and simple symptom modification:

Urban respondents endorsed routine care and medical interventions for their relatives that were more aggressive than those endorsed by their rural counterparts. (Gessert et al., 2006, 7:26)

Several urban respondents rejected hospice and palliative care options that had been offered to them and regarded hospice as inappropriate under their specific circumstances because hospice care was seen as "not aggressive enough." "The hospice lady cornered my one brother ... and she really tried to get him to sign on the line ... we can't go along with that thinking ... they had the hospice person come every day and I mean I'm fully aware of what hospice is..." (Gessert et al., 2006, 7:31)

The acceptance and denial of death and dying were identified throughout many of the included papers, represented in carers' preferences of treatment or care for their relative (Gessert et al., 2006a, Forbes et al., 2000, Caron et al., 2005a, Treloar et al., 2009, Lawrence et al., 2011, Harrison-Dening et al., 2012b, Thuné-Boyle et al., 2010). Many carers discussed various types of treatment that could be delivered to a person with dementia at the end of life. As mentioned these treatments included; antibiotics, artificial nutrition and hydration through feeding tubes, mechanical ventilation, and

resuscitation. Some were adamant that they did not want any such treatment for their dying relative:

I'm not happy about it [feeding tubes]. If he gets to that stage, I just want him to go – slip away. That's not living, that's existing. (Thuné-Bolyle et al. 2010, 6:18)

At one point, they thought that maybe she had pneumonia. So, I met with the doctor. She said, "We can treat it, we can give her antibiotics and that will prolong her life." I said no because I knew that it meant that she would suffer longer and because of how she was, there was no point in prolonging. (Caron et al., 2005a, 2:22)

Interviewer: "So you're saying that it was important for you in those last moments, first of all, to be sure that she was not in pain?" Family caregiver: "Yes" (Caron et al., 2005a, 2:17)

However, there was not complete agreement with these preferences and therefore what was inferred as 'good' quality care varied. Some believed that there were treatment options which were acceptable at the end of life, in particular those treatments seen as less invasive and used to maintain comfort, such as the use of antibiotics for an incidence of pneumonia:

Antibiotics were viewed as a comfort measure, not as a technologic means of prolonging life, even for residents with very severe dementia. (Forbes et al., 2000, 4:13)

Many family members said they were comfortable with decisions to forgo heroic efforts such as the use of ventilators, but were generally in favor of the use of antibiotics and some were confused about the use of feeding tubes. (Forbes et al. 2000, 4:12)

[…] treatments such as antibiotics and feeding tubes should be offered as long as patients were comfortable. This was often the case even for those relatives who were against resuscitation (Thuné-Boyle et al., 2010 6:16)

Urban families, in the study by Gessert and colleagues, who were less likely to accept their relative was dying, suggested that measures such as ventilation could be used but only on a short term basis. This suggests a position in-between acceptance and denial on the spectrum, and towards comfort treatment along the spectrum:

Urban family members expressed a range of attitudes toward feeding tubes and respirators but were receptive to their use under defined conditions, as long as they did not become permanent. "Q: You would try to offer her healing with what? A: Well, I mean the medication. I mean whatever antibiotics. I mean as if she were anyone else. Q: As if she were you? A: Yes. Q: Complete with hospitalization and using the breathing machine. The ventilator? A: Even using

the breathing machine if it's not for … if you don't foresee long-term use of …
that machine." (Gessert et al., 2006, 7:28)

In contrast, other carers, who despite accepting that their relative was dying and the death would occur eventually, placed some conditions upon the acceptance of death. This meant that under some circumstances it was not 'acceptable' for death to occur. In particular if there was a treatable option, for example, pneumonia treatable with antibiotics. This indicates that these participants perceived antibiotics to be a life sustaining treatment compared to those discussed previously who considered it a comfort measure:

Death was forbidden [by the family] if the resident had any treatable conditions,
such as a urinary tract infection or pneumonia, or if a physician had not
declared the resident as terminal. (Forbes et al., 2000, 4:3)

Comfort and treatment often caused internal conflict and turmoil for many carers. This seems to reflect an uncertainty about the acceptance of death and dying, and their preference for treatment:

As long as I feel that he's comfortable and he's not in a lot of pain and that. I
think he should have treatment to the limit. (Thuné-Boyle et al., 2010, 6:17)

If she got pneumonia next week, I'm not sure of what I would do. I would
probably still have her treated. (Gessert et al., 2006, 7:17)

Some were confused and unsure about the entire approach and the thought of dying. They sometimes reverted to their own preferences to guide their decisions and thoughts on care:

Relatives' views on resuscitation were mixed and mainly depended on patient's wishes, patient's quality of life or what relatives would want for themselves if they were in a similar situation (Thuné-Boyle et al., 2010, 6:11)

"I just can't decide that right now [about feeding tubes, resuscitation], we will have to take it on a case-by-case basis." (Forbes, 2000, 4:20)

Those urban respondents who expressed their acceptance of death usually did so tentatively and with evident ambivalence. Many appeared to be reluctant to make statements that might be seen as too "friendly" toward the approach of death. (Gessert et al., 2006, 7:11)

However, moving away from acceptance of death and those measures which are seen as more for comfort, there were those who favoured more intensive and potentially invasive treatments which were aimed at cure. This reflected those who are perhaps in denial about their relative dying:

I think I would want the feeding tube because the rest of her body wasn't going … that was the only thing that was holding her up was the fact that she wasn't eating. Then she's starving herself to death rather than dying, you know … I would ask for a feeding tube until her body seemed to be all complete, be going,

you know. I don't want her to starve. I think that would be more painful in a

way, you know. More harder. (Forbes et al., 2000, 4:16)

Others felt that 'starving' their relative to death was unacceptable and that everyone 'should be given a chance' by providing life prolonging treatments until the very end:

Well, we must feed her in any way, by mouth or by tube, by anything. (Thuné-Boyle et al., 2010, 6:19:20)

Others felt their relative would want to live: "Yes . . . because everyone wants to live as long as they can. You can't just say, you know, go out, like . . . someone's got to bring her back." (Thuné-Boyle et al., 2010 6:14)

Some were described as thinking that their relatives deserved more in terms of treatment and should not simply be left to die because they were old:

The carers felt that medical decision-making and the use of end-of-life care pathways could invalidate their ACPs [advance care plans]:

. . . you are put on the short count to death row [End of Life Care Pathway] . . . I think a lot of elderly people are put on that path because it happens to be convenient . . . just because they are old basically, the plug is pulled . . . that decision can sometimes be made too early. (Harrison-Dening et al., 2012, 9:9)

I think things should be done as if she were just 20 years younger (Gessert et al. 2006, 7:19)

There was a group which struggled to discuss specific details but wanted comfort measures and treatments that were aimed at symptom modification rather than cure:

Participants discussed the desire for preserving dignity, promoting comfort, and ensuring good day-to-day care, but had difficulty incorporating goals such as comfort care into specific treatment plans. Comfort was a dominant goal and emerged in discussions of pain and suffering. Examples participants gave were, "I don't want my mom to suffer." "I hope she can go peacefully in her sleep and not have to suffer." Family members were unable to move beyond a broad description of comfort to specific care options. (Forbes et al., 2000, 4:8)

As seen by the discussion and quotations above it is evident that some of the four quadrants, were easier to fill than others. The evidence appeared to be clustered around two areas in those who accepted death and their choice of treatment was aimed at promoting comfort/or symptom modification and not life prolonging. It was also concentrated around those who did not accept death and wanted 'aggressive' options of care. There was some clustering around the centre of both these spectrums representing some ambivalence. However, there was less evidence which suggested that carers denied death but wanted non-'aggressive' or just comfort care, with only the one quote appearing to touch on this perspective (see figure 3.3).

3.4.2 Explorations/interpretations of why carers have these opinions of care and adopt a stance of acceptance of the dying process?

This section will explore some of the potential reasons to why carers had their views about death and treatment. These included: the professionals as a core component of care quality, emotional and commitment pressures of caring, and finally carers' ability to discuss/think about death and dying.

The professional as a core component of care quality

Across the studies professionals were seen as important to carers and several points regarding professionals emerged as particularly significant to help explain the carers' views. Factors included: providing contact, provision of information and support/relief/reassurance for the carers. Professionals varied amongst the studies with reference to GPs, social workers, district nurses, and other types of physicians.

Carers felt an important aspect of a professionals' role was simply providing contact between them, the family and the person with dementia:

> *One of the greatest dissatisfactions expressed by the family caregivers who participated in this study relates to the limited contact between themselves and the providers working with their family member.* (Caron et al., 2005a, 2:8)

If professionals had more contact with families and patients there was more opportunity for them to get to know their patients and offer personalised care. Carers were particularly happy when professionals spent the time getting to know the person with dementia, what they were like. This led to a subsequent element of trust:

There was a general fear and uncertainty with a lack of trust in medical decision-making:

…being sure that treatment is in my best interests... It means that you have got to trust in people who make the decision... (Harrison-Dening et al., 2012, 9:7)

My mother-in-law is someone who liked a little glass of brandy before supper. So when they asked us if she had any medication, we said no, but we said that she likes a little glass of brandy before supper. They said "Well, bring us the bottle of brandy." So, when they handed out the pills to the patients, she'd get her little glass of brandy with water. (Caron et al., 2005a, 2:7)

For many carers, contact did not just mean professionals getting to know the individual. It also consisted of formal meetings with them as carers, therefore the involvement of carers was important. The desired frequency of these meetings varied, with some feeling it was necessary to have regular contact:

[…] need, perceived by carers, for someone who would visit regularly, advise and bring in other people. (Treloar et al., 2009, 3:15)

When [the doctor] came out to the house to see her, I really think that made her feel better, and I know it made me feel better. (Holley et al., 2009, 8:7)

Others did not feel the need for frequent meetings but rather more regular contact to give an update on their relatives' condition:

Certain people hoped for fairly frequent meetings (frequent need to validate perceptions and receive answers to certain questions), whereas for other people, a regular, but not necessarily frequent, contact (i.e., once a year) would have been sufficient. (Caron et al., 2005a, 2:20)

The purpose of these meetings or interaction with professionals varied, for some it was for provision of information about the current condition of their relative. For others it was simply for information about dementia and the kind of care now appropriate. This allowed them to make decisions about treatment and prepare them for the death of their relative:

Old Age Psychiatry input was 'indispensable'. The style of input by this service had been regular visits to monitor and adjust medication and care input, to give advice and discuss worries etc. as well as visits at request for any reason. (Treloar et al., 2009, 3:3)

Well, for me, I think that in terms of the relationship [with the] family, it might have been good to have meetings with the staff, to see what is going on with [my relative], treatments, the evolution of the disease as well as getting to know each other a little bit. (Caron et al., 2005a, 2:10)

[…] nursing facility staff, occupied with day-to-day tasks, did not discuss with or prepare them for the death or dying of their loved one's. The lack of communication with a consistent provider impeded discussions of death and

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dying, implicitly reinforcing the belief that death is to remain hidden or unacknowledged. (Forbes et al., 2000, 4:4)

Lacking information about their relative but also lacking information about dementia and what palliative care entails, and what to expect at the end of life, carers not surprisingly conveyed their views that they lacked knowledge and understanding. This was evident in the accounts of some participants who possibly did not understand some of the symptoms of dementia at the end of life:

*Many family members said they were comfortable with decisions to forgo heroic efforts such as the use of ventilators, but were generally in favor of the use of antibiotics and some were confused about the use of feeding tubes. (*Forbes et al., 2000, 4:12)

Many family members did not view pneumonia as part of a "natural death" for someone with severe dementia, and agreed to hospitalization or to use of aggressive treatment in the nursing home, such as the use of intravenous antibiotics for the treatment of pneumonia (Forbes et al., 2000, 4:14)

Some had unrealistic expectations of end of life care, wanting advance notice of their relatives' imminent death. As discussed in chapter two this may not always be possible:

I mean I'd like to know … what are the last 2 days … so I can have at least 2 days warning. (Gessert et al., 2006, 7:8)

In addition some carers seemed not to understand that dementia was a terminal illness:

> *Families were aware that their relative's memory problems would deteriorate in the future but were often unaware of the terminal nature of dementia and its physical consequences.* (Thuné-Boyle et al., 2010, 6:25)

However, meetings between professionals and carers were also seen as a way of providing vital support and 'relief' for the carers, with professionals answering any concerns:

> *Summarising their views on ACP, NG 1 [nominal group 1] felt that carers' needs should also be taken into account: . . . it's having support to whatever you want to do at the end, in the most comfortable way not only for you but also for your carers.* (Harrison-Dening et al. 2012, 9:14)

> *In their view, such meetings would provide (a) an understanding of the evolution of the condition or illness of their relative, (b) an opportunity to receive answers to their questions from knowledgeable professionals, (c) reassurance, with doubts dispelled, and last, (d) a sense of being involved* (Caron et al., 2005a, 2:15)

The role of professionals to act as a source of reassurance may have helped many who were ambivalent towards death and the type of treatment provided. However, to provide information and reassurance, professionals need to be knowledgeable and respected. This was often described as not the case, with hospital staff typifying such deficiencies:

For many, this typified hospital staff's lack of understanding of the needs of people with dementia and what to do to meet them:

'There was no people feeding them [patients] and I went, I used to go in and feed her and they said, 'Oh no, she's here to be rehabilitated, you shouldn't feed her, it's spoiling her, she can do it herself,'' well . . . she couldn't do it at all and as I say her eating was getting worse and worse at that stage.' (Lawrence et al., 2011, 5:4, 5:5)

Many relatives also said that hospital staff did not seem to understand the needs of their relative: It was astonishing how little understanding the [hospital] staff had of him, of his condition, even though I did tell them . . . but I wasn't there all the time . . . so they were asking him questions, but obviously, he didn't even try to answer. So they were asking questions and then gave up and left him . . . and they seem to be nervous of him. (Thuné-Boyle et al., 2010, 6:2)

Such criticism applied to more than just the knowledge of hospital staff about feeding and understanding the needs of the patient and their family. It was also about deficits in comprehensive knowledge of dementia, palliative care and end of life care:

A parallel concern was having access to a practitioner trained in geriatrics, palliation, and end-of-life care. One caregiver said: The only thing is that what we really needed was an expert geriatrician who knows a lot about the medicines. (Holley et al., 2009, 8:5)

Conflict between professionals and carers also appeared to cause difficulties with treatment choice and the acceptance of death. This indicates that although some may be influenced by the information provided by professionals, some will already have made up their minds. Other factors must therefore influence their ideas about quality treatment and care:

> *In fact, several of the rural respondents anticipated that they might have to fight with medical personnel to prevent interventions in the dying process:*
> *'If that ever happened…I'd have to fight the doctors and everything else because they wouldn't go for it. … Yeah, the medical side would…want her to be treated'* (Gessert et al., 2006, 7:14)

> *That's what I was annoyed about because it [DNR] wasn't discussed with us or anything. He [the doctor] was very abrupt at first. Then he said, I'm sorry, but, you know, he won't be coming out'. So I said, 'That's for God to decide, not you'. So he said, 'That can be interpreted lots of ways'. So I said, 'Well, maybe'.* (Thuné-Boyle et al., 2010, 6:21)

Emotional and commitment pressures of caring

The papers briefly described some of the emotional strains and commitment pressure which carers have when caring for a relative with dementia. A link was identified between emotional strains and commitment pressures, and participants' choice of treatment and acceptance of death.

In particular adult children found caring demanding. They often had to strike a balance between 'normal' family life with their children and caring for their relative. At times they were not able to devote as much attention as needed to the person with dementia. This potentially led to more trust being placed onto professionals:

Family members expressed the pain of splitting themselves between their own immediate family, their personal needs, and the needs of the family member in the nursing home. A daughter said, "I mean it's totally on my shoulders too. And sometimes the amount of guilt is there, I mean it just weighs me down so much. But then I have to split myself, I still have kids at home, and I have to split myself there too." (Forbes et al., 2000, 4:30)

Many family carers also experienced guilt, with many feeling that they were torn between their thoughts of acceptance of death which could lead them to be seen as an 'agent of death', and their thought about the tragedy of death. Forbes described this as the 'two faces' of death. Creating a sense of uncertainty about death and treatment preference:

Torn between death as an acceptable blessing versus a forbidden tragedy, family members did not want to be an "agent of death." Family members wanted peace of mind, to believe that they had done everything possible and that death was beyond their control (Forbes et al., 2000, 4:22)

Unfortunately many in this study arrived with unresolved burden and guilt, having travelled through unknown territory (Forbes et al., 2000, 4:23)

Feelings of guilt were not restricted to guilt towards the person with dementia but there was also an element of feeling guilty about their preference of care and being judged by the professionals. Some feared a lack of support from the system and professionals:

> *I was afraid of being judged at times.* (Caron et al., 2005a, 2:26)

> *The carers challenged 'the system' arguing that if health and social care were effective in supporting people with dementia and their carers, 'burden' would not be an issue.* (Harrison-Dening et al., 2013, 9:12)

Carers' ability to discuss/think about death and dying

Some family carers struggled to discuss end of life care and the prospect of their relative dying. Many had previously never discussed or thought about what may happen in the future or postponed such tasks:

> *[…] but I haven't broached the subject of the future. I just can't bear to think about it really.* (Thuné-Boyle et al., 2010, 6:7)

> *I just can't decide that right now [about feeding tubes, resuscitation], we will have to take it on a case-by-case basis.* (Forbes et al., 2000, 4:20)

However, for some it was less of a fear, and more of an uncertainty about the future and how to plan. They were also concerned if plans would remain the same with the doctor possibly changing them. The person with dementia may have also changed their preference for treatment had they been able:

The carers felt it was difficult to plan ahead and anticipate what may or may not happen: ...you don't know what changes will happen, when it will happen . . . (Harrison-Dening et al., 2012, 9:8)

If he made it clear that he didn't want to be resuscitated, whether he's changed his mind about that now . . . people do sometimes, you know. I thought he would change his mind about that, but he was quite adamant at the time that he didn't want to be (Thuné-Boyle., 2010, 6:3)

However some, potentially those more accepting towards death, did not struggle to think or plan ahead:

One family member commented that advance care planning might alleviate the burden associated with this role. 'I think it makes it easier for the carer if they know because then you haven't got that moral dilemma. Because like I was placed in . . . was I stopping her having her last chance of life by not letting her go to [hospital] for the dehydration? . . . Would she have wanted it? You know you tear yourself in pieces.' (Lawrence et al., 2011, 5.12)

3.5   Discussion

The limited number of studies which were retrieved and included in this review highlights the lack of research within the areas of dementia, end of life care and carers' experiences. Surprisingly, (as previous work had shown the majority of work was emerging from North America (Peacock, 2012)) there were similar numbers of studies

conducted in North America and the UK. This is especially encouraging as the WHO has stated that the *"transferability of learning and experience is contextual"* (World Health Organization, 2006). It is not necessarily the case that the success of a quality improvement in one setting will be the same in another. There could be strong cultural differences, for example, differences in culture and health structures in the UK and North America that may mean that preferences for treatment and care would vary. This is evident in the difference between palliative care in the UK and hospice care in the US as discussed in chapter two.

This review indicates there is no definitive answer to what quality end of life care for dementia looks like from a carer's perspective. The studies showed carers range in their acceptance of the death of their relative, from complete acceptance and in some cases even a wish for death, through to complete denial of death. This is by no means an attitude which can be categorised. Carers are positioned along a spectrum and potentially move along this spectrum through the course of the 'caring career'. Many carers often do not know what to do for the best, how they feel, or how the person with dementia would feel. They can be left feeling unsure and often trapped between two ends of a spectrum about the views of treatment. This review's conclusion confirms the findings of Peacock who highlighted carers often felt ambivalent about the death of their relatives (Peacock, 2012). Peacock noted that there may be other studies which describe this, but do not name feelings of ambivalence. The current review confirms this and has reflected this in the spectrum of acceptance of death. This review suggests that this ambivalence is not only about acceptance of death but also about the level of appropriate treatment and care at end of life.

Carers' acceptance of death and acceptance that their relative is dying may have consequences for their possible grief and subsequent mental health. Hebert and colleagues in the REACH study demonstrated a link between the preparedness of death and mental health symptoms among bereaved carers, including; depression, anxiety and complicated grief symptoms (Hebert et al., 2006). However, what has been found in the current review is that acceptance of death seems to be related to the level/type of treatment deemed acceptable by carers at end of life.

This review has explored why carers think about acceptance and the type of treatment the way they do. It has highlighted a variety of reasons as to how carers may derive their preference of treatment level and acceptance towards death. Professionals appeared to play a key role in explaining carers' thoughts and behaviours. They seemed often able to exert influence through the support and knowledge which they were able to provide. The emotional and commitment pressures of caring also impacted on thought processes. Finally, carers' ability to think about death and dying also impacted upon these processes. It is possible that these factors may be interconnected, but the evidence available is too limited to draw firm conclusions.

3.5.1   Professionals as a core component of care quality

At the end of life a range of different professionals may be required to help a person with dementia receive 'good' quality end of life care. This fits with the WHO's definition of palliative care being holistic in its approach (Sepulveda et al., 2002). The review highlights the importance of communication among the triad of carer, person with dementia, and professionals. However, caution must be taken to not over emphasise the importance of the carer and 'force out' the person with dementia (Fortinsky, 2001).   This review supports Hennings and colleagues'   views that

communication often does not happen at times of crisis, leading to rushed decisions and possibly 'poor' quality care (Hennings et al., 2010). The current review highlights it is not enough for professionals to just communicate, they must also be knowledgeable and respected. This is often difficult as many professionals have little training and opportunities to train in both dementia and palliative care (Raymond et al., 2014a), despite many wanting to know more (Davies et al., 2014b). Although, as Davies and colleagues suggest training is not simply acquiring new skills, it is also about confidence and personal skills (Davies et al., 2014b). Many professionals have difficulty supporting carers, for example, through one to one discussion of needs and concerns (Hudson, 2013).

3.5.2   Emotional and commitment pressures of caring

As outlined earlier in this chapter, caring can be an especially demanding and difficult role which many do not aspire to and rather have forced upon them (Payne and Grande, 2013). Caring for someone who is dying, as shown in the findings of this review, can cause feelings of guilt, not simply due to the decisions about treatment they have to make. Guilt is also experienced because of the dual commitments to other family members, for example, in cases of adult children. However, it is not only relationships with other family members which may become strained. The commitment needed for caring can affect the carers' social life, resulting in feelings of social isolation (Leong et al., 2001). Some have suggested that the closer someone is to the person one is caring for, the more difficult caring can be in psychological and emotional terms (Payne and Hudson, 2008).

3.5.3 Carers' ability to discuss/think about death and dying

The current review found that many carers seem unable to think about the death and dying process of their relative. This corresponds to perceptions that healthcare professionals have about families' reluctance to discuss planning for end of life (Stewart et al., 2011). However, there may also be reluctance among professionals themselves to discuss end of life care (Livingston et al., 2011). Similarly, Sampson and colleagues designed an intervention to improve end of life care through advance care planning (ACP) for people with advanced dementia, however, they struggled to engage carers in ACP (Sampson et al., 2011b), with only seven carers making ACPs out of a possible 22. More research is needed to understand the thought processes of carers of people with dementia. Harrison-Dening and colleagues have also suggested that more understanding is needed about how to better engage carers and people with dementia with ACP (Harrison-Dening et al., 2011). At present they found that carers were unprepared for decision making. Harrison-Denning and colleagues suggest carers need emotional support, information about dementia, and an understanding of the issues in palliative and end of life care.

End of life care for dementia requires input from many different professionals, including social workers, GP's, district nurses, and potentially in some cases specialists from palliative medicine and geriatrics. This potential team and their possible interactions are important, potentially providing vital and often valued information to family carers. A carers' ability to think about death and dying may be facilitated if carers have a key health professional with whom they can liaise or contact. Again, this exemplifies the importance that professionals play for some carers.

3.5.4 Alternative reasons

The current review focussed on three main explanations of why carers may support the treatment options that they do and their levels of acceptance of death/end of life, that were present in the included papers. However, there may be other reasons which were not present in the studies included in this review. Other papers have reported the influence of religion, quality of life, personal history of the person with dementia, and preservation of dignity, when exploring decision making in family carers of people with dementia in care homes (Hennings et al., 2010).

Due to the nature and focus of the review other papers may provide alternative explanations to these choices and preferences, particularly surrounding the decision making process. Hirschman and colleagues concluded that carers were influenced by the best interests of the person with dementia when making their decision about treatment (Hirschman et al., 2006). Cox and colleagues suggested that public attitudes in general towards death and dying could be related to gender, ethnicity, and any previous experiences of death (Cox et al., 2013).

3.5.5 Limitations

Despite a systematic approach taken to the search for papers for this review, there may have been papers which were not identified. Studies which were included used various methodologies, with authors from a range of backgrounds, both professionally and epistemologically, making them difficult to synthesise.

It has to be acknowledged that this is a secondary analysis using thematic analysis on data which has been removed from its original context, for example, from the carers' original interview. This goes against the grain of qualitative research (Campbell et al.,

2003), where context is vital. The data extracted for this review included both original quotations from the carers in the original research and the text and discussions around these from the authors. Therefore some of the interpretation and analysis within this current review is based on previous authors' interpretations, making it, at times, a step removed, from carers. However, this also acts to maintain the context as much as possible.

Ultimately this review is limited by the small number of studies which have been published within this field from which to make conclusions.

3.5.6 Gaps in the literature and future research

The results from the included studies in this review generate a rather two dimensional picture of carers' experiences. More information from carers is needed to provide greater depth to these experiences. On-going research in a study called 'Compassion' has recruited carers to explore their experiences with end of life care and dementia; however, results are yet to be published at the time of writing this thesis (Jones et al., 2012).

There is a lack of research exploring quality from the perspective of different types of carers (for example adult child or spouse). This review has begun to highlight variations in what many individuals think is 'good' quality care or a preference of care compared to others. It has alluded to the differences which may exist between spousal carers and adult children. They may have differing priorities, such as an adult child's family and therefore this needs to be considered. Further qualitative research is needed to explore these differences in more depth. Although previous research has identified differences in the grieving process, strain, and satisfaction with support services (Savard et al.,

2006, Chan et al., 2013, Diwan et al., 2004, Meuser and Marwit, 2001), relatively little is known about how different carers' views on quality of care may differ. It would also be valuable to understand differences between those who are currently caring compared to those who are bereaved.

With many carers reported to be not accepting the death of their relative, this creates concern about their wellbeing and reaction to the death. Hudson has urged greater investment in bereavement related carers research (Hudson, 2013), and this review strengthens this call. Research from Kiely and colleagues using quantitative methodology, has suggested that bereavement may not be much different in dementia than in other diseases (such as cancer) however grieving processes may be longer (Kiely et al., 2008). Quantitative studies, such as this, support a call for more qualitative research to facilitate better understanding of the complexities of bereavement and grief (Kiely et al., 2008).

As discussed in chapter one, the withdrawal of the Liverpool Care Pathway (LCP) has left a potential guidance gap for practitioners providing end of life care. The independent review of the LCP has recommended developing disease specific guidelines and personalised end of life care plans (Neuberger, 2013). The withdrawal of the LCP has coincided with the development of the recommendations of providing palliative care for people with dementia from the EAPC, as described in chapter two (van der Steen et al., 2014). With reports from families potentially responsible for the failure of the LCP as discussed in chapter one, it is important that that variation of views of carers are captured and incorporated when developing new guidelines and frameworks. More qualitative work is required to gain a better understanding of what

carers feel and believe to be 'good' quality end of life care across all settings of care for people with dementia.

3.6 Conclusion

In answering the review question of *'what do we understand about quality end of life care for dementia from the perspective of families?'*, it is clear that quality of care perceptions are affected by the carers' level of acceptance that their relative is dying and the type of treatment that they feel is appropriate at this stage. This illustrates that quality of care is difficult to conceptualise and has a range of meanings for different people. Further work will be needed to understand how family carers conceptualise quality of end of life care. It may not be possible to develop a generic concept of quality end of life care for dementia from carers' perspectives.

Many of the studies identified focussed upon carers and their experiences of care as opposed to the quality of care given to the person with dementia. This demonstrates it is difficult to separate out what is 'good' quality care for the patient and what is 'good' quality care for the families/carers. The care needs to be inclusive of both groups, highlighting the importance of recognising the dyad relationship between carers and the person with dementia, but suggesting the person with dementia does not always come alone (Fortinsky, 2001). Hudson argued that carers should also, where appropriate and desired, be considered as care receivers too (Hudson, 2013). Twigg suggests health and social care systems may view them as receivers of care in a more pathological sense when they conceptualise some carers as 'co-clients' (Twigg and Atkin, 1994).

Carers should be involved in the care and decisions about care. However, this conclusion is drawn from studies which appear to have consulted carers who have a good relationship with their family member who has dementia. Not all people have good relationships and not all want to be included in their relatives' care. There are many different types of carers including those whom are disengaged and do not wish to be involved in the care for their relative (Sanders et al., 2009) and those who are abusive and neglectful.

The studies reveal little qualitative research with carers investigating the quality of care at the end of life for someone with dementia. This limited research is important as the person with dementia is often unable to communicate at the end of life if they have reached the advanced stages of dementia. However, the search identified many quantitative papers which have examined a variety of satisfaction and quality of care among family carers. These may be much less informative as they are unable to explore in depth the experiences of family carers (Cohen et al., 2012, Rurup et al., 2006, Teno et al., 2011, Shega et al., 2008).

Hennings and colleagues argued that the classification of carers as curative or palliative in their beliefs is not helpful for carers of people with dementia at the end of life (Hennings et al., 2010). Carer's opinions fall more on a spectrum rather than into a category, with all seeming to share same interests of ensuring comfort, quality of life and good all round holistic care.

Care purely aimed at symptom modification

Hope that death would be quick and peaceful (7:3)

I wish there was something other… something else wrong with my mom so that … she'd just go (7:5)

Many families members said they were comfortable with decisions to forgo heroic efforts such as the use of ventilators, but were generally in favour of the use of antibiotics and some were confused about the use of feeding tubes (4:12)

Participants discussed the desire for preserving dignity, promoting comfort, and ensuring good day-to-day care, but had difficulty incorporating goals such as comfort care into specific treatment plans. Comfort was a dominant and emerged in discussions of pain and suffering. Examples participants gave were, "I don't want my mom to suffer." "I hope she can go peaceful in her sleep and not have to suffer." Family members were unable to move beyond a broad description of comfort to specific care options (4:8)

Accept death   Deny death

Treatments such as antibiotics and feeding tubes should be offered as long as patients were comfortable. This was often the case even for those relatives who were against resuscitation (6:16)

Several urban family members described their roles in actively resisting the approach of death (7:9)

One doesn't want to think about it because one doesn't know the answer and it's a life decision answer. I'll give you an example. When I saw my father last Friday, I thought he was going to die and I thought to myself, let's give him every chance, because I know that he would want to live. I know he'd want to live because I thought, he can't talk. He can't this. He can't that, but if we could do something or they can do something here, we must do it. We must ensure that it is done because I know he would want to live. So I would give it to him. (6:15)

Active/invasive/ aggressive treatment aimed
at cure

Fig 3.3 Family carer variation of beliefs of death and the approach of treatment for end of life care

CHAPTER 4:STUDY RATIONALE

4.1   Introduction

As shown in chapter one there is a wealth of knowledge and literature on quality of care, however this begins to narrow within the area of end of life care. Chapter two clearly demonstrates that this is even more limited with end of life care for people with dementia. Understanding of the term 'quality' in health and social care is at best limited, contested and difficult to conceptualise.

There is increasing research into end of life care for people with dementia. The last two decades have witnessed the development of a better understanding of the symptoms and complications at the end of life, as shown in chapter two. However, our understanding about what is 'best' for people with dementia at the end of life is limited. Existing evidence is primarily based on quantitative findings, with the majority of research conducted in North America.

People with dementia towards the end of life are generally not able to communicate for themselves and cannot express their experiences of end of life care verbally. It is therefore important to talk to those closest to the person with dementia, often family carers, to understand their views of end of life care. Currently we know little from the perspective of the family carer at the end of life of their relative. The majority of research has focussed on the stress and strains of caring, which can be even higher for carers of people with dementia than carers of people with other diseases such as cancer.

Chapter three identified only eight qualitative studies in this area, half of these were conducted in the UK. Studies have focussed on the experiences of the carer and their

experience of caring. Studies have not focussed on the quality of care for the person with dementia. Chapter three identified many ambiguities around end of life care and the views of carers. In particular, the lack of direct discussion around quality of care reported in chapter three demonstrates that this is an understudied area and has identified a gap in the literature.

This thesis now turns to focus on quality in end of life care for people with dementia. Using qualitative methodology the views of family carers were sought to understand what 'good' and/or 'bad' quality looks like in England.

4.2   Research question

What are the features of 'good' and 'bad' quality end-of-life care for people with dementia from the perspective of family carers?

4.3   Study aims and objectives

1. Explore the experiences and perspectives of family carers who are caring for someone with dementia.

2. Explore the experiences and perspectives of family carers who have cared for someone with dementia.

3. Understand what family carers expect of end of life care for their relative with dementia.

4. Understand what family carers judge to be 'good' quality end of life care for their relative with dementia.

CHAPTER 5:METHODOLOGY

5.1   Introduction to methodology

This chapter will begin by discussing what qualitative research is and the theoretical underpinnings which frame it. I will explain my position and beliefs which influenced the research from design through to analysis and discussion of the collected data. The position and beliefs of the researcher can affect the research design, analysis and their interpretations of the findings (Kelly, 2009), but are rarely discussed by authors (Snape and Spencer, 2012).

5.2   What is qualitative research?

The definition of qualitative research has been discussed at length for many years, with, as yet, no definitive answer or definition (Ormston et al., 2014). Ormoston and colleagues noted that researchers take different approaches to qualitative research, with many different beliefs about the social world and qualitative research. In defining qualitative research some take the definition as being a naturalistic and interpretative approach, exploring phenomena from the interior (Flick, 2009). Qualitative methodology can be thought of in terms of the methods used including: interviews, field notes, photographs and recordings (Denzin and Lincoln, 2011, Ormston et al., 2014). However, as Denzin noted there are no agreed upon procedures or methods for abstracting data in qualitative methods (Denzin, 2009). Qualitative research questions usually address the 'how and why' as compared to quantitative research which investigates 'how many' (Murphy et al., 1998). Qualitative research is often described as providing richer data in which hypotheses can be derived and generated rather than the hypothesis driving the research and data analysis (Silverman, 2011).

5.3 Philosophical underpinnings within qualitative research

There are two areas of debate which underpin qualitative research and influence the approach that researchers may take (Murphy et al., 1998). The first of these concerns the nature of the social world, known as ontology. The second is the nature of knowledge; how we can learn about the social world and what is the basis of our knowledge, known as epistemology (Ormston et al., 2014).

5.3.1 Ontology

Ontology focusses on what form of nature and reality is, and what is there to know and learn about reality (Guba and Lincoln, 1994). The questions driving this approach concern reality. Is there a social reality which exists independent to human conception and interpretations? For example, are the phenomena that we are studying in research simply made up of our ideas (idealism) or do they exist regardless of these ideas (realism)? Is there a shared social reality or many which are context specific? (Giacomini, 2013). There are two main ontological positions, realism and idealism, which can encompass many variations and subtleties within these positions (Ormston et al., 2014).

Realism is the belief that there is a social reality which is independent of the beliefs or understandings of people. There is a difference between the real world and what people may interpret it to be. Variations within realism range from 'naïve realism'- that reality can be observed directly and accurately (Madill et al., 2000), 'cautious realism - reality can be approximately known (Blaikie, 2007), through to 'subtle realism'- which asserts that an external reality exists but we can only know about this through the mind of others and meanings which have been socially constructed (Blaikie, 2007, Hammersley, 1992). Finally 'materialism' recognises there is a real world which is independent of our

human mind and ideas but only material features hold that reality (Ormston et al., 2014). For example, economic features or physical features, but the values and beliefs one holds arise from reality and do not construct or form part of reality (Ormston et al., 2014).

Idealism suggests that reality is socially constructed and only exists in an individual's mind (Rolfe, 2006). It can therefore only be told through the human mind, with no reality existing which is independent of human ideas. There are various perspectives within idealism with slight nuances. 'Subtle idealism' suggests that the social world is constructed and shared by people in particular contexts (Ormston et al., 2014). 'Relativism' asserts that there is no shared social reality but instead there are many different constructions, and therefore there can be many different realities (Ormston et al., 2014).

The final ontological question raised concerns the similarities and differences between the physical and the social world. Specifically, whether they exist in similar ways or the social world is different as it is open to interpretation by individuals. Some believe that the physical world and social world exist in the same way and are governed by the same laws (Ormston et al., 2014). However, others argue that humans are able to make choices and therefore the social world cannot be governed by the same laws that we see within the physical world (Giddens, 1984, Hughes and Sharrock, 1997, Patton, 2002). Ormoston and colleagues argued that qualitative researchers would accept the second of these views, that the physical and social worlds exist in different forms (Ormston et al., 2014).

5.3.2 Epistemology

The epistemological debate is focussed on knowledge and the way we learn and know about the social world. For example, how do we learn or know about reality and what is the basis of an individual's knowledge? (Ormston et al., 2014). The debate incorporates three main issues. The first of these issues explores how we learn about the world and proposes two answers; induction and deduction. Induction is the process of collecting information and data which generates theory, and hence a 'bottom-up process' (Barbour, 2014). Deductive processes involve collecting data to test theory, therefore a 'top-down process' (Barbour, 2014). Qualitative and quantitative methodologies both use a blend of both deductive and inductive techniques (Blaikie, 2007).

The second issue within the debate is the position of the researcher and their relationship with the phenomena being studied. For example, some believe that the researcher will have no influence on the research or the people/phenomena being researched, this is more in line with the natural sciences. However, others argue that there is an interactive relationship between the researcher and the studied (i.e. the social phenomena). In this case the researcher does not produce an objective, neutral account of the phenomena being studied (Ormston et al., 2014). My view within this thesis is that I, the researcher, will influence the interviews and family carers in their responses. Similarly, my interpretations and assumptions about the data will influence the analysis. As will be discussed subsequently, the use of in-depth interviews enables the participants to talk more freely and may reduce the influence of the researcher on their answers. The use of a team based approach to analysis also reduces any one individual's influence on the data analysis (Mays and Pope, 1995).

The final issue concerns what it means when something is said to be accurate or true. Ormoston and colleagues note that in the natural sciences, traditionally correspondence is used. For example, observations made in research about the phenomena being studied, match the 'independent reality' (Ormston et al., 2014). Ormston and colleagues argue that the more appropriate theory for studying the social world is inter-subjective or coherence theory of truth. That is, the 'independent reality' can be gauged only by a consensual rather than an absolute way. For example, if several reports confirm a position or statement then some would say it is true and this is a socially constructed reality (Ormston et al., 2014). An example from qualitative research is if several interview participants explain the same phenomena then this is considered true as it is the general consensus. This idea complements the theory that reality can only be gaged through the human mind.

5.3.3   Paradigms

It is argued that questions of method are secondary to questions of paradigm (Guba and Lincoln, 1994). Paradigms are the models of ontological and epistemological beliefs which guide a researcher's approach to research. Therefore it is important that I discuss my beliefs and position before proceeding with the methodology of this study. It is generally accepted that there are four different paradigms, within which qualitative and quantitative methodologies can be positioned (Guba and Lincoln, 1994). These include; positivism, post-positivism, critical theory, and constructivism (see table 5.1 for an overview). In this section I will provide a brief overview of the four paradigms.

Positivism

Positivism, also known as the 'scientific method' or 'received view' (Guba and Lincoln, 1994), is what many qualitative researchers would argue is the opposite of their

approach to research (Ormston et al., 2014). Positivists in their approach try to distance themselves from the researched and try not to influence the phenomenon being studied (Guba and Lincoln, 1994). Procedures are set and rigorously followed to ensure bias is limited (Guba and Lincoln, 1994). Knowledge is obtained through direct observation (induction) with the view that reality can be known accurately (Ormston et al., 2014, Guba and Lincoln, 1994).

Post-positivism

The positivist approach was later revised and influenced heavily by Karl Popper. Popper argued that if a law was derived from observation then there would be a possibility that a future observation could disprove the law (Ormston et al., 2014). In this sense the positivism approach changed to one of more deduction with the generation of hypotheses which are developed from existing theory and tested. Popper emphasised the use of falsification with the development of a null hypothesis which could be rejected. This strikes a contrast to positivism, that reality can only be known approximately.

Constructivism

Constructivism emphasises the importance of how human beings interpret the social world and not simply the direct observations that we make as in positivist and post-positivist approaches (Murphy et al., 1998). Constructivists pose that individuals construct their own reality (Ormston et al., 2014). Therefore reality cannot be accurately captured, but is more or less true (Guba and Lincoln, 1994). This paradigm focusses on the lived experiences of individuals. Constructivism adopts an inductive approach to the researched, but accepts that theories may influence ideas and assumptions of the researchers. The approach also suggests that researchers can become engaged within the

research and not simply observe without having an influence on the phenomena being studied.

Critical theory

Critical theory encompasses many different theories including neo-Marxism and feminism (Ormston et al., 2014). Critical theory places high emphasis on the influence of social circumstances for example, age, sex, ethnicity, class or sexual orientation. The data are often analysed in light of these concepts and it is thought that these factors have shaped reality over time (Guba and Lincoln, 1994). In critical theory approaches the role of the researcher has an influence on the phenomenon being researched (Guba and Lincoln, 1994).

5.3.4   Position for thesis

It has been challenging to choose one theoretical or methodological camp to which guide my approach to research. I have described below a description of my ontological and epistemological beliefs. This description demonstrates the struggles of one theoretical stance being adopted.

I believe there is a truth to be found for some situations and quantitative research methods are useful and the correct approach to use, for example when examining something such as death rates. This would appear to be a more positivist/post-positivist approach. However, for this thesis and the research question which I have tried to answer, my position based on the four paradigms detailed in table 5.1, tends to lean to a more constructivist position. Despite this I see the value in many of these approaches.

The ontological position I take which has guided me in this thesis is that there is not an external reality, but one that is created by one's own beliefs and understandings of the world. It is socially constructed and we can only understand this by 'tapping' into the minds of others. In this sense I feel there is not a collectively shared understanding, adopting a relativist approach of idealism. However, I do believe in some situations there is an external reality. Therefore I argue that I hold an idealism belief, but by giving my value in the positivist/post-positivist also indicates an acceptance of some realism and hence bordering a position subtle realism. This has influenced my choice of methodology and methods for the current study. The use of interviews allows me to answer the research question which is to 'explore' views and understand their realities.

The epistemological position I took for this thesis was an approach which fits within constructivism. As mentioned above I believe that I influenced participants when interviewing them. Similarly my pre-conceived perceptions influenced the data analysis; ultimately this means there were some deductive processes to the analysis. However, I emphasised an inductive approach. Measures through the use of a team approach were taken to reduce the bias from myself and any other researcher involved in analysis.

The struggle I have had with my position for this research, which is not rare within qualitative research (Barbour, 2014), and my changing views, based on the type of research question being answered, lead me to think I also took a more pragmatic approach. This means I believe that the most appropriate methodology and methods to answer the research question need to be chosen. This may not always fit within the philosophical point of view all the time. As Snape and Spencer have suggested is common, I am concerned with attempting to ensure quality and the rigour of the

research practice as opposed to ensuring it fits with certain philosophical stances (Snape and Spencer, 2012). Ormston and colleagues argue that researchers 'should not be forced into a theoretical or methodological straightjacket' (Ormston et al., 2014) and Barbour encourages a 'hybrid approach' using a mix of methods suitable (Barbour, 2014). This therefore disagrees with the view of Guba and Lincoln that methods are second to questions of paradigm (Guba and Lincoln, 1994).

5.4   Design

A qualitative methodology was adopted, using in-depth interviews with a topic guide developed from reviews of the literature (Davies et al., 2014a, Raymond et al., 2014a, Raymond et al., 2013, Raymond et al., 2014b). This study adopted both a prospective and retrospective approach to provide a clearer understanding of the complexity of dying. This allowed for some triangulation of data (Teno, 2005). Triangulation refers to two or more different methods of data collection, such as interviews and questionnaires, or can refer to two more sources of data collection; for example, bereaved and non-bereaved participants (Mays and Pope, 2000). Triangulation allows for a more comprehensive analysis of the data (Mays and Pope, 2000) and different perspectives on phenomena.

5.4.1   In-depth interviews

The interview method with open questions aims to explore people's views and experiences without imposing preconceived ideas and a rigid structure. It is an appropriate method to use when dealing with complex and sensitive phenomena such as the current topic of end of life care (Gysels et al., 2008). Many who have used interviews for sensitive topics have argued that interviews have a therapeutic benefit to participants (Allmark et al., 2009).

In-depth interviews have been likened to a conversation by some (Lofland and Lofland, 1995), allowing researchers to understand the social world through 'normal' interaction. However, interviews will never be entirely 'normal' interaction. We can relate the constructivist theoretical stance this thesis takes to the use of the in-depth interview method, known as the 'traveller metaphor' (Kvale, 1996). This takes the position that knowledge is created and negotiated, and the interviewer goes along a journey with the interviewee and they build up a meaning from the story through interpretation. In this approach the interviewer is very much part of the interview and development of the data rather than simply a transmitter of someone's story.

In-depth interviews can be long; this allows the participant to talk at length with the researcher probing for further detail, allowing for depth of information (Britten, 1995). This longer period of time allows the participant to provide examples when discussing their thoughts and feelings. This helps the researcher to contextualise what the participant means. This period of time also allows for the researcher and the participant to build up a rapport which is important, enhancing trust and the ease with which participants reveal information (Yeo et al., 2014). This was of particular importance in the current study when discussing the sensitive topic of end of life care and death. In-depth interviews are far less structured than other types of interviews such as semi-structured interviews and allow the opportunity for the researcher to be flexible in their approach to asking questions (Britten, 1995). Flexibility and the interaction between the researcher and the participant enables the researcher to tailor the interview questions and approach to the individual (Yeo et al., 2014).

Table 5.1 Summary of major paradigm positions adapted from Guba and Lincoln (Guba and Lincoln, 1994)

Issue	Positivism	Post-positivism	Critical Theory	Constructivism
Ontology	Positivism was known as the "received view" which dominated both physical and social sciences for some 400 years. This is the view that there is a true reality and that one is able to discover this, through verification of theory.	Developed from positivism, postpositivism accepts that there is a truth, however, one cannot be entirely sure about the truth when searching/researching it, one can only be probabilistic about the reality, reality is probabilistically apprehendable.	Critical theory assumes that there is a virtual reality which is shaped over time, as a mass of social, political, cultural, economic, ethnic and gender factors and crystalized over time.	Constructionism adopts a relativism approach when there is a belief in local or individually constructed realities. A relativist believes that there are multiple, socially constructed realities which are not governed by natural laws causal or otherwise.
Epistemology	Knowledge exists external to the observer/researcher. The researcher observes/studies the phenomenon and is not part of the phenomenon. Findings are true.	Findings are probably true.	Knowledge is acquired through interaction with the environment, value-mediated findings.	Knowledge is acquired through interaction with the environment, created findings.

Methodology	Experimental quantitative methods, with verification of hypotheses.	Modified experimental, falsification of hypotheses.	Dialogic/dialectical	Hermeneutical/dialectical (Hermeneutics seeks a dialogue among differing views which allows for on-going iteration and analysis leading to a joint construction of a case)
Quantitative or Qualitative	Quantitative	Mainly quantitative but may include qualitative	Qualitative	Qualitative

5.5   Sample

5.5.1   Groups of carers

The participants recruited for the current study were family carers of people with dementia. Three distinct groups of family carers were recruited:

1. family carers of people who had recently received a diagnosis of dementia

2. family carers currently caring for someone with dementia

3. bereaved family carers

This follows the Lindgren model of the caring trajectory in dementia (Lindgren, 1993). She posed that there are three stages which mirror the three groups of family carers: an encounter stage (diagnosis and loss of previous life patterns), enduring stage (managing extensive care routines and social isolation) and finally an exit stage (the relinquishment of caring through the death of the spouse or their admission into care). However, for the final group, many would argue the admission into a care home is not the exit stage; for example, many relatives may still care for their relative when they are in a care home. These stages will also not fit all situations as some people never receive a formal diagnosis. Some families simply do not wish to be involved in the care of their relative. As noted in chapter three not all people with dementia are "loved ones" or have family who want to care for them (Sanders et al., 2009).

5.5.2   Inclusion and exclusion criteria

Due to the sensitive nature of the subject and the anticipated low uptake in recruitment of participants for the study, there were few inclusion criteria to make inclusion as broad as possible. For this study an element of self-selection was inevitable. Participants themselves decided if they were eligible based on the knowledge that the research was investigating family carers' perceptions of end of life care for people with dementia.

This study did not limit the sample to people with advanced or severe dementia as much of the previous research into end of life has done (Mitchell et al., 2009, Sachs, 2009, van der Steen, 2010, Hughes, 2010). Not all people with dementia at the end of life will reach advanced dementia and end of life care may begin before the advanced stages of dementia (van der Steen et al., 2012a). Carers were not eligible to participate in the study if: they were unable to provide informed consent; had suffered bereavement within the last three months, and for whom an interview could be a burden or upsetting; and finally those carers with cognitive impairment. This was a national sample from England and participants were not excluded based on geographical location.

5.5.3   Recruitment

The participants were purposively sampled from the records of a national dementia charity Dementia UK. The charity has developed a network of carers who are willing to participate in research and the network contains over a 1000 carers who are currently caring for someone dying with dementia, who range in their length of time caring, as well as bereaved carers. Invitations were composed by myself and sent out by Dementia UK via email in two rounds of recruitment in May 2012 and February 2013. The aim was to purposively sample participants to fit each of the three distinct groups of carers. Recruitment continued until saturation of themes was established from the data. This was expected to be 10-15 participants per group based on previous research and experience. In the invitations I emphasised that I was interested in speaking with carers who had both 'good' and 'bad' experiences of end of life care.

The role of gatekeepers in recruitment is very important (Webster et al., 2014); in this case the gatekeeper was Dementia UK. Time was taken to ensure that staff working at

Dementia UK were fully aware of the details of the research so they knew which types of carers to contact on my behalf.

5.6   Ethical considerations

Ethical approval was obtained before commencing the study from University College London Research Ethics Committee (3344/001). Potential participants were provided with written and verbal information before participating in the study and were given an information sheet to keep. All participants provided informed written consent for the participation in the study and to audio record the interviews before being interviewed. Participants were informed that the audio recordings would be destroyed after transcription. I abided by University College London's lone worker policy. This included a member of the Centre for Ageing and Population Studies team always being aware where I was when interviewing and being informed when the interview was complete and I had left the interview. Agreements were made between myself and supervisors for the management of participant distress and for reporting any concerns of maltreatment or carer distress. All participants were assigned a participant identity number which ensured anonymity. All data were stored in accordance with the Data Protection Act 1998.

5.7   Topic guide

The topic guide was developed from initial scoping of the literature performed before the review in chapter three (Davies et al., 2014a) and a rapid appraisal of literature as part of the IMPACT study (Raymond et al., 2014a, Raymond et al., 2013, Raymond et al., 2014b). The topic guide was initially developed as a semi-structured interview guide and was pilot tested with a small number of participants. Following pilot testing of the interview guide it became apparent that the interviews needed less structure. The guide

required a more in-depth approach to the sensitive and complex topics which were being discussed. The topic guide became a short list of topics to prompt the interviewer to explore participant views as opposed to a series of questions and prompts. The topic guide was developed iteratively as the interviews were conducted, adding further topics to be covered as the interviews progressed (see appendix 3 for the development of the topic guide). The topic guides from this study have been used to teach students about the development of a topic guide for the 'Qualitative Research Methods in Health' MSc module taught at UCL.

The guide allowed for additional topics to be covered within the interviews and gave participants the freedom and flexibility to discuss topics which were important to them.

5.8 Data collection

Face to face interviews were preferred by the research team due to the sensitive nature of the research and the in-depth approach that was taken for the study, however, telephone interviews were offered to participants if they preferred. All interviews were recorded and field notes were written for many of the interviews. Field notes may aid analysis by reminding the researcher of the context of the interview. Participants were given a choice of being interviewed at their own home, at their work place, at University College London, or an alternative neutral venue, for example the British Library or a local museum. Participants were asked to read the information sheet (see appendix 2) if they had not already done so, together with a brief explanation of the research, this allowed the opportunity to ask questions, and finally asked to sign the consent form (see appendix 1). Participants were informed that the interviews were informal and were asked to try to ignore the audio recorder. The interview began with

participants describing who they cared for and how long they had been caring for that individual. This allowed for a 'natural' discussion of the participant's journey of caring for their relative. Participants often started with the diagnosis stage, then care home admission (if applicable) and finally moving on to discuss the end of life stage. If participants became distressed they were given the opportunity to have a break or stop the interview. The interviews were brought to a natural close with participants given the opportunity to add any additional thoughts or experiences which they wanted to discuss. Finally, I remained with some participants for a short period of time after the completion of the interviews to ensure participants did not remain distressed. For example, some participants offered an additional cup of coffee which was always accepted; however many happily drew the discussion and meeting to an end.

Participants were contacted the following day by email to thank them once more for their participation, particular attention was paid to those who became distressed during the interview. This also allowed them to say if they would like support, from a support service which they could be directed to.

5.9   Analysis

Thematic analysis methods were adopted to analyse the data for this thesis. Narrative analysis and thematic framework analysis were both also considered, however, after discussions with experts in qualitative methodology it was considered that thematic analysis was the best approach to adopt to answer the research question using the available data. These alternatives are discussed in more detail in chapter seven.

Thematic analysis is the most common method of qualitative analysis used in health research (Pope et al., 2006). Coding has an important role in thematic analysis, and uses initial and axial coding. This allows for the breakdown of the data initially into simple components (initial coding) and then to reconstruct the data illustrating links amongst the codes (axial coding). This permits the researcher to analyse the data in-depth.

Thematic analysis fits with the epistemological view I took within this study and has the strength of flexibility to allow the researcher to take both an inductive approach, and a deductive approach when required. Although thematic analysis synthesises data and therefore the collection of views from participants (i.e. their realities) it also allows for the consideration of differences amongst the data. This fits the relativism approach I take from the ontological position.

It is important within all research to ensure quality within the results. In quantitative research this is discussed in terms of validity and reliability. Within qualitative research however, results are discussed in terms of rigour. One of the key elements of ensuring rigour within qualitative research is adopting a team approach to analysing data, which is becoming increasingly common within qualitative research (Mays and Pope, 1995). A team approach to the analysis of data allows for a variety of ideas about what the data means. It offers an opportunity to reflect on what has been read, discuss thoughts and ideas, and can reduce the potential bias any one researcher may have about the data (Lewis and McNaughton Nicholls, 2014). Several other measures were taken to ensure rigour in this study. These are discussed in more detail in chapter seven in the methodological strengths and limitations section.

5.9.1 Analysis team

I led the analysis and was assisted by a team of researchers. The team for the analysis of the data from this study consisted of a Research Associate (LM) an anthropologist working for a national dementia charity, and two academic general practitioners (SI and GR) who were the supervisors of this PhD.

5.9.2 Analysis as performed

For the purpose of this study the following steps to analysing the data using thematic analysis methods were taken. The analysis was supported using ATLAS.ti version 6.2.15 computer software to manage the data (Muhr, 2010):

1. All recordings were transcribed verbatim by either myself or a professional transcriber.

2. I read all transcripts whilst simultaneously listening to the recording of each interview to check for errors in transcription and to immerse myself in the data collected.

3. Selections of transcripts were re-read by both myself and LM to increase familiarity with the data. We both wrote ideas about the interviews on post-it notes attached to the interviews, columns of the transcripts and used a data analysis notebook. The notes taken and thoughts about these interviews were discussed in brief with all members of the analysis team. This not only began discussion of thoughts around the analysis and introduced the whole team to the content of the data, but also helped to refine the plan to analyse the data.

4. Five interviews were deliberately chosen as containing a variety of experiences and stages within the caring 'journey' to begin analysis. To increase rigour within the analysis both LM and I read and coded the same five interviews

independently. Example codes which we agreed upon included 'carer – desire to protect loved one'; and 'reduced services on the weekend'.

5. LM and I met on four occasions to discuss the coding of the first five interviews, with meetings lasting between 2 – 7 hours each. Any differences in coding were discussed until we both agreed on the code to be used. Differences were discussed with the other two members of the analysis team (SI and GR). This allowed for an agreed coding strategy for the remainder of the interviews. These meetings increased the rigour of the results allowing for, as previously stated, reflection by all coders on what they had read, and discussion of fresh ideas. It also allowed for a reduction of bias by any one researcher, in particular myself having collected all the data. I may have had pre-conceived ideas about the data having interviewed all the participants.

6. With an agreed coding strategy I independently coded the remainder of the transcripts adding additional codes as needed taking an iterative approach. LM reviewed the coding of an additional random selection of eight transcripts to ensure agreement, any disagreement was discussed as previously described in step five.

7. Following the completion of coding, LM and I met to discuss clustering the codes into categories and deriving provisional themes from the data. All information within each theme was read and considered, revising each theme iteratively. Opposing evidence (negative/deviant cases) was searched for to ensure the themes were supported and were strong (Mays and Pope, 2000). Discussions with SI and GR also informed the development of themes.

8. Refined themes were defined and named, going back to the transcripts to re-examine and ensure that all themes could be identified within and supported by

the data in the transcripts. This was led by myself but all members of the analysis team read a selection of transcripts to ensure the themes fitted with the data.

9. The final themes were examined for relationships between the themes. This was led by myself with regular discussion amongst all members of the analysis team.

10. Each theme was reported with a full description and illustrated with direct quotations from the transcripts.

5.10   Reflections on interviews

To ensure that participants were comfortable with both the topic and the situation I tried to put the person at ease by starting with a general conversation. I began by introducing myself and the research topic; however, there was no 'one size fits all' approach to this, as some were more comfortable than others. Often once the participant knew the study was part of a PhD project they became more relaxed. Similarly so, some became more relaxed when they were told it was also part of a larger project (IMPACT) and 'not just' a PhD project.

The setting of the interview was important, in particular how the participant and I sat, often appearing to set the tone of the interview and depth of information. For example, there appeared to be a difference between participants who invited me to sit in their lounge as opposed to their office. In the office it became more formal and often controlled by the participant with them asking me more questions. This appeared to often elicit less information than if I were sat next to one another or sat more informally in the lounge for example. Similarly many participants offered tea and coffee. This did

not necessarily always reflect how much the participant was at ease as this appeared to be done when very relaxed and when quite nervous. But it demonstrated how willing they were to discuss their experiences with me and how open they would be with me. On several occasions the participant said; "I have not told anyone this", or "I have not even discussed this with my family".

Patton has suggested three main strategies for maintaining control in interviews (Patton, 1987). Patton recommends knowing what you want to find out, asking the right questions, and giving appropriate verbal and non-verbal feedback. However, it can be difficult to strike a balance of appropriate and non-appropriate feedback. Similarly, there was no 'one size fits all' approach, and not all questions were appropriate for all participants. This required the skill of the interviewer to ascertain what is right to ask combined with thinking on the spot, after knowing relatively little about the participant.

There were some difficulties in audio recording the interviews, in particular when the participant wanted to meet in a public place. This often meant the environment was quite noisy, in particular if meeting in a coffee bar. Unfortunately, due to the sensitive nature of the topic being discussed it was not always appropriate to suggest meeting elsewhere. It was important that participants were in an environment which they were comfortable with to allow them to discuss sensitive and personal experiences. Often the participants were elderly women and therefore it was understandable that they did not want to be alone in their house with a young unknown male. This demonstrates (as previously discussed) the impact of the researcher on the social phenomena being studied. Not only does the stance of the researcher (for example) have an influence on the design the study, conduct of interviews, and subsequent analysis of the results, but

the characteristics of the interviewer such as age, gender, professional role and ethnicity can have an influence on the interviews (Richards and Emslie, 2000). Some interviews were undertaken with individuals from ethnic minorities and therefore the ethnicity of the interviewer (white British) may have had an impact upon the discourse. On reflection this may have been a positive influence and factor. In two interviews with individuals from ethnic minorities they assumed I was ignorant of their cultures and clearly expressed what their culture said about the topic and how that affected the way their relative received care.

CHAPTER 6: FINDINGS

6.1   Participants

This study recruited 47 carers, conducting 45 individual in-depth interviews, and one interview with two participants (a husband and a daughter). Recruitment continued until data saturation was reached and no new information or themes were being discovered from the interviews. The majority of these interviews were face to face either in the participants' homes, University College London, or a public meeting place (n= 42). Some participants requested that interviews be conducted over the telephone (n= 4). Participant demographics are provided in table 6.1. The time since the death of the person with dementia ranged from 3 months – 10 years in the bereaved group. The participants were recruited from Dementia UK a national charity which has a network of carers interested in participating in research, see chapter seven page 347-350 for a discussion of potential limitations of using this sample.

Table 6.1 Demographics of participants (n=47)

	Recently Diagnosed	Currently Caring	Bereaved
Total interviewed	1	14	32
Male	0	2	8
Female	1	12	24
Age range	Early 60s	50-78	39-90
Spouse	1	8	11
Adult child	0	5	21
Family friend	0	1	0

6.2 What is palliative care and end of life care?

For this thesis carers were asked to define end of life care and palliative care and hence their eligibility for inclusion in the study. As discussed in previous chapters, I have taken the view that end of life care is part of palliative care with palliative care being the overall approach, adopting the WHO's definition (Sepulveda et al., 2002). End of life care is not limited by time as such, but is more a period of time when the patient, family and professionals come to the realisation that the person with dementia is dying (Lukas Radbruch, 2009). It is clear from talking with participants that imposing definitions and criteria was not helpful or useful when talking about palliative or end of life care.

Participants spoke about end of life care and palliative care in general with little reference to these terms and there was a lack of clear distinction between the two. In many of the interviews, palliative care was only discussed if the interviewer approached the topic. However, participants spoke about 'end of life care' independent of it being asked as a topic by the interviewer, and the term being used.

6.2.1 End of life care

Participants were made aware of the aim to discuss end of life care in the interview before agreeing to participate. For many of the participants, everything that they discussed was end of life care regardless of the time point in the course of dementia. However, others clearly pointed to a time or an event which they felt was the beginning of the end of life care period. These participants had to be asked directly to provide an answer to when or what they thought end of life care was.

Although participants did not impose strict or tight definitions or time frames, the discussions about what end of life care was appeared to be split between discussions of

time frames and discussions of events defining when someone was receiving end of life care.

Time frame

Participants found it difficult to place a time on when end of life care began. This is shown by the many different times given by different family carers in this study. For some, the recognition that dementia was a terminal and degenerative condition which was only going to get worse meant that end of life care started as soon as there was a dementia diagnosis:

> *"Well with dementia it begins as soon as you get that diagnosis."* (030, 14:33)

For others end of life care began or would begin in the final months of life:

> *"I think by that stage, probably eighteen months, to me that was the end stages because he couldn't...*
>
> ***The last eighteen months was the end of life?***
>
> *Yes."* (031, 26:5)

> *"[…] If I were going to talk about end of life care, […] that is a situation where I expect life to finish in a matter of months, rather than over a number of years […]"* (036, 20:30)

For some this was an even shorter period of time restricting it to the final days of the individual's life:

"[…] You've sort of got that very short end of life care, which is at the immediate end. And, for me, that is sort of like the last week, the last sort of few days […]" (050, 16:38)

However, many were unsure about the time frame and simply provided an answer as they were asked, seeking reassurance from the interviewer:

"End of life care? Well I suppose it was probably just the last two days, something like that. Does that sound a reasonable answer?" (038, 13:44)

Or simply avoided answering the question and diverted the conversation:

"And so, to you, what is end of life care for you?

I guess what I, for me, I'm trying to describe - are you asking what I, what kind of care I provided him with or what am I expecting?

Yes, what are you expecting? When is it, for example, when is end of life care?

Right.

Or, and then what type of care would you expect?

I guess we were in the mode of, you know, the bit where he started to, to look as though he was dying, you know. I mean sort of there was a whole bunch of sort of signs. I didn't want to get in the game of predicting that. I mean one of the things - I do quite a lot of talks about my caring for my dad. And I always remember one at a hospice, which I found really interesting. It was around the time that the, the Mental Capacity Act came in [...]" (021, 41:29)

Many suggested that definitions or criteria for end of life proposed by the government or professionals, for example 12 months as end of life in the National End of Life Care Strategy were not really feasible or accurate. Their definitions described end of life care as far too late:

"We disagreed with the NHS about how you define that [end of life care]. And [friend of the family] knew that in research terms and medical terms, end of life care is much longer than the last three weeks sort of thing. So, of course, when you talk with the NHS about that, what you're doing is arguing about money, because if they agree that it's end of life care, they have to give you back your funding." (042, 9:48)

One carer was able to describe how their view as a health professional would have been different to what they now believed having had personal experience as a family member:

> *"I probably put end of life care a lot sooner than maybe a lot of professional people do, says she that's been a professional, but, you know, from a family perspective [...]"* (025, 27:82)

Critical event

Timelines were not just the only way for participants to define end of life care. They often associated an event with end of life care which suggested to them that end of life care had started. Several highlighted that the transfer to a care home was a sign of the loss of independence, frailty, and potentially quality of life. This was the start of a decline which to them indicated end of life:

> *"[...] If I think about it in a rational way, their end of life care started probably when they went into the care home, because that's when they were no longer able to lead the sort of life that they want to lead [...]"* (025, 27:52)

> **"When does end of life care begin for you, has it begun yet or is that...**

> *Well that begun when he walked in there [care home], because I didn't think he would last more than five minutes."* (028, 31:15)

For others the 'critical' point or turning point for end of life was focussed on symptoms. In particular those which indicated a downward spiral, such as chest infections, difficulties of swallowing, frailty, aspiration, and when the person fails to recover from infections as quickly as previously:

"She was very frail both physically and mentally, so perhaps we'd reached the, you know, we really had then got into an end of life stage with it all anyway possibly." (060, 3:3)

"So I imagine the end of life care will be the last few days, will be when he stays in bed, when he's stopped eating, probably stopped drinking. Yes stopped eating and drinking. And I have to rely on the staff to know the point at which he stays in bed instead of being got up." (029, 6:35)

"I suppose it was when the Macmillan Nurses got involved." (044, 8:33)

For some it was simply when there was a clear indication that the person with dementia was not going to get better:

"So I call that the end of life care period, when what you could say is that this person is not going to get better. There is not going to be any improvement. What's going to happen is that he's gradually going to deteriorate and be able to do less. And you can see it day by day. I call that end of life care really." (020, 10:11)

6.2.2 Palliative Care

Participants spoke less about palliative care than they did end of life care. There appeared to be a general lack of understanding and perception about what palliative care was and when their relative would become 'palliative'. Participants often answered the questions around palliative care by posing a question back at the interviewer. Many likened palliative care to care that was provided to people who had cancer, or at least traditionally thought of it in this way:

"Was your mum ever offered any palliative care? Or do you think she had that?

What exactly is palliative care?

What do you see it as? What's your idea of palliative care?

Well if somebody has cancer and they don't actually treat them for cancer but they make them comfortable. Is that the sort of palliative care? Making them comfortable." (038, 13:45)

"I think the sort of palliative care is ongoing. When you're sort of, when you're - it's different, I think it's different in the, depending on the diseases isn't it, because I mean we've always associated palliative care with people with cancer. And it's sort of like been the, you know, you know that they're not going to get any better." (050, 16:38)

However, a stark contrast was depicted between palliative care provided for people with cancer and that received for people with dementia, when participants had experience of both:

"[…] In terms of palliative care, what could have been better for us? Everything could have been better for us. You know, a direct comparison with cancer, night and day really." (015, 46:62)

What does palliative care entail?

Many of the tasks within palliative care were seen as keeping the individual free from pain and ensuring they remained as comfortable as possible without extending life. This seemed to equate to participants talking about quality of life:

"[…] Should be looked after in a such a way that what remains of their life is as good as it can possibly be in terms of pain free and some pleasure and enjoyment and so on, such as is possible." (042, 9:51)

"Well, palliative care I think is making life as comfortable as possible while life is there. But, to me, it's not to extend it by any means that would bring you back to an inferior type of life." (012, 12:22)

"[…] But it's how you manage their care to ensure that their quality of life is as good as it can be for the length of time they've got. And then you've sort of got that very short end of life care, which is at the immediate end." (050, 16:38)

One carer discussed how although her mother was receiving active treatment for cancer, the approach to treatment and care was still 'palliative':

*"**Where does palliative care fit with that for you?***

Palliative care comes, God that's a tough one really. I suppose, for me, you know, if I look at my mum now, in some respect I think, although they're actively treating the breast cancer in the fact that she's having this hormone treatment

that is treating it, I have helped instigate a more palliative approach to that, in the fact that we're not having the intervention. So, I know it's active treatment, because she's having the drugs. But the whole approach that we're having is more a palliative approach. Does that make any sense?" (025, 27:53)

Some thought of palliative care as an approach which was focussing on management. In particular managing medications:

"They [palliative care team] were, they were about managing his, his agitation, managing his medication […]" (062, 24:32)

"You know, I think palliation for my mum, in some respects is, she gets incredibly anxious now, incredibly distressed, and it's about how we manage that as well." (025, 27:53)

When does it become palliative?

Participants often spoke less about timescales and more about what they thought palliative care entailed, labelling it as more of an approach to care or a process.

Participants often did not know when palliative care started or would/should start. It appeared to come as a surprise to many of the participants being asked about palliative care. But upon reflection, some thought they were 'probably' providing palliative care currently to their relative:

"Well I think I'm probably doing some palliative care now." (036, 20:31)

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"Palliative care is probably what T is receiving now because he's terminally ill. What we don't know is when the end will come." (029, 6:42)

Palliative care was often thought of as an on-going process and not necessarily having a definitive time. This was similar to participants' ideas about end of life care, alluding to the intangibility of palliative care:

"So when, does palliative care begin, like end of life care does after you've been diagnosed, or does that come later?

Well, it depends what you mean by palliative care. I mean there's a sense in which the whole process is palliative, isn't it, in that you know it's, you know that there's certainly going to be one outcome." (030, 14:32)

"I think the sort of palliative care is ongoing." (050, 16:38)

For many, palliative care began when they came to the realisation that their relative was not going to get any better; this was not necessarily a definitive time:

"I wasn't aware of, on reflection, I didn't understand the severity of it, I didn't understand that my dad was dying and was going to have a very lengthy death. And I think from the outset, it was palliative care, to be honest, because he wasn't going to get better. There's no good news with vascular dementia, you know." (041, 11:18)

"I've never actually met a palliative care nurse. So it's an interesting question for me. It's a word and to me it implies that the person is going to die." (042, 9:51)

However, for some there were other signs that the person was now palliative. This was linked to how much of the individual was 'lost'. In particular this related to their physical abilities such as their mobility, with some suggesting palliative care was when an individual was bed bound:

"I think I'd say it was palliative care when, not perhaps when he stopped walking, when he lost his standing balance. Certainly by the time, a year later, he'd lost his sitting balance, and I bought a special chair to support him. I think we were definitely on palliative care then. So the disease had taken away his mobility, taken away even his ability to sit unsupported, taken away his speech, taken away his facial expressions. Yes. So it's probably the extent of the damage in the brain that maybe makes me think, yeah, yeah." (029, 6:46)

"I don't understand how they define palliative care - what, you know, at what point is somebody receiving palliative care? I mean I would have said dad was from the minute he became bedbound really." (012, 48:5)

6.3 What treatment do carers want for their relative?

The focus of many of the interviews was on what treatment carers wanted at the end of life or through the course of dementia. This is difficult to describe because there was a lack of consensus with a variety of responses provided by participants. Fitting the

responses of the participants within the two categories of a palliative approach or an active approach aimed at cure was difficult. Some believe in a palliative approach but with the opinion that you still treat some symptoms or conditions. It could be argued that actually this is a palliative approach as definitions of palliative care describe an element of active treatment aimed at relieving symptoms and maximising comfort. This was also seen on page 212, quote 025, 27:53. The best representation of these results seems to be the same as illustrated in the literature review of chapter three, a spectrum. This ranges from minimal treatment with the sole aim of increasing and maintaining comfort, what clinicians and researchers term palliative care, through to doing all treatment possible to 'preserve the light of life'. In more clinical or research terms this would be seen as active or aggressive treatment.

The choice to use lay terms for the approach to treatment that participants took was due to the realisation that professionals (either clinical or academic), try to enforce definitions and categories for standardisation. However, as mentioned previously, for patients and carers this is not always quite so easy, needed, helpful or something which they understand.

As discussed in chapter three the decisions about the type of treatment or approach (minimal/palliative treatment aimed at symptom modification or active aimed at cure) to treatment that carers make appeared again in these interviews to be linked with the concept of 'acceptance' of death. However, when thinking about what influences a carer's decision about the approach to treatment, it is not simply whether they accept their relative is dying or not. Several additional factors influenced their decision, as will be discussed below.

Participants felt that times had changed; they thought in previous years death had been seen as a normal process with which people were comfortable about and accepted. They perceived that currently there was a move towards a view that life needs to be saved and interventions, often invasive, or investigations, such as blood tests or scans, need to be performed:

"[…] There's still a kind of residue of this notion that death is a failure for them, because they haven't actually prolonged life, even though, you know, it's inevitable for everybody." (030, 14:43)

"I think we have to get back to a sort of rather more basic idea of life and death […]" (060, 3:68)

Some participants recognised dementia as a terminal illness and had accepted that their relative was dying. Some commented that this was about 'wishing' them to die sooner to be out of their pain and 'suffering':

"I mean it's a horrendous disease and in some instances you feel that, you know, you're planning for them to die. But you know he's going to die from this and I just want him to die with some dignity and in a way that - our watchword is 'comfort' and 'contentment'." (019, 39:11)

"[…] I wanted my Dad out of it […] if I could have ended my Dad's life earlier, I would have done it." (041, 11:77)

"[…] She's so worried and frightened; you wouldn't let an animal carry on like this […]" (054, 21:21)

This wish for their relative to be free from their pain and 'suffering' did not fit with a hospital admission and care:

"I really didn't want him near […] a hospital because the hospital is purely, 'We want to make you better.' You know, they're still trying to make you better when you're on your last legs, you know." (021, 41:35)

Interventions which carers particularly highlighted included the use of artificial means of feeding and nutrition. Many rejected the distressing thought of using tubes to feed their relative which would only result in a poor quality of life:

"But I suppose me, as a non-medical person, it did come as a slight, 'Ooh heck.' Because I suppose the other thing is, oh this sounds dreadful, I didn't actually think that they would think of putting a sort of PEG [percutaneous endoscopic gastrostomy] in or a feeding tube, you know. I just thought, 'Oh crumbs, no.' You know, it was quite shocking that they would think of doing that really." (060, 3:64)

"[…] We have also made clear that we don't want NG [nasogastric] tubes and artificial ways of feeding mum. […] I think, we think that it would be - she'd be more in pain and uncomfortable." (056, 7:21:22)

However, other less invasive interventions aimed at relieving symptoms were welcomed up to a certain point, for example antibiotic treatment and certainly pain relief right to the end:

"Sometimes they treat them [urinary infections] with antibiotics. I will, for the time being, go with that if she's growing anything because, again, that's unpleasant for her and it causes her distress. So I would want her to continue to have things that made life more comfortable for her […] But equally if she got to the point where my dad was, where he was practically comatose and not aware of it, then I would say, 'No.'." (025, 27:56)

"[…] We'd got what I'd hoped was an agreement that if he were to go, if he needed an infection, if he had an infection that couldn't be treated by mouth, that he wouldn't be hospitalised […]" (062, 24:15)

There was less clarity about participants not accepting death, as this could only be interpreted through participants wanting to pursue more treatments. This does not necessarily mean however, that carers did not accept that their relative was dying, either with or from dementia. For example, some carers wanted to try treatments and felt that their relative should not to be 'given up on' and tried to intervene to preserve their life:

"And what about, you mentioned tube feeding just a second ago.

Yes, quite, yes. What's it called - a PEG system?

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Yeah.

I think that could be managed at home. […] But I would try to think that I could do that at home.

So would you be in favour or using the PEG feeds?

Yes." (036, 20:36)

In addition to acceptance of their relative as 'dying' the other factors influencing the decision about the route of treatment participants took included: 1) carers' understanding of dementia and the disease, which in itself was affected by the level of information they received; 2) beliefs and wishes of the person with dementia; 3) perceived quality of life of the person with dementia and finally; 4) quality of life of the carer.

6.3.1 Carers' understanding of dementia and the disease

Despite many participants demonstrating that they accepted that their relative was dying, carers thought they needed to be knowledgeable about the disease which was causing dementia, the course of disease and its terminal nature. Some illustrated this through their opposition to interventions, speaking about the futility of invasive or "massive" interventions in particular:

"[…] There has to be a point where you have to say, dementia you can never get better from. I mean from a cancer you can get better. In fact I wish my husband had cancer, to be quite honest […] dementia you can't get better." (018, 23:9)

"I didn't want any massive intervention [for example PEG feeding tubes]. I didn't want – what, what was the point?" (041, 11:50).

For carers to have the knowledge of dementia to inform their decision making, they argued that they needed to be provided with the information from professionals. In many cases there was complaint of a distinct lack of information provided. There were consistent reports from participants about being left to use the internet or books to find out information about dementia:

"I actually felt, I sort of felt I was slightly inventing the wheel, you know, that a lot of it was down to me to discover what we were going to need." (042, 9:18)

"It's the first point anyone said vascular dementia to me. But I knew my dad had vascular dementia. How did I know? Because I'd looked on the internet" (041, 11:25)

"I wasn't scared by any of it, because I knew, I knew what it was, because I'd sort of like read up on it. But none of the staff ever took us through any of that. They never sort of, there was nobody that sort of sat us down and said, you know, 'Your mum is reaching the end of her life, you need to prepare yourselves for this,' […]" (050, 16:18)

However it appeared that this was not just about the families' knowledge and understanding but also it was about how prepared for end of life care the families were.

6.3.2 Beliefs and wishes of the person with dementia

The wishes of the person with dementia and their beliefs were important in the decisions the carers took. They said they knew the person with dementia best; they knew what the person with dementia would have wanted despite not being able to communicate with them:

"[…] She's the person that's receiving the care is the most important person. And it's what they want, it's not what - because it's not about you feeling good and thinking that you've done the right thing. You've got to make sure that you're doing what the person themselves want." (050, 16:36)

"They wanted to do a bone scan first to check and see if, you know, what, how bad the osteoporosis was. And I said, 'No we're not going to do that. She doesn't want to go to hospital.' That is so intrusive for her and will cause her so much distress, you know. She only goes for a finger prick and she's like really wound up." (025, 27:47)

However some revealed it would have been helpful for them to have been able to talk to the person with dementia about decisions around treatment:

"In fact I wish my husband had cancer, to be quite honest, because at least I could talk to him and discuss things with him and do other things." (018, 23:9)

6.3.3 Perceived quality of life of the person with dementia

Participants often expressed concern about the level of their relatives' quality of life. They found some symptoms very distressing and perceived this had a big impact on the

person with dementia's quality of life. Many felt that the quality of life was so poor for their relative that there was 'no point' in pursuing more treatment or life sustaining treatments such as antibiotics for recurrent infections:

"I said 'definitely not'. I've seen PEG feeding, and there was no way I was going to put her through PEG feeding.

And why was that?

Because the quality of life is not there

Okay. And when you say 'quality of life,' what do you mean?

She didn't know that she was existing. So why do you prolong it and cause her more suffering?" (034, 12:18)

"[…] 'Do not resuscitate.' Because it's dignity, you know, but I just felt her quality of life was so poor at that stage. If she'd been looking at herself, she would have been uncomfortable, that's putting it mildly." (038, 13:20)

"[…] We think that it would be - she'd be more in pain and uncomfortable. She hates to be touched because I think she has been in the hospital all these times where they are putting a drip in or they are getting bloods and she really resists it. So we don't want her to go through all the pains. And we know that it will be not a good quality of life, even if she makes it through." (056, 7:22)

Some carers expressed that they did not feel there was any quality of life for the person with dementia at the end of life. End of life care and dementia could not equate to quality of life:

> *"[…] But don't call it a quality of life please. You know, if you'd asked my mother, you know, thirty years ago, I think she would have taken a ticket to Switzerland, to be honest."* (060, 3:87)

> *"[…] Some people say, 'Where there's life, there's quality,' it's whatever your belief Nathan. For me, personally, that wasn't a quality of life […]"* (041, 11:86)

> *"[…] I did not want to see my mum going through any more. She was at the stage where she had no quality of life any more. […] you could see that the physical side of her health was beginning to decline. And she couldn't talk any more, she didn't know us any more, she was doubly incontinent, she couldn't feed herself. And I felt that she had reached the stage where she should be allowed to die with dignity."* (008A 008B, 34:18)

Quality of life was also considered in relation to an individual's age. Several carers commented on the relevance of treatment for someone of their relative's age who had had a good life:

> *"[…] She's eighty-eight, she's 89. She's going to die of something ultimately."* (025, 27:50)

"[…] For some - and families, they have PEG fitted for feeding. And I can understand why some people would particularly, where perhaps a person is younger." (041, 11:51)

6.3.4 Quality of life of the carer

It is not just the quality of life of the person with dementia which needs to be considered but also that of the carer themselves. Caring for someone with dementia has a great impact on the carer and causes large disruption in their everyday life, with some acknowledging this more than others:

"And I've, you know, I've spent many a night and I'm still spending - the nights are the worst - awake, wondering, you know, what, when, how? And we've got grandchildren [abroad]. We haven't seen them for three years because he hasn't been - they came over here three years ago. But they're getting too old to be taken out of school in our summer. And I want to book a flight to [abroad], but I can't, not while he's alive. So I'm not wishing him dead.

No of course not

But I'm wishing him out of - he is suffering, he is suffering now, both physically and mentally, I know, I know. He looks sad'." (016, 44:48)

Sometimes, however, it was 'simple', that enough was enough, and it had come to the point where it was time to just let them go:

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"[…] And I said 'you know, he's had every antibiotic there is' I said, 'can you just stop all the antibiotics?'." (031, 26:23)

"[…] In a routine scan of his lungs, there appeared to be a tumour on his lung. So, you know, in some ways, I mean, in some ways I was a bit relieved actually that there was a sort of core morbidity thing going through that possibly might get him before, before the dementia really […]" (041, 41:15)

6.3.5 Perception of how carers are viewed by others

As a result of the decisions or the approach that participants took, there was a perception, or apprehension (maybe even fear in some) about what others, in particular professionals, thought about them:

"[…] The nurse came in the room. So she stands in between and she said, 'You can't do that. You can't. And I said, 'Will you just go out?' And l literally, I pushed her out of the room. […]The nurses looked at me as if I was a murderess." (031, 26:23)

"My dad didn't want to go into hospital, so I didn't want my dad to go into hospital. And I think my GP thought I was trying to bump him off, to be perfectly honest." (025, 27:30)

"The GP comes the week after, sees him sat up in his chair, and he said, 'So you were wrong.' So you're up against this - the GP said, you know, 'You're trying to see him off, he's not ready to go yet.' And all this sort of thing." (025, 27:32)

6.3.6 Treatment of other medical complications/diagnoses

As the majority of participants were discussing someone with dementia who was elderly, there were often many other medical complications, including cancer in some cases. This forced carers and the wider family to consider how they would approach these further complications. Many opted to not treat additional complications which required 'large levels' of intervention:

> *"[…] To be honest, he [GP] hasn't [checked on the cancer]. And, to be honest, I've not pushed him to because I know that my mum doesn't want to do that [receive treatment]. And, you know, ultimately, as long as she's okay."* (025, 27:49)

> *"[…] They had said to me that she also was in congestive heart failure. And I said to them, 'I have Power of Attorney, if she goes into cardiac arrest, I do not want you to resuscitate her. There is absolutely no point now in you trying to do anything else.'[…]"* (008A 008B, 34:17)

> *"And I thought, well if she's going to suffer with the chemo, it might make her worse, it's not a good quality of life, it's not worth doing."* (044, 8:6)

However, again at the other end of the spectrum of views from carers, some felt that just because one has dementia or is old, one should not just simply be given up on:

> *"[…] [the nurse said] 'why did you send for the ambulance?' And I said, 'Well my husband is dying, he's unconscious.' She said, 'Yes but he's got dementia.' I said, 'Oh right, so we leave him here to die, do we?' You know, if he fell in the*

river, would you say, 'Oh forget about him, he's got dementia. Just, you know,

carry on.'." (045, 19:10)

6.3.7   Outcome of decision

Depending on the route of treatment that the carers opted for, this appeared to lead to either the emotional acceptance that their relative had died, or apparent anger and distress which often followed the 'do all you can to preserve the light of life'. Feeling anger following the death of their relative was often associated with the 'do all to preserve the light of life' ethos, and peace and acceptance appeared to be associated with the 'maintain comfort' position.

6.4   What constitutes good end of life care for someone with dementia?

The main focus of this study was on what are the aspects of 'good' and 'bad' end of life care for people with dementia. There appeared to be two aspects of 'good' or 'bad' end of life care discussed by participants. One focussed on what carers thought was 'good' or 'bad' care for themselves as the carer. The second was what they thought was 'good' or 'bad' care for the person with dementia. This distinction highlighted the dyad of carer and person with dementia.

In this section I will describe the important aspects of end of life care for the person with dementia as perceived by carers before moving on to important aspects of care for the carer.

Throughout the interviews, the carers presented their ideas of care for someone with dementia as not necessarily that different to someone else who was terminally ill, such

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as someone with cancer. However, they acknowledged that complications caused by dementia sometimes made the care more complicated, particularly the lack of ability to communicate.

6.4.1 Attention

For the participants there were many aspects which were important to ensure that their relative was still seen and treated as a person. Key to this was the attention and time that they received from the professionals who were caring for their relative. This attention initially began as talking to the individual, making sure they had everything they needed, and getting to know the person. If this was not possible due to the advancing dementia then they could get to know the individual through the family:

> *"They looked at his individual needs. They looked at him as a person. They discussed with him what was important to him […]"* (025, 27:13)

> *"We saw a doctor who, I must admit, was absolutely fantastic with him. He was just, he was a fairly young guy, hugely respectful of him, just listened to him. I was like, 'My dad has dementia' and he's like, 'Okay, but I'll still talk to your dad and I'll talk to you.' And he was just brilliant."* (041, 11:24)

Later in the course of the dementia this progressed to more detailed aspects of attention, for example, from sitting with the person with dementia and feeding them, being patient with this, ensuring that despite not being able to hold a conversation they still talked to them about what they were doing whilst providing care (i.e. whilst changing them), through to ensuring their mouth was moist and swabbed.

"[…] They were really, really doing everything they could to try and ease things for mum and for me. I think they were, that's right, they were swabbing her mouth with water as well because she needed, you know, fluid." (038, 13:25)

"The good quality, the regulars would do - would perform, you know, in terms of how we moved her, like always this habit of, whenever you're going to do something, you say you're going to do it and then you do it. So it doesn't come as a surprise or a shock. […]" (030, 14:22)

"[…] She [Macmillan nurse] was just so good with [person with dementia], the way she was talking to him. And I just thought, 'I'm going to be okay with you.' Because she just kind of connected. But she made the effort to connect, you know, she didn't just come in and sit there with a clipboard. She made the effort to connect with him." (009, 30:24)

Sometimes this attention was lacking and this appeared to be more common or talked about in respect of care received in a hospital setting:

"Well in hospital they taught him to be incontinent […] well they never took him to the loo. So, you know, it was just waiting until he either peed or pooed and then clearing it up." (042, 9:14)

However, it was not restricted to hospital care, as there were also examples of care homes and home care staff not showing enough attention. At times this was blamed on the lack of continuity and staff turnover or shifts.

"[…] I cleaned his mouth. But I found sandwiches from the night before [pressed] into his cheek. And I got the manager up and I said, 'Look his mouth hasn't been looked at for days, something has been in his mouth all night.' […] and [I] said, 'This is not okay, what's this about?' you know. 'Has anybody even looked at my dad overnight, let alone done any mouth care on him?'." (062, 24:21)

"[…] They [care home staff] just look in on him. What they do, they open, the door is open, his door is always open. The nurse or the carer on duty will look in on him. Now that is not 24 hour care. Opening the door or putting your head through and seeing that he's in the bed, that he hasn't fallen off the bed and he's still alive or whatever, is not really looking after him." (006, 36:29)

"The care was absolutely fantastic inasmuch as it was a small home, the staff turnover was incredibly low." (008, 34:30)

This approach to attention was considered important to enable the professionals to know the person well enough to tailor their approach to care with them.

6.4.2 Personalisation and tailoring to individual

Many felt that their relative was seen as 'someone with dementia' rather than 'someone' and therefore professionals often adopted what appeared to be a generic approach, 'the dementia approach' when caring for them. 'The dementia approach' was what many participants perceived professionals to take. This approach meant there was no tailored care for individuals, for example all people with dementia had to drink with a sipping

cup instead of a 'normal' cup. All people with dementia were old and therefore all liked the same things and the same interests that 'old people' have:

> " […] They wanted to feed my mother and they also wanted to give her, her, her drinks in a drinking cup because they'd been told that dementing people can't feed themselves and they needed drinking cups. And, of course, my sister said, 'No actually, mum is perfectly capable.'." (060, 3:24)

> "[…]But they [care home] didn't realise, they'd got a template for how to deal with dementing people, you know, 'Here we go, this is the template, this is the protocol, you know, all dementia sufferers can't feed themselves, so we'll feed them, you know.' And, of course, it wasn't right at all for mum." (060, 3:25)

> "[…] An occupational therapist […] she came bustling in and she went right up to my mother and sort of did this to her [touched cheeks], you know, how you do. And she said, 'Oh hello K, I love to see your lovely smiley face.' And you thought, 'Any moment now you're going to get hit over the head woman,' you could see it, you could see mum bridle, because as I said, there was this Edwardian business about, 'Don't come near me' […]" (060, 3:18)

However, despite being 'the dementia approach' it was also a standard care approach, with medication given at standard times and meals at a standard time. There was a reluctance to deviate from 'protocol' for what some believed to be convenience and others simple fear:

"I think the nurses could be able, flexible - I've had, the other thing that I've had to troubleshoot again and again and again and again and again, is giving him medication when he needs it. They become very rigid. They have a clipboard and on it, it's got his drug rota. […] So, quite often I have been there and seen him in a state of desperately needing medication. So I've had to go along to see the chief nurse and I've said, 'He's desperate for medication.' He looks at his watch and he says, 'Oh well it's not 2 o'clock yet,' or, 'He's not due his next door until 6.30.' And I want to say, 'Fuck the next...' You know, you look at the patient. Why are you being ruled by a clipboard? A clipboard is a tyranny." (006, 36:15)

"I just think, I think it's the fear that, of litigation and a lack, lack of communication and continuity between practitioners. But everything's disjointed nobody has time to find it out. And so they do what they do. What they do is, they give antibiotics for an ear infection, a chest infection or if went off his legs, so this team that's coming into the nursing home to try and prevent admissions to hospital, said, 'He's gone off his legs, he probably has an infection, let's treat him […]" (062, 24:36)

There were many examples of care homes in particular taking a welcomed interest in the person with dementia's past role or hobbies, such as one care home's handyman allowing a resident to help him paint and go to the DIY store:

"And, fortuitously, there was a caretaker there who was just a lovely guy, and um because my dad was quite sprightly, very, very physically fit, um he was

really good with my dad, and he said, 'Come on J, we're going to B&Q,' and

he'd take my dad along to B&Q. My dad thought that he was working there. He

was always grumbling about not getting paid. But he was dead good, he had my

dad doing decorating. And, you know, he couldn't, he couldn't be doing very

well. And he would tidy up what my dad had done afterwards. I mean my dad

was obviously a hindrance. And uh, he was just a fantastic guy." (002, 38:5)

For other people with dementia who were more towards the end of life but still able to eat, one family carer described how the care home made notes of what food and drinks they provided them with and whether they liked it:

"But no, what makes the care good? They keep a very close record of what

everybody's eaten and drunk. They then try and offer something different if they

haven't eaten or drunk whatever it is." (016 – 44:18)

6.4.3   A sense of 'normality'

An element of normality for as long as possible was deemed important by participants. In particular, when in a care home or at home they wanted their relative to do as much as possible as close to what they had been able to previously. They wanted to keep them socially active despite having advancing dementia. Many care homes in particular had many activities to keep residents active and stimulated. However, when carers spoke about keeping the person with dementia active and about activities, it did not necessarily mean sitting down and having a painting day, or having a quiz. It did sometimes, but much of the time they were talking about something much simpler. This was social interaction or doing something that they would have normally done, such as housework, DIY, or gardening, hence maintaining a sense of normality:

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"[…] In the better care homes, they would have a corner, if you like, where - and it's not always possible, where they - where it was safe, where they would just put a load of towels or tea towels or whatever and say, 'E, can you just do that for me love?' and some days she'd do them and some days she didn't. But she had a choice." (043, 063, 22:30)

"And in the first week they'd taken him out - she rang me up and said, 'Am I allowed to take your dad out?' 'Of course, where are you going?' 'We're going to the pub.' I said, 'Well he's not a big drinker, but if he does drink, it will be mild.' But, you know, that was normal." (005, 32:24)

As the dementia progressed, this 'normality' simplified into just 'fitting in' with normal family life and remaining part of the family unit, for many participants who wanted their relative to remain at home. But it was also just important to maintain a connection with the person:

"Fitting in with the household because my children come and go quite a bit." (042, 9:25)

"I would wheel her through to the kitchen and she would sit at the table and we'd have some nice calming music on, and she would watch me cook and then try things […]" (030, 14:18)

"I started music therapy for her and she loved that. And when she was very, very poorly, you know, we had little drums and things like that and mum would start

stroking the drum. […] But when mum was sort of more poorly, she - the therapist came right up until the day mum died, and in fact she was due that day - would sit with mum and mum would just love rubbing the drum or listening to her playing the flute or singing […]. And I had puppets, because that helped with mum's speech and trying to get communication with mum. And Play-doh. And we had lots of sensory things. I had lots of materials so mum could just sit and stroke." (049, 25:30)

6.4.4   Respect and dignity – dementia made it a 'dehumanising experience'

All participants were concerned with the level of dignity that their relative had or perceived that they had. When discussion turned to end of life care this was one of the key criteria to 'good' quality care. They wanted to ensure that their relative was still treated as a person and an individual with respect and dignity. They were less concerned in the early stages of dementia. In the final stages the person with dementia was no longer able to communicate and preserve their own dignity.

There were many examples of how people with dementia had been treated with both the respect and dignity that families felt they deserved. To participants dignity encompassed being gentle and caring with the person with dementia who now had limited communication abilities. They needed to feel safe and secure with people who were familiar to them:

> *"[…] She was respected and treated with dignity. And they used to be very gentle with mum, knowing that she doesn't speak and she was very - like she used to fear people touching her because she probably had fear of injections or something. But they used to make sure she was fine […]"* (056, 7:26)

"[…] The familiarity of the people around you and being treated with respect and dignity. It's - we find that, you know, as the person gets older, the most important thing is to be in the comfort of your own home for a sense of security as well […]" (056, 7:28)

Participants, in particular, mentioned incontinence when they spoke about dignity, often with negative examples and often because of individual staff members, rather than a system fault:

"[…] You press the bell, you want to go [toilet] then, you don't want to go - 'I'll be along with you in a second, I'll just finish with this person.' No, they need to go, you can hang on a little bit but you can't hang on for ten minutes, which is what they expect you to do. 'Well you've got a pad on, use that.' I'm sorry, but you may have a pad on, but you don't want to" (026, 2:4)

"[…] But I said '[my husband] wouldn't know what a toilet was, he has to be taken to the toilet, he doesn't know the difference between a toilet, a bath, a sink, he doesn't know what a toilet is'. […] And she said [nurse], 'Oh,' she said, 'Not to worry,' she said, 'If he pees on the floor, that's okay'." (013, 43:11)

"[…] And everything about it was a thoroughly dehumanising experience because they would only help me change my mum when she'd wet herself […]" (008A 008B, 34:9)

Similarly, participants were often concerned about the dignity of their relative in relation to personal care. Some explained how home care workers did not shower their relative with respect or dignity due to 'health and safety' (owing perhaps to limited allocated staffing and lack of aids and adaptations), but rather used flannels with the person with dementia naked:

"[…] They stood him in front of the sink, with a wet flannel, up his front, down his back. Again it was totally humiliating […]" (004, 33:20)

"The idea that just because somebody has dementia, they have no sense of modesty or privacy, do you know what I mean - the idea that you can just strip somebody naked and start washing them. I mean they wouldn't bath him because that's health and safety. They wouldn't shower him, that's health and safety. So there was only a flannel. Well, can you imagine, if you had, even if you only had half your marbles, what it is like to be washed with a flannel by somebody who you've never seen before, in your own home, and your wife's there? […]" (004, 33:22)

And two participants described how their fathers had been left naked in hospital:

"They thought it was alright for some guy to be lying naked in a bed rolling the sheet up, exposing himself. And you know, and including at visiting time! […]" (002, 38:43)

"[…] It was then the discharge suite. I walked in to pick him up and he was sat in a green gown, half naked. So it was up to here. His legs exposed. He was soaking wet, soiled himself and he had somebody else's glasses on. You know he had no sheet or blanket or anything covering his dignity […]" (015, 46:42)

Some were unable to come to terms with providing personal care themselves. They were often the son of the mother or daughter of the father and they felt it was inappropriate. In these cases they would not be treating their relative with the respect and dignity they deserved if they were to wash, take their relative to the toilet, or change their incontinence pads:

"I had to wash him, I had to shave him, I had to shower him and, you know, I had to wash all his genitals. I mean I found that really stressful because I didn't realise how intricate it is to wash a man like that […]" (045, 19:1)

"[…] He was a very proud man. I mean the fact that I shower him, I mean that would be against everything that he would want." (018 – 23:8)

"[…] Suddenly I was faced with the prospect of having to give my mum a wash and this is a person - my mum, I'd never seen her naked or top half-naked or anything like that. I never washed a woman […]" (011, 35:25)

"[…] For me to do that for my dad was, I was cursing him. And it was really, it was a very grave situation […] 'So we'll get an Asian man,' and like, 'No there are no Asian men, they'll be Asian women,' and I'm like, 'No, no, no, you're not

getting it. I need an Asian man to come and do this.' […]Here I am changing

my dad's. You know, I'm cursing him every time I do it. Yeah, he's obviously

dying, you know." (015, 46:30:34)

It was also important that as an older generation, many would not have been comfortable with having a carer of the opposite sex, especially providing personal care. Where possible there seemed to be an attempt to prevent this, however, this was not always possible:

"Well no because they got, they got carers and some of them were men. So

there was a woman and a man in my mum's room and my mum would look at me

and I knew the look she'd give me would be like, I knew her look." (049, 25:43)

"And (brother) saying, 'Yeah this isn't, we can't have some strange woman

coming in to this house, changing dad.'" (015, 46:34)

Throughout this theme it appears that some carers thought their relative was discriminated against because they had dementia. This impacted on their ability to be treated as an individual and as a person being seen as someone with a disease, or just being seen as dementia:

"And she - they put her on to the acute ward, and it was from there that I

realised that there's - the only word is 'discrimination', that people with

dementia are discriminated against because everybody else in the hospital has

no idea what they're dealing with. And I mean from consultant to floor worker."
(036, 20:1)

" 'She's definitely got vascular dementia with a bit of Alzheimer's […] and she's depressed.' So she said, 'I'm going to give her, write her up antidepressants for her to have as well.' And she said, 'And then once she gets home, give us a ring.' So she was in and I, I would have said that the attitude changed overnight to how they cared for her.

In what way?

In that they wanted rid of her.

Because of the dementia?

Because of the dementia." (022, 4:48)

Despite this fear and occasions when there was discrimination because of the person having dementia, there were also signs of relief that their relatives were being treated with the respect and dignity any individual deserved:

"They keep the respect of the people. I know that sounds probably silly. But, you know, he's not just a bod, you know […]" (018, 23:17)

"Treating the person as a person and not somebody with an illness. I think that's the most important thing. I mean they still have a personality even if they can't express themselves." (018, 23:20)

"[…] They treated him, I think with the respect that, you know, they treated him as a person and not as, you know, the patient in the bed." (025, 27:28)

6.4.5 Basic care

In addition to maintaining the individual and seeing them as a person still, carers also suggested that there were other key elements to 'good' quality end of life care. Some carers were keen to point out on several occasions that many of these core principles to 'good' quality end of life care were often rather basic. These elements did not require a great deal of skill or knowledge about dementia or the person they were caring for. However, this did not mean that they did not believe and recognise that caring for a person with dementia was difficult and exceptionally demanding.

Compassion and kindness

Caring, kind and compassionate staff were described by many carers as qualities which were required:

"You need to have compassion if you're looking after somebody at the end stage." (008A,008B, 34:29)

"[…] The staff need to be compassionate and I know they see patients dying all the time, but somebody younger and with a family who are very obviously don't

quite know what to expect, I do think they could have been a bit more helpful."
(031, 26:36)

The lack of care and compassion from staff was described as being evident in the way they spoke to the person with dementia or the manner in which they approached the care for them. Comments varied from talking about a GP visiting the person with dementia through to the standards of care of nurses and healthcare assistants in hospital and of care workers in care homes:

> *"[…] And when he finally did get somebody [GP] to come and see him, he [GP] just looked at him at home and just said to me, 'Hopeless case.' […]"* (031, 26:8)

> *"There was one point where we went in to see a junior doctor. And I had to try and wheel my mum in through his office door. And I couldn't even get the wheelchair through the door. But nobody, he didn't stand up to help me. And it was a door where you couldn't, you know, you couldn't actually kind of get the chair through the door. So we kind of half had the consultation with me standing, and my mum was out here in the wheelchair […]"* (008, 34:13)

> *"[…] Then this doctor came in and he quite openly was telling us that mam has this massive bleed and all this. And he walked out the door a couple of minutes and me and my sister, me and our L were there. And me mam sat up and started to shout. And, 'No, no, no, no, no it hurts, it hurts, it hurts, it hurts.' And she was in an awful state […]"* (022 – 4:22)

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There seemed to be an emphasis on disappointment/anger with 'poor' care from the nurses as opposed to the doctors or other care staff. In particular, when highlighting 'poor' care in hospitals, illustrations were based on the role of the nurses and what participants saw as a failure of their role:

"But the nursing standards were dreadful. And when she came out, having gone in able to walk and talk, she could no longer walk and talk." (020, 10:8)

The description of 'poor' nursing care was described as ignoring the needs of patients whether these were the medical needs or simple needs such as the delivery of food:

"And then that was another sign of the nursing care. You'd quite often find that the drip was not operating or be empty of something of that sort […]" (020, 10:17)

"I have never seen such appalling bad nursing in my life. Medically - I can't fault the doctors […] Leaving the medication on the side of the bed, having told - putting him in a ward with three old women. Telling him not to get out of bed, that was the pacemaker, he was all wired up - not to get out of bed, but not showing him, well they did show him. […] so when he got out of bed to go to the loo, which he didn't know, there was no bottle, but even if there was, he wouldn't have known where to find it - obviously bells rang in the computer room because he was becoming detached. And they were, I walked in at that point and there were two nurses berating him. You know, 'We told you not to get out bed, you know, da, da, da, da, da.' I said, 'What do you think you're

saying to him? How do you think a man with dementia ...' […] You know, they

just had no comprehension." (016, 44:44)

"One of the nurses accused my father of being [trouble], you know, she was a -

you know, if I ever see her again, I'll take a baseball bat to her face, I tell you!

That's how strongly I feel about her. I will punch her lights out. […] Because he

took out his catheter, you know. […] I told them not to stick him by a - because

he had like an electrical box. And I told them not to put him there, because I

could see that he, he was going to try and get to that […] So he ripped out his

cannulator to try to open the electrical box. And obviously there was blood

everywhere. And then they just flipped over the pillow. You know, and there

was another chap in there who was in his nineties and he was like dad, a

wanderer […] he was going round switching off machines […] [another

patient] was running round after him, switching them all back on again. But all

he wanted was someone to chat to. […] Then he went wandering again, you

know. And this auxiliary nurse came, grabbed him by the shoulders and put him

on the bed and said, 'Will you fucking stop moving?' And I just thought, and

those were the words." (015, 46:45)

Participants perceived there to be many reasons as to why some professionals were not

as caring as they thought they should be. Participants felt that professionals were under

many different forms of pressure which impacted upon their care including time, and

health and safety regulations. With these pressures there was a fear from professionals

that there would be a backlash from the system if they did not perform, or provided a

level of care which was outside the realms of the organisation/agency/trust. As with the

understanding of dementia on the families' behalf, it was important for professionals to understand this too. Finally, nurses were thought to be required to complete vast amounts of paper work rather than being able to continue with their 'caring' and 'nursing' role as families perceived them to have done traditionally:

"[…] It's just a real difficulty at the moment in the NHS, that nurses do not see their role as caring, they see it as some kind of paramedical role. And no, it was completely disastrous." (004, 33:35)

"I just asked the nurse, who was walking along, could she help me? And she said, 'No I haven't got the time.'." (003, 42:27)

"The nurses were dreadful, the care assistants were very good." (033, 15:19)

There was a perception that when nurses provided 'good' care it may have been due to the leadership they had:

"[…] The ward manager was a really good leader. She was out there, she was working with people, she was supporting them […] I think she was, her leadership actually - they were a lovely team. There wasn't one member of staff on that ward that wasn't, that in my opinion wasn't there to do the very best that they could for patients […]" (025, 27:27)

It was not just the nurses in hospitals who carers perceived to not have enough time; some thought this of the doctors too:

"But the medical profession, I don't think has enough time […]" (030, 14:45)

Some discussed how care in the community was also limited by time:

"[…] They'd [home care workers] be like booked for half an hour and they'd be here for about ten minutes. But they were on such a timetable, it was just a case of that was the way they were making their money" (034, 12:11)

Not all home care workers however stuck to a 'strict' schedule of time:

"A few were really good people and became friends. Three actually particularly became, you know, we still email each other from time to time, and that sort of thing. And had their hearts in the right place and were efficient and didn't worry about health and safety too much, and, you know, just coped like I did with what needed to be done. And weren't strict about shifts and didn't clock watch and so on. But there were some that were not like that at all. You know, they would just come in saying all the things they were not allowed to do." (042, 9:19).

One carer thought that nursing homes had got the approach to care correct:

"[…] The nursing home had always been so good because their approach had always been, 'It wasn't a problem.' I think, on reflection, they appreciated it was a natural progression. They understood that this illness was going to

progress to the point where dad was going to die. And they knew that […]"
(041, 11:65)

For some participants they believed that selected care workers were just simply in the wrong job and doing it for the wrong reasons:

"[…] Because carers - I put them - the caring carers and the 'pin money' carers. And what you had was those, not an ageist thing this way, but those in about their thirties and forties and things like that were really caring ones and they were great. And then we had these, what I call the 'pin money' carers, mostly youngsters, who were very often doing the night duties, would come at night. And all they were interested in was getting round as fast as they could, even some of them - they had their children with them in the car, they were left in the car outside […]" (034, 12:9)

"And I just think, you know, 'You should not be in the job. You should not be in the job if you don't, if you don't care, if you've not got the compassion, you should not be in the job,' you know […]" (050, 16:21)

Although some 'horror' stories were reported by a number of the participants, they did also talk about occasions where they had experienced 'good' levels of care. They believed these occasions were underpinned by caring and compassionate staff. They were seen as able to sympathise, and to show concern or consideration for the person with dementia:

"[…] He [GP] had a completely different approach and was, you know, 'What can we do to make him comfortable, what can we do to support you?' And I thought, I don't know if that's because he's coming from a mental health field, and if he's got a different perspective or if it's just, he's just a really nice guy and he's caring and compassionate […]" (025, 27:59)

"[hospital] Ward was probably one of the nicest because the nurses seemed to bother, they seemed to care, they seemed to, they were still just as rushed off their feet, the still spent far too much time on their computers. But they seemed to be much more caring, much more gentle […]" (026, 2:12)

Carers spoke highly of professionals who were willing to stay longer after their shift had finished. As mentioned previously, under the subtheme of attention, this was to ensure the care that they started with the person was finished, or to check they returned from hospital safely. Some professionals were described as sitting with and caring for the person through their final hours when it was apparent they were close to death:

"The person who stayed with him, bless her, the home were brilliant, they said - she said, 'I've got to stay with him, but I just need to go home and then I'll come back […]'" (041, 11:63)

"[…] And he came back from the hospital about seven in the evening and I was already there. And bless, the carer [care worker] who was with him, she was way over her shift and whatever, and she said, 'No I'm going to sit and make

sure, and cook, let's get him some pudd,' because my dad liked pudding […]"
(041, 11:48)

Participants appreciated the mixture of both a professional side and a human and emotional side to the professional care staff. In particular, when care workers became emotional when the person with dementia had died, to them as a family it showed that the professionals (both care workers and nurses) did actually care about their relative:

"And they were really upset [when the person with dementia died]. You know what I mean, it's weird really, in a weird way that as quite comforting that they were so, you know, you knew it was going to happen, I was upset because, even though you sort of knew he was dying, you'd lost him, he'd gone, but they were upset as well, which I think again was - you knew that they cared." (041, 11:67)

"Their humanity actually. I mean they cried, I, you know what I mean. They were, they treated him like a baby, you know, so, with such gentleness, with such sweetness. I mean even when he'd died, you know, they kind of straightened his body, but did it with just such gentleness […]" (004, 33:62)

"So there was a balance between them being professional but also being human?

Yes, just human, yes. And that compassion that was just coming from them as people as well as, you know, their profession." (049, 25:65)

The factors of time, reluctance to stick to the apparent rules of health and safety (as perceived by the families), allowing for a bit of flexibility within these and 'go the extra mile' in the care of the person with dementia, together with a good understanding of dementia, seemed to form the crux of a caring, kind and compassionate professional.

Maintaining the individual

Participants believed that some of the aspects of basic care were not to do with the medical aspect of care but to do with the personal approaches care workers took to caring for someone with dementia. In particular, this included the individual's appearance. Participants spoke of distress when their relative was dressed in other people's clothes, because this appeared to be convenient for the care home or hospital staff, or because there was a lack of care and attention paid to their relatives' belongings that tended to get mixed up with those of others:

> *"[…] It sounds really stupid, this does - but my dad had a moustache, he was always very proud of his moustache. And they shaved his moustache off without saying anything to me."* (041, 11:93)

> *"She'd have other people's clothes on, you know, despite the fact that we'd carefully labelled everything. And, you know, we were reassured that everything went down to the laundry and came back and was put in everybody's own rooms. And, you know, these things still kept happening."* (050, 16:11)

It was not simply other people's clothes, it was also whether their appearance was different because the care workers may not have known how they were used to dressing

or appearing. The families knew that this was no fault of the care home staff or hospital staff, but nevertheless this was for some a distressing and upsetting situation:

"[…] And sometimes, in terms of how he was dressed, it would be like odd colours together. And I think things like that are really important. But you sort of have to accept - I think I started to accept in the big scheme of things, did this really matter?" (041, 11:93)

In particular, one participant spoke about how their mum did not recognise her husband who had dementia and this caused her great distress, as he was wearing someone else's clothes whilst in hospital:

"When he was in the hospital, you know, I made sure I gave them a whole suitcase full of labelled clothes. And the first time I went to see him, he was wearing somebody else's clothes, with his glasses had gone, his stick was gone and his hair was wild and he just sort of looked like a wild man. And I thought, you know, why have you put him in somebody else's clothes? My mum couldn't recognise him. You know, that's how different he looked, you know." (062, 24:12)

This also occurred in the care home too:

"In the care home it wasn't quite so bad, although, although we did find that he was in other people's clothes and other people were wearing his clothes. And that distressed mum terribly because she, she recognised his clothes. He had

very distinctive jumpers and she would practically go and tear them off people. You know, because they were his. She was so protective over him. And it was, it was - I understood how that happened, but it was distressing to see it, because it was distressing to see mum's distress at it. And, but the little things do matter very, very much, and they are what you remember clearly, because that's what I remember now. You know, the fact that he'd not got his glasses on distressed mum terribly and staff didn't seem to understand." (062, 24:13)

Participants appeared distressed by such encounters, and this really mattered to them. It seemed that the dementia was causing the person that they had known for so long to fade away and they were left with just the physical part of this person. However, the physical appearance of this person was also now beginning to become unfamiliar. Participants thought this was as if they were losing another part (the physical being/appearance) of their relative.

Finally, making an effort over the little personal things such as dressing up on a special occasion and receiving beauty treatments was seen as an indicator of 'good' care:

"[…] There was a hairdresser, so she went once a week to have her hair done. I mean you pay extra for that but it makes them feel better. And you'd go sometimes, like special occasions, for like mother's day or Christmas Day. And the staff, whoever got her up that day, had put her in a posh frock, you know, they recognised, 'Oh yes that's a posh frock, she can wear that today because it's a special thing,' rather than just, 'Oh God, put that on.'" (054, 21:15)

"But the first thing they did, when we walked in, we got out of the ambulance and went in - a nurse turned to J [person with dementia] and said, 'Would you like your hair washed?' And I nearly collapsed because no one had washed her hair in the four weeks she's been in the other hospital. And she turned to us and said, 'We're not supposed to do it, but I wouldn't like it if my hair wasn't washed.'" (003A, 42:28)

Pain management and comfort

A priority for all participants was to ensure that their relative was comfortable, peaceful and free from pain at the end of life, which in many occasions the person with dementia was thought to be. However, there were some distressing occasions when the person with dementia was thought to be in unnecessary pain, as a result of pain medication being difficult to access because of weekend services, for example:

"The patch didn't come because it was the weekend, so she couldn't take her pain relief. She hadn't got any pain relief at all. And over the weekend, the nurse, well I mean they - yes there was a nurse there, but it wasn't the usual one. And I just feel we totally let mum down over that last weekend, because she hadn't got the pain relief, she was in pain, wasn't getting her medication, she couldn't swallow it." (038, 13:24)

"[…] I think that's the major thing that was wrong and this was the pain relief not having been sorted out. I mean I think they would say that she went downhill very quickly at the end. But there should be some way of providing continuous pain relief once somebody is unable to swallow the tablets, it should

be there straightaway with patches, because I know they take a little while to actually take effect […]" (038, 13:29)

Some participants saw no reason as to why pain medication was not administered in a timely fashion other than simple 'neglect' by members of staff:

"And it's supposed to last about 24 hours. And it always seemed as if it was a big surprise to them when the thing went off, because about an hour before it ran out, there was like a beeper would go off. So then you would go and say, 'Oh the beeper's going on the thing, would you come through and sort it?' 'Oh it's just a reminder for the thing, alright, oh yeah.' You know, and then they would go up again. It always ran out because it was the time of the handover. So we would say to the nurse - 'Oh right, well the sister is just in handover.'." (022, 4:18)

Others considered it was policies and procedures which meant staff perceived it difficult to provide pain medication:

"In a hospital they would never give him morphine for his pain, for instance. I was taking it in, in the end, because I had it here. And they said, 'It's every four hours, it's only written up every four hours.' And he'd be crying with pain, so I'd just take some in and give it to him. And, because I had said to the palliative consultant, she said, 'give him as much as he needs, just give it to him.' And I said 'well what happens if I give him too much?' And she said 'He'll go to sleep. That's all that will happen, he'll go to sleep and he'll wake up again, and you

know, you'll know that that's his threshold, but at least he'll be asleep, he won't be in pain.' So I said, 'Okay, fine.' So I was never worried about this. Hospital, no, you can only give it four hours, you know, there's no question, you know he can be screaming, and you have to wait for four hours. And I just thought,' I'm not having this'. So I just took it in and gave it to him." (004, 33:57)

"And it took three days to get Paracetamol for the pain. I went down myself with a prescription in the end to the surgery, because the surgery hadn't passed it to their pharmacy and the pharmacy hadn't dispensed it. And nobody from the nursing home had been to collect it. And I said, surely any nursing home with registered RGNs, can give, from a stock bottle, Paracetamol. But apparently they can't. […] what's the word – policies that says, 'No, everything had go to be prescribed.' […] to me, to leave somebody in pain for two days […]" (016, 44:28)

Pain management was more than simply providing pain medication for the person with dementia. It also included being gentle and careful, particularly with people who are bed bound and as a result may suffer from bed sores or suffer pain from simple touch:

"I heard this scream, that was my mum. She hadn't been able to talk or anything like that, but she managed to scream because she was in so much pain. I mean they wouldn't have been doing anything to her other than just moving her, you know, to change the sheets." (038, 13:24)

Comfort

Making the person with dementia 'comfortable' was the key word or phrase used for 'best' care at the end of life by many of the participants:

> *"[…] We just want to make her as comfortable, as comfortable as possible in her own familiar surroundings with the family and friends around. And just in comfort."* (056, 7:23)

> *"I wanted her to be – well I wanted her to be comfortable and not suffering pain, that's the thing I wanted most […]"* (044, 8:11)

> *"[…] I think, if you have got someone with dementia, it does come to, you know, it does come down to very basic things – making them comfortable, warm, reassured, not frightened, not distressed, with no pain. You're coming back to the, some very basic – it's like childhood isn't it […]"* (030, 14:31)

As can be seen in the extracts above, hospitals were perceived to have less of an understanding of this and took more of a medical approach to the patient care, such as wanting to provide explanations for the families about why the person was in pain. However, care homes moved away from the medical approach in terms of the language used with families. They simply addressed areas of concern for relatives, such as pain and comfort which were the main concerns for carers:

> *"[…] There is a medical aspect of it. But I think they [care home] detach it because I think, I think they had a better understanding of what you're*

concerned about because you don't look at your dad and go 'Oh my dad has

vascular dementia, what's the medical prognosis for that?' You look at your dad

and think, 'oh my gosh, what's going to happen to him? I don't want him to be

in pain, I don't want him to be in distress. This is bloody awful what's

happening to him." (041, 11:75)

From the illustrative quotes above, it appears that in order to provide a pain free and comfortable death, preparation is needed and a crisis can and should be averted through careful planning and preparation of 'just in case' medication or equipment. In some accounts this was evident:

"I think we had the stuff if we needed it, but we didn't actually need it. So we

thought ahead, certainly the doctor had been very good about, you know, they

said, 'I can give you all the stuff here, so we have it on hand, and if we do need

it, then it's there.'" (030, 14:31)

Familiarity and continuity

It was felt by many of the carers that they thought the person with dementia needed and appreciated familiarity to feel safe, cared for and contented. Familiarity was important and in particular carers talked about the importance of a familiar environment, being in their own room in their own home. This was either the 'family home' they had lived in for many years, their adult child's house, or a care home which they now considered to be their home:

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"So the last few months of her life, she just wanted to be in her bedroom. If she was happy there, that was the best place for her. If she was in a care home, in a room she didn't recognise, it wouldn't, you know, it wouldn't have [been] good care, it wouldn't have been good care." (011, 35:34)

"Quite often she just preferred to stay in, she was quite happy in her own house. I mean she'd done a lot of home crafts. So a lot of her furniture was made by herself, you know, and stuff like that. So her home was really her home with all her nice things around her, you know. And in the care home, it wouldn't have been - I know you're allowed to take a few pieces of furniture but it's not the same." (017, 37:16)

"[…] By 3.30 he was back in the care home […] And, you know, he was very pleased to be home in his room, in, you know, by this stage his room had sort of you know morphed into being his home, you know, and it was nice and compact and not too cluttered and surrounded by his stuff and he liked the staff." (021, 41:18)

But for many it was more than just a familiar environment which was important, it was also about the familiarity of those around them and not being alone at the end. Participants spoke about the continuity needed with staff and how having a high level of staff turnover was not acceptable at the end of life for someone with dementia:

"Well it's very nice to have continuity of care. Of course you very rarely get that because the staff, like some staff go off on a different duty, that the rest are just changed, they just go. And it's the good ones that go." (031, 26:39)

"[…] I realised that the thing was, what you wanted to do was to have as little disruption as possible. So as was a long a period of time with the same person, because every time a new person came on, along, mum was on edge." (026, 2:15)

"The only thing I didn't like was that they [professional carers] did change at a moment's notice. I thought [the organisation] should have made sure that where at all possible, that someone with dementia particularly got the same two or three people and that they didn't change. At one time we went through five changes." (036, 20:19)

One participant discussed the highly stressful situation of home care workers being withdrawn from her after an alleged complaint about her treatment of the care workers. She believed this was due to one carer worker taking offence after being told to change her clothing to be more appropriate:

"[…] Basically they [carers' agency] gave me seven days' notice [to stop providing home carers]. There wasn't even a, there wasn't even a, 'let's talk about it, let me hear your side of what's been going on,' or anything. And mum was, I said, 'My mother is dying.' I said, 'And the very reason, all I have worked towards, you know, in terms of having the carers that I've got here and mum not having different carers and everything, was at the point of mum dying,

there would be people around her who she knew and who knew her.' And I said,

'And you're taking them away?' And do you know, I'm not known for this, but,

you know, but this was about my mum, not about me. I begged them not to do it.

And they said, 'No, we're giving you seven days' notice.' And then they walked

out. And then they left […]" (049, 25:42)

The view of continuity applied to all professionals and not simply to carers (home based care workers or care home workers), including GPs and specialists such as old age psychiatrists. The desire to see the same professional was often due to a desire for continuity to ensure that they understood their relatives' case. They would have previous knowledge and experience of them and not only for familiarity of faces for the person with dementia:

"[…] You don't see the same GP any more. Right, we've had three, four

different ones, you know, in the surgery and there are three partners there. So

some notes are on the computer, but I don't think there's, so really they don't

know the patient very well." (057, 17:30)

"Yes because he was getting infections and things. So again we weren't, we

weren't getting the same doctor. So we were having different doctors. And one

of the things that I found completely draining was you had to say the same

bloody thing every time somebody walked through the door. Now that could be

on a weekly basis. I mean it wasn't really, but, you know, what with the nurses,

the physio, occupational therapist, doctors and then at some stage they brought

in the community matron. And in the end, after the third different one, I said,

'Don't come back, any of you, I don't want you here. We have enough different people coming in the house. I have to keep telling every single one of you every time you come all, all the same thing over and over again despite the fact you've got it in your notes in front of you, you know,' I said, 'I'm not doing it anymore.'" (012, 48:31)

"Continuity of the same people coming in to the house - very, very important, because I think you have to build up a relationship, particularly with the person with dementia [...]" (003, 42:23)

6.5   What constitutes good end of life care for the carer

6.5.1   Support for the carer

Participants clearly illustrated that caring for someone with dementia was demanding and challenging, with many carers feeling exhausted both physically and mentally:

"It's like you were fighting the whole time to actually get the best possible care, and it's exhausting, you know, absolutely exhausting, and you don't need that because obviously it affects the quality of the care you can give." (012, 48:27)

"[...] I didn't know how long I was going to be [abroad] because I was so burnt out, I was practically on the verge of a breakdown." (012, 48:53)

Some participants felt that they should be considered as a 'unit' and not simply the person with dementia and then the carer as separate:

"[…] My GP had also tried again to refer him [person with dementia] to palliative care. They were trying to refer me to palliative care [wife with a cancer diagnosis]. Neither of us reached the criteria. And it was the Admiral Nurse (specialist dementia nurse) that said, 'This is just absurd. Neither of you reached the criteria individually, but as a couple you obviously do reach the criteria." (004, 33:30)

Carers' ability to live and maintain some 'normality' in their everyday life was often a challenge. This presented different problems for people who were adult children caring for a parent, for example, compared to those who were much older and caring for a spouse. Adult children often had other family members to support and work commitments limiting their ability to be able to care for their relative. For many this gave rise to increased guilt, both on the part of not being there for the person with dementia but also not being able to be there for their family. Older carers struggled with the physical caring activities. Younger carers perceived difficulties that might affect older carers, including, having sufficient mental strength to make complaints:

"I was working - it just couldn't carry on doing all the roles. I had young children, a job, I mean …" (057, 17:19)

"I mean what I'm realising now, I'm going to see our MP next week, because what I'm also realising is that, if you're a carer who is older, more fragile, feels exhausted anyway, maybe ill, you don't go doggedly on with all this appealing stuff. You just give up." (042, 9:50)

"[…] But her mum's in a home, and she's got young children, so I think when she got to a certain stage, her mum went into a home because she couldn't cope. And not that she couldn't cope mentally or physically or anything, but just because she had a young family and, it's priorities. I mean I haven't got that. I've got no one and I'm really lucky from that point of view. I've got no one making demands on my life." (014, 47:8)

Given the reported strain of the caring role, it was clear that a key criterion for 'good' end of life care was support for the carer. However, as can be seen from the quotes above, support meant many different things and did not simply mean helping the carer to do all the physical caring. In order to better understand what carers meant by this, it was important to break down the caring role as perceived by the participants. Some expressed resentment that they were known as a 'carer', they felt they were unable to just spend time with their relative. They had to manage everything and everyone around them, on occasions cope with deficiencies in services, and deal with staff who were there to support their relative with dementia, but not there to support them:

"[…] Overnight you stop being a wife and become a carer. And actually I didn't feel I was a carer. It's a term that I really objected to. Yes I did a lot of caring. And yes, but when the carer was here, I could be a wife again. And that's what I liked." (004, 33:71)

"[…] No I'm not a bloody carer, I'm his wife. Will you please kind of get that right." (004, 33:68)

"So what did you think about that term being used, the term 'carer,' to describe yourself?

Well it wasn't me, you know, that didn't sound like me, you know, to be a carer. I was his wife, you see." (045, 19:6)

However, others were less concerned with being referred to as a carer:

"And then finally, the term 'carer', did you see yourself as a carer?

Yeah, absolutely.

Yes, and how do you feel about that?

It's quite alright." (030, 14:36)

To others the role of carer was part of their role as daughter or wife, for example:

"[…] I think for me, I was just his daughter, as simple, as simple as that. And yeah he'd got another daughter who didn't take that responsibility. I suppose that's slightly different. But no I think I felt totally responsible for him and love." (041, 11:90)

The participants highlighted three main duties to their role: the physical aspects, the care management aspects such as coordinating homecare workers, and finally simply being

with the person with dementia. This final role was the most important aspect to their role as a carer for many.

Many participants felt that they were the best person to do the caring for their relative and found it difficult to relinquish such control. They believed that they were both the generalist with knowledge about end of life care and dementia, but also being specialist within those two fields. Professionals however were thought to specialise in only one of these areas.

Some further resented that there was no help there for them in this 'journey'. The over resounding resentment, however, was that dementia had 'stolen' their relative from them and disrupted their positions within the family and their 'normal' family life:

> *"So I had to tell everybody [health and social care professionals] and saying - I mean it were obvious that she did [had dementia], because they'd come on and then they'd come again and she didn't know who they were and, you know, we'd go through the - so yeah they did know. But I didn't feel they knew any better than me, you know, how to deal with that really. But people have their own - they seem to just specialise in one thing, don't they?"* (044, 8:48)

The carers had become the experts through their experiences and wanted things done in a particular way because they believed that was the best way. They did not want to give up that control over the care they had:

"Of course, when you're caring for somebody suffering from dementia, you're dealing with it every single day of the week, and you do become the expert. You do become the expert in that. I became the expert in my mum's care." (035, 35:15)

"I got rather a reputation for coming in and saying, you know, 'Could you please do it this way?' or, 'You haven't done that the way we said,' or his food was a big problem, because he had serious swallowing problems. And they didn't understand about pureed diets, which was odd for a care home. But anyway..." (042, 9:37)

"And I says [to a dementia conference of professionals], 'And you are now lucky enough to be sitting in the company and listening to an expert. I am an expert. I am an expert, I am a carer. And any one of you who has never cared for a person with dementia, doesn't know what the bloody hell you're talking about, none of you." (043, 063, 22:24)

Some carers felt that their expertise extended not just to the way to provide care, for example, how to lift the individual, but even more detailed aspects of care such as medication:

"I've got him on permanent Cocodamol now because I think that he is in pain some of the time and I don't want to risk him not being, it not being covered. You know, he was on Paracetamol as needed, which the nurses could give. But they're not necessarily going to be noticing tiny signs of pain like if I go in and

he's grinding his teeth or has a very red face, something like that, then - or just looking, I don't know. Even though he doesn't have any facial expression that sort of changes, you can spot - which I don't think the staff are necessarily going to spot because they're not - okay they're with him much more time than I am, but not with the intensity that I am. So I've pushed for this Cocodamol so that I know he's being given it because it's prescribed." (029, 6:58)

In order to achieve this role, carers acknowledged they needed support and could not perform the role without professional input, certainly not without great difficulty. The support they therefore needed was split into three main categories: 1) support with care management; 2) support for physical aspects of caring; and 3) support for their own emotional needs:

"[…] It's understanding because what I say is, as a carer, you need to have resilience, because there are challenges navigating the system, whatever and sometimes it's, you wake up so many times in the night. So basically, you know, you just need time to kind of recharge and you need a support structure. Nobody can do it alone. So, for me, it's how - I'm not saying you give your caring responsibilities to somebody else, but how can you make this role have enough resilience that you can carry on, rather than having a breakdown. It doesn't help the person who needs the care or yourself." (057, 17:1)

Support with care management

The care management role of the carer was seen as the one that participants resented having to do. They saw this as someone else's role or as one that should not need to be

done. This side to the role encompassed contacting various services, both health and social services, to visit the person with dementia. This, at times, involved liaising and acting as carer as 'case manager':

> *"But the GP was sort of saying, 'Okay we'll see.' But the social services, 'No, this is the equipment we provide.' It took a lot of negotiation between the two. And I feel now that everybody's budgets are just so constrained."* (057, 17:35)
>
> *"Yes, yes exactly. I was the one having to make the, I didn't have anybody to ask. I was the one - if any situation came up, if I heard something on the radio, I might have gone, 'Oh that could apply to me,' then I would still have to look on the internet to figure out what it was and whether it did apply.*

> ***And how do you feel about that, looking back?***

> *It would have, I don't feel, how can I put it? I feel, well I don't feel angry about it. I do feel disappointed that I didn't have somebody to - it would have helped me a great deal if I could have say, ring up whoever and just asked, which the group I coordinate to this day, sort of does that to a certain extent."* (011, 35:29)

> *"So suddenly X [referring to self in third person] was on the phone again ringing up and saying, 'I want you to come because I don't want the police involved at the end of all this, I've got enough problems.' So I suddenly found myself again having to remind the doctors."* (003, 42.14)

One carer likened the care management side of the role to becoming a 'chief executive of their mum's life:

"[…] The live-in carer system, which was a nightmare.

What, the live-in carer system?

Yes.

Why was that?

Carer management. I became sort of chief executive of [mum's] Enterprises really." (033, 15:2)

Part of this care management role encompassed the carers acting as trainers of professionals. They often found that many of the professionals themselves had a lack of knowledge and experience around dementia and believed carers were the experts. They then felt an obligation to train the professionals and 'police' their work:

"And your input was important?

Yes, very, and I kept a very watchful eye. And so that was like being a kind of trainer, because often they didn't have enough training." (042, 9:22)

"And, of course, my carers [care workers] had never used one [hoist]. So I showed them all how to use it. And they had their trainer come and I showed her how to use it." (003, 42:43)

Finally, there was often a lot of paperwork associated with being a carer, such as having to complete funding applications. Participants did not need someone to complete this paper work for them, but they did need to know what they were entitled to. This issue therefore also encompassed having someone with knowledge and the experience of the health and social care systems:

"*So yes there's a specialist mental health nurse [Admiral Nurse], so they have an understanding of the mental health issues, whereas a dementia support worker, yes they can fill out forms but I don't need an administrator, I can do my own admin. And that's why we come to blows really because I feel they're just like administrators. 'Oh no, no we do a lot more than that now.' Yes, yes, yes, right, okay. But that's just my little, my little pet thing now."* (018, 23:29)

"I think - this is the other thing, of course, it's always very difficult with any illness, a terminal illness, is that I, unfortunately, I think, quite often, the level of care that is given depends on how aware the family is of what the options are of what they can ask for. And so that's again what I would say, for education, is that families must be aware that they can ask for things." (060, 3:67)

Participants perceived that the duties of care management were onerous and they were often left with little support. They were on their own, without knowledge of the systems, often relating this to difficulty over the provision of information:

> *"There's sort of an assumption that you'll go and find stuff out and you're okay. And because I work for the council, you know, the fact that I work, did something very different, didn't seem the point."* (041, 11:27)

> *"Without that person [Admiral Nurse], I would have been, I would have been collapsed long before, because what you need is, is you need somebody to talk to about stuff and somebody who knows the system."* (023, 5:7)

However, participants acknowledged that other members of the family may have been able to receive information or even offered support but they were reluctant to receive or acknowledge their own need for support and help:

> *"And I used to go and see her. I think part of it was - I mean me husband kept saying to me, you know, 'You're going to have to like step back a bit,' but I was so used to like sort of nearly spending all my days at mam's sorting things out and stuff. She did have carers [care workers] going in, but, you know, I did spend a lot of time round at mam's. And he said, 'You're going to have to, you know, settle down and leave it to the home really.'"* (022, 4:31)

> *"The difficulty with my father of not really wanting to, as he saw it, expose my mum's frailties when she became ill - he, he really didn't want - so he didn't ask*

for help. That was the one, you know, big stumbling block. You know, if anybody came or, you know, yes I mean we would have difficulty perhaps him even admitting to us that things were a bit rocky, you know." (060, 3:14)

As such, participants felt that they needed to be a strong individual in order to manage the care of the person with dementia. Many felt that it was because they were a strong and often a forceful individual that they were able to take on this aspect to the role:

"[…] Reflecting on it, I think that perhaps, you know, if you were, if you have been in education, you're naturally predisposed to being bossy - so, you know, you don't worry about telling people what you want and in the nicest possible way." (030, 14:5)

"You see, I have a problem with myself. Go back a sentence - when I was telling someone else about my problems to a man whose mother had had dementia, Alzheimer's disease with dementia, he said to me, '[…], you have to be bloody rude,' he said, 'You have to go in,' he said, 'You have to use four letter words.' And so I said, 'It's not me,' he said, 'You won't get anything done.'" (036, 3:14)

In reference to these issues and having to be a forceful individual, participants often talked about 'battles' with professionals, services and systems:

"But because we were doing all this fighting with the battles, I kept leaving it and leaving it until I finally got a letter and went, 'No.' And then you think,

'Well shall I take this to the European Union?' No I've got more important things to do." (018, 23:18)

"And it was a fight [dementia journey] every inch of the way." (004, 33:72)

"Yes, [...] this is your job to fight for your, you know, your loved one." (030, 14:41)

One carer who had worked clinically still found it difficult to navigate systems and considered it still to be a 'battle' with services:

"With all of my knowledge and of the conditions, clinically, but also systems around health and social care, I have to say that nothing, prepared me for fighting my battles through the system to get the right care at the right time for my dad." (005, 32:3)

This care management went right up to the final moments in some cases:

"And I had to sort of tell everybody by word of mouth, you know, that that's what I wanted. And I was never sure - and it turned out that this member of staff [care home assistant], who was relatively new, didn't know any of this. And I was completely in charge of it [relative's death]. You know, sort of I - she was absolutely lost, completely." (062, 24:24)

Due to their experiences of care management while caring, many former carers were now involved in organising and running carer and peer support groups as they felt there was a need for an information and support service:

"I get carers ringing me up at home and saying, 'How do you deal with this?'" (011, 35:29)

"So mine was more the support groups face to face. But I think the online ones are really useful as well. And I'll probably get involved more. But in some ways, with the group that I'm running, and I also go to the Alzheimer's Group in [x], and other things like this Dementia UK initiative to train carers to be trainers to go into care homes and things - in some ways that gives me a lot of contact with other people, where you get that chance to sort of talk." (014, 47:20)

"I mean normally because I always make sure that there are discharge letters or whatever is available. But, as I said, because I am articulate, I understand the system, I can navigate it, but not everybody can navigate the system. So, for me, running the support group is actually giving them, you know - okay, if you're a GP, now in our area there is an urgent care centre which is 24 hours. So, you know, they said, 'Okay if you don't want to go to the hospital, maybe you could go into an urgent care centre.' So I've become like a conduit of information and running the support group actually, that there's something new to talk about at the next support group." (057, 17:33)

The care management role encompassed looking after the welfare of their relative and acting as their advocate, but this evidently was not so simple:

> *"[…] your ability to actually not be bossed about into areas you don't particularly think you're the person you're caring for, I think you have to be their kind of ward of court, in a sense, that you're actually going to, you know, you're going to fight their corner."* (030, 14:39)

Support with the physical aspects of caring

Many who were still caring for their relative at home found the physical aspects of caring quite demanding:

> *"And we've got a seat in the car, the seat he was sat in is an automatic seat and it turns out. And I got that and that's eased my life so much with getting him in and out of the car, because he's just a dead weight now. Fortunately he's not that heavy. But he is still a dead weight."* (018, 23:18)

The physical demands were often a key reason for a move into a care home, as they no longer felt like they were able to 'cope':

> **"So what was it that made you look into a care home in the first place?**
>
> *Well because there was no one, there was no one else to help with the care. We did look into the possibility of having someone live in, but frankly his house wasn't suitable anyway. I mean he can't do stairs now."* (028, 31:31)

"So, you know, it was that, becoming, beginning to get slightly incontinent and being very agitated and walking and walking and endlessly walking. And, of course, tripping more with the walking. Those were probably the triggers [to care home placement]. I just couldn't, you know, I can't keep him - they're only little rooms, I couldn't keep him locked in one room. And although I was at home all the time by that stage, or had a bit of help two or three hours a week, I couldn't be in the same room as him all the time." (031, 26:7)

"It was actually physically lifting him changing pads or whatever, I couldn't do it alone. I mean, because as I said, I said I had broken nights and I was physically - because, you know, initially you just take on the role whatever demand it makes of you. But a time comes that I physically couldn't do it any more" (057, 17:12)

However, once people were not doing physical caring roles as their relative was being cared for in a care home, this led them to feel that they were no longer a carer. Caring to them involved the physical aspects of caring:

"I probably wouldn't have given the label 'carer,' because you tend to give the label 'carer' when, I tend to think of caring more as physical care you're doing the caring for. I considered myself totally responsible for him. So I was a carer from that perspective. I didn't physically care for him. I totally cared for him in terms of his welfare. That was, as far as I was concerned, I was totally responsible for that." (041, 11:88)

However, placing their relative in a care home for some was too distressing and simply not an option, so they looked to alternatives. These were often home care services:

"[…] Go into a nursing home, which would never have been an option for me to let her go to a nursing home." (044, 8:18)

"[…] I've got to be pretty ill. I'm going to have to be incapable of looking after my wife at all for that to happen. Or, I cannot see that her needs are going to be beyond me, provided I keep my health. If I don't keep my health, then she would [go to a care home]." (036, 20:24)

Some who did place their relative into a care home were very emotional about this and often felt the care home was not doing as good as job as them:

"[…] And I gets out and I can hear thunder, and she is banging, she's like that, hands on the top, legs at the base, and she's banging on the top and she's kicking the bottom of the door and she's shouting, I could hear her through it, 'M, M, why are you leaving me here, what are you doing to me? I'm your wife.' […]" (043, 063, 22:20)

Support with psychological and emotional consequences of caring

The role of a carer was described as emotionally and psychologically demanding. There were many reasons why such experiences were cited. These included uncertainty about the pathology and symptoms displayed as part of the dementia. This uncertainty about what to do often led to the searching for reassurance from professionals and 'experts'

that carers were doing the right thing. This was especially so for carers who were new to the caring role and had not any previous experience of caring for someone:

"So I suppose the support I needed were emotional to make me think that I were doing the right thing by keeping her here, because I did doubt that at one point, you know, am I doing enough?" (044, 8:36)

"And you take them [nurse] over lots of things [concerns] because you're worried, because we [carers] haven't got the background. So the ankle's swelling, should they be? You know they're looking really bad […]. Well they may see it a hundred times a week. We don't and this is your loved one." (014, 47:10)

But participants in general simply found the whole experience of caring very stressful and psychologically draining. For some it was not always simply the demands of caring, but other pressures:

"I couldn't have dealt with that stress as well, because it was very stressful looking after mum." (049, 25:18)

"[…] There's other family stuff that was challenging while I was doing it, you know, it was grim. So I, at that point I rang up a helpline that was, it was the organisation which was then called, 'For Dementia', and is now called 'Dementia UK'. And it was really helpful to have someone to listen to." (053, 28:37)

Some carers experienced multiple depictions of facing loss, having to come to terms with 'losing' their relative both physically as they were dying but also before the physical death they were losing the individual and the person they once were:

> *"[…] And the terrible thing is, you see, they, people cannot understand how it is bad for a carer, very, very sad to see the person that you've known for 58 years or any number of years come to that, just slipping away."* (048, 18:20)

> *"You know, as I said before, a very generous, warm, demonstrative woman became this rather Edwardian tartar."* (060, 3:47)

> *"So it was just - and also it's just horrible watching your mother deteriorate, you know.*

> **Yeah.**

> *It's sort of like somebody's crumbling inside and very, very difficult. […] But it was just, you know, she was gradually slipping away, but still alive."* (017, 37:2)

These feelings of loss were sometimes made worse by the uncertainty of when the final loss, death of the individual, would come:

> *"I mean it's bad enough that you're dealing with bereavement as well because you're constantly grieving in terms of the person you've lost, because that person is not the same as who you knew. But you know they're going to die.*

And you don't know when they're going to die. So that in itself is stressful, very, very stressful." (012, 48:33)

This area of concern and need for support was often related to the availability and usefulness of Admiral Nurses. Not all participants had an Admiral Nurse but many were aware of them and their role. Those who did not have an Admiral Nurse wished they had (having subsequently been informed through their volunteering work for Dementia UK), and those who did were extremely grateful and satisfied:

"But I have to say, throughout my whole journey with mum, the thing that gave me more stress than anything else was all the professionals, I have to say, except for the GP, the latter consultants and certainly, you know, the consultant we had at the end and H [Admiral Nurse]. So H, the GP and - and the district nurses, they were my - so when other things happened like, you know, you'd get, you know, because mum eventually was in the mental health side of things. And you obviously had the social workers. And they were all very good. They all knew their job. But it just created so much stress for me, you know what I mean? Whereas H would just, she would just, she would just inform me and keep me, you know - and also things like, I have to say, because she knew I was interested in the sort of the sort of therapeutic side of things and I worked very hard at that." (049, 25:29)

"As far as I'm concerned, they [Admiral Nurse] were my salvation. [Admiral Nurse] was, I've always said it, haven't I? She was a wonderful - because she knew what to say and what to do. Nothing overboard, nothing gushing about

her. She was just there. She was wonderful. [...] but her primary job was to look after me.[...] She came one day when J was in [hospital]. And I said 'There's no J here.' 'Great,' she says, 'Let's go and have a drink.' And I said, 'You what?' 'Let's go and have a drink.' And we went down to the [local pub] and I had a couple of pints and she had a full glass of orangeade[...]" (043, 063, 22:17)

This support was only valued because they were able to build up a rapport with the carer. This continuity and hence the ability to develop a relationship was critical in the eyes of the carer, they did not want someone new repeatedly, as mentioned previously in the subtheme familiarity and continuity:

"And you build up a rapport with them. I think that's the most important thing. So you can more or less discuss anything with somebody if you have a rapport with them" (018, 23:32)

"And that's the key thing with the Admiral Nurse scheme, no doubt about it. That's what carers want. They want somebody, just somebody they can phone if they're able to phone, email, however. But a name, a person." (013, 43:42)

The role of the Admiral Nurse was seen as one to 'be there' for the carer, provide them with information and prepare them. They were seen as having the ability to give them confidence to move forward with care and, when needed, to challenge professionals. With the Admiral Nurse simply being present and providing them with more information some carers felt a lot more prepared and confident:

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"[…] She [Admiral Nurse] gave us confidence. She gave us confidence to understand that we were taking risks about Dad staying alone at home." (005, 32:5)

"And the Admiral Nurse then provided me with support and helped me through the journey with my dad .[…] But longer term, actually, it was the Admiral Nurse who helped me to prepare for the future. It was only with the – I guess, the knowledge that she gave me about how the disease was actually impacting on Dad an an individual, rather than as a textbook sort of situation" (005, 32:4)

"So she [Admiral Nurse], so she was able to help me with the, you know, the progress of, you know, of, of dementia, if I had any questions about it." (049, 25:23)

Overall the presence of such a professional seemed to enable many carers to feel as if they were no longer alone; they had someone, a key contact for information, coordination and emotional/psychological support. However, many did not have this professional which could have left them feeling slightly lonely and isolated.

6.6   Place of death/care

Many participants were either caring for their relative or their relative had died at home or in a care home, which they considered to be their own home. However, there were some carers whose relative had died in hospital.

Participants felt that it was important to have the option and choice for their relative to be able to die in the place they would have wanted and where the family thought it was the best. They often considered this to be their own home, whether that now be the care home or the family home. Many participants thought it was important that they should be allowed to transfer their relative from hospital to the preferred place of death when the time came:

> *"And what I actually wanted was I wanted for her to go back to her home and to die at her home if she didn't die in hospital."* (008, 34:19)

> *"I mean if someone had said to me, 'Look, you know, this is really, there is no coming back from this,' even for them to have said to me, 'You know what, we're going to discharge him but actually there's nothing else we can do,' you know what I mean. But at least giving me the option, you know. I could have made an option about wanting him to die at home or wanting him to die in a hospice or, there was nothing, just totally unprepared all the way through. So it just felt like we were going from crisis to crisis to crisis. And that shouldn't be how someone ends their life."* (015, 45:51)

Participants were particularly keen to emphasise that they did not want their relative admitted to hospital at the end of life; they perceived care in hospital to be of a lower standard and far from the best place for someone with dementia:

"Yes it was an easy decision [to not admit to hospital]. Yes it was an easy decision. I didn't want him to go anywhere, I didn't want him to go to hospital." (041, 11:63)

"[…] I said, 'I don't want him to go into hospital unless he breaks something'." (031, 26:37)

"[…] I'm a nurse by background and I hate hospitals for older people. So I was quite happy to stay there and look after him." (025, 27:6)

There were many different reasons behind participants' perceptions about hospital care. These often confirmed what has been highlighted earlier in this chapter, perceptions that hospitals were not able to maintain dignity, provide the adequate amount of attention a person deserved, and were likely to leave hospital worse than when they first entered:

"[…] but actually they - what they did was to sort of teach him to be incontinent because nobody paid enough attention. You know, so he was always wetting himself and pooing in the sheets in the bed, and, you know, it was just terrible." (042, 9:9)

"But the nursing standards were dreadful. And when she came out, having gone in able to walk and talk, she could no longer walk and talk." (020, 10:7)

"But dad ended up probably inappropriately in an acute hospital ward for a week while I was away. He never lived alone again after that." (005, 32:7)

"And I watched my wife's weight, that she was weighed once a week. And I watched it on the chart go down like that. And at four kilograms lost, I went to the sister and said, 'My wife's losing weight, and she's lost four kilograms.' 'Oh dear,' she said, 'We'll have to do something about that. That can't be allowed to go on.'" (036, 20:5)

Again many of these areas of 'poor' care were often blamed on the nurses and not the doctors. Nurses were seen to be the frontline of the NHS and not doing an 'adequate' job:

"Nursing staff is pathetic." (036, 20:7)

"The nurses were dreadful, the care assistant were very good." (033, 15:19)

"Well I'm talking about the hospital which I know, which is the local one. And having known several people who have been in there, the nursing care is all, always is bad, that nursing care, unfortunately." (038, 13:39)

Hospitals were perceived to be set up more for cure and not for the treatment of someone with dementia, or to communicate with families:

"Because I don't think hospitals can generally provide a good dying experience because they, they are there to get acutely ill people well enough to discharge." (029, 6:28)

"Because I mean it's not being rude to hospitals, it's just that they're not set up for that sort of care." (029, 6:63)

"[…] At the hospital it's all about, 'This is what it says on this scan and this is,' you know, so they have this very medical approach towards your care. You know, 'Your dad has vascular,' you know, 'Your dad now has vascular dementia.' What does that actually mean? And they'll tell you in very medical terms, 'Oh well, you know, it's this on the brain and this happens, and this is why he's behaving in a very, you know, in an aggressive way,' and you sort of think, 'Oh okay then.' But nobody actually tells you what that will mean day in, day out, for this person." (041, 11:72)

Carers also argued that their relatives would not have wanted to have been in hospital:

"My dad didn't want to go into hospital, so I didn't want my dad to go into hospital." (025, 27:30)

"[…] You can be, kind of slightly bulldozed into going off to hospital and that can make for distress in somebody, especially for like my wife, that, you know, it was was, you know, a very - strongly sort of hated hospitals and anything to do with medicine etc. That would have been traumatic if we had been bullied into that, you know." (030, 14:11)

The main reason seemed to be the participants' perceptions of hospital care was based on their previous experiences, for example, when their relative had been in hospital

earlier in the course of their dementia. Hospitals then were seen as likely to fail to meet the previously discussed requirements of 'good' quality end of life care for people with dementia, including providing attention, respect and dignity, or even the many elements of basic care:

"Well in hospital they taught him to be incontinent. And so that was more or less it. He was then incontinent for the rest of his life." (042, 9:14)

"[…] That was another sign of the nursing care. You'd quite often find that the drip was not operating or be empty of something of that sort. The hospital was a short term, it was big in our minds because when she went in, she could talk and walk. And when she came out, she couldn't do either of those things. And she was wheelchair bound for the rest of her year's life." (020, 10:17)

These experiences led carers to trust hospital less than other settings, such as care homes:

"But when you thought, when he was so vulnerable, they could have done anything to him, and he wouldn't have been able to tell me. That was really difficult. Really, really difficult. Partly why I would - I just did not want to put him hospital. I less trusted the hospital than I had at the home. So I think that partly influenced, if I think about it, I think that partly influenced my choice. But I trusted them completely that they would do what I wanted. And I just had a horror I'd end up in the hospital and they'd got him on some ventilator or something and they were going to start doing stuff." (041, 11:91)

"[…] To me, it was much better him being managed by the people who understood him, who could manage him, he knew them, rather than taking him off to the hospital." (025, 27:25)

With this impression of hospitals, some carers felt it would be futile and inappropriate to admit to hospital:

"[…] When it was fairly clear we were getting towards the end, and I've got a really big important point to make about the whole death side of it - we, I had established with the doctor that we were not going to do a hospital, we were not going to go into hospital etc.. There was no point, you know." (030, 14:3)

"[…] And not keep dragging them to hospital, because certainly with dementia, there is no point. They're just, you know, they're just confused and upset and why would you do that when it's, unless it's necessary?" (028, 31:22)

For some participants where there was not a health and welfare Lasting Power of Attorney in place, they felt they had sometimes lost the 'battle' with staff and their relative had been admitted into hospital:

"[…] So I had said to them, I wanted my mum to stay there if she was unwell. But, of course, it wasn't written into the new style Power of Attorney. So they called an ambulance, they came and tried to resuscitate my mum, and I said - the manager of the home had called me and I said, 'Don't, I don't want it to happen, I want to speak to them.' And the paramedics would not speak to me.

And they couldn't resuscitate her, so they took her to the [hospital], but the manager of the home then said to me, they thought she had already died, you know. They'd taken her from the staircase, sat her in her favourite chair in the home and they knew that she was slipping away. So even by the time the paramedics got there and worked on her, she had a pulse but it wasn't a proper pulse. It was, you know, just her body winding down." (008, 34:35)

"But we had two episodes where I was overruled and they took him to the hospital. And it was just awful. And, you know, he get [got] admitted to the hospital [...]" (025, 27:25)

However one carer did want her husband admitted to hospital at the end of life, as she felt it was the most appropriate place with all the necessary and relevant equipment:

"[...] As soon as I'd seen him, I knew he was dying then. So I said to him, 'Have you been in touch with the doctor to recall him?' He said, 'Yes but I can't get through.' And I said, 'Well right, where do I stand then? He's in your care. Are you going to phone the ambulance?' And he said, 'Well I need to see the doctor first.' And I said 'Right, well where do I stand? If I ring up 999, what will happen then?' He said, 'I don't know.' I said, 'Well that's a 'no' to me.' So I started dialling 999." (045, 19:9)

"So why did you think it was a good death [in hospital]? What was it about it?

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Because, well because he had all the equipment didn't he? They were aspirating him and everything." (045, 19:20)

CHAPTER 7:DISCUSSION

7.1   Introduction

In this chapter I will summarise the main findings and discuss them in relation to the published literature. I will outline the strengths and the limitations to the methodology applied in this study, and consider the implications for future research, policy and clinical practice.

This study was guided by the research question:

What are the features of 'good' and 'bad' quality end of life care for people with dementia from the perspective of family carers?

The objectives were:

1. Explore the experiences and perspectives of family carers who are caring for someone with dementia

2. Explore the experiences and perspectives of family carers who have cared for someone with dementia

3. Understand what family carers expect of end of life care for their relative with dementia

4. Understand what family carers judge to be 'good' quality end of life care for their relative with dementia

7.2 Summary of findings

The findings reported throughout this thesis, including the review in chapter three and the interviews with carers in chapter six, highlight the variation in views of carers. This thesis adds to the literature by providing an exploration and understanding of carers' views of quality end of life care for people with dementia.

7.2.1 Systematic review

The systematic review reported in chapter three found relatively few published qualitative studies within this field. Many of the included studies did not discuss 'quality of care' in great depth. This strengthened the rationale for the current study and demonstrated the difficulty in conceptualising 'quality end of life care'.

The review found that there was much variation in carers' acceptance of their relative as dying, or of their death. There was no simple categorisation of 'acceptance' or 'denial'; instead views spanned a spectrum from complete acceptance to complete denial. Similarly, carers' views of the treatment and care for the person with dementia varied and formed a spectrum. The spectrum ranged from treatment/care aimed at comfort and symptom modification only through to active/invasive or aggressive treatment aimed at cure. However, many of the participants were unsure about what was the right thing to do and found it difficult to reach conclusions about what was indicative of 'good' quality end of life care.

Within the literature there were some potential explanations for the views that carers held about end of life care. Their interaction with professionals appeared important. In particular the amount of time professionals spent with the individual or the support they provided for the carer was important. There was some discussion within the papers

about emotional and commitment pressures which influenced carers' views. In particular carers struggled between accepting that their relative was dying but also dreading their dying. Some carers were concerned about being seen as an 'agent of death'. There was some limited evidence of the tensions experienced by adult child carers balancing their 'normal' family life with their caring duties. Finally, some carers found it difficult to discuss end of life care and death, therefore they were unable to address treatment or plan for future care.

7.2.2   Qualitative study

What is palliative care and end of life care?

Chapter six introduced how participants defined palliative care and end of life care. There was clearly much confusion around these terms. Engaging participants in talking directly in terms of palliative and end of life care was challenging. Some participants did not understand these terms or did not want to use them; the term 'end of life care' appeared easier to discuss than palliative care. This was indicated by the more frequent use of this term and the greater clarity regarding this term in comparison to 'palliative care'. However, the title of the research, the study's information sheet (see appendix 2) and my introductions at the interviews all mentioned end of life care and therefore this may have influenced the thinking of the sample which was recruited and the language they used. Palliative care was often associated with care for people with cancer, in the participants' minds. The use of jargon and medical terms were not useful to participants. When discussing their understanding of these definitions, participants talked primarily about time frames (with some uncertainty) and events that led to end of life care. For palliative care they talked about what the care entailed and when they thought the person became "palliative".

Palliative care was seen more as an approach to care and was focussed on managing patients' symptoms, including agitation and pain, and was not restricted to a specific period of time. Although many carers were surprised to be asked to talk about palliative care, due to its connotations with cancer, many believed on reflection during the interview that they were providing palliative care for their relative. Palliative care was discussed in terms of specific points when the person became bed bound or mobility was lost.

When expressing a time frame for end of life care, participants varied greatly in their responses. Some expected it to begin from the diagnosis of dementia and others believed it was the final few days. In particular, carers felt that their views were not the same as professionals', and that the Department of Health's definition of 12 months, was too short. Often participants talked about the transition period of the person with dementia, such as the time when it became necessary to move to a care home, as the start of end of life care. The events participants spoke about usually indicated a decline in the physical health of the person with dementia.

What treatment do carers want for their relative?

The uncertainty of carers' views continued into their discussion of what treatment they would want or had wanted for their relative at the end of life, supporting the findings of the systematic review presented in chapter three. Views spanned a spectrum; at one end participants wanted all treatment possible to preserve life, and at the other end participants wanted minimal treatment which was aimed at maintaining comfort. This fitted with the idea of active treatment at one end and palliative care at the other end of the spectrum. Due to the difficulty of terminology already discussed, during the

interviews I avoided using complex medical language. This fits with the theme of this thesis as hearing the voices of family carers.

There were many factors that appeared to be linked to the level of treatment that participants wanted including carers acceptance that their relative was dying. Many participants wanted their relative to be removed from what they perceived to be a state of discomfort and 'suffering'. This appeared to be a contributory factor in the choice of treatment.

Further factors which also contributed to wishes about treatment included: carers' understanding of dementia (which in turn was affected by the level of information provided to them), prior beliefs and wishes of the person with dementia, the quality of life of the person with dementia (as perceived by the carer) and the quality of life of the carer. This often led to participants describing how others viewed them. Participants described how professionals had spoken to them or treated them about their choice of treatment, sometimes using emotional and powerful language to describe this (e.g. "murderess") see quote 031, 26:23 on page 225. However, most participants were not deterred by this and continued with their course of action regardless.

What constitutes good end of life care for someone with dementia?

There appeared to be two inter-related topics of discussion within the interviews regarding quality of care. One focussed on participants' views of care for them as carers and the other discussed care for the person with dementia. This highlighted that there was not just one 'patient', but the carer who could also be recognised as 'a patient'.

They are two separate entities, however carers perceived themselves as one unit or dyad.

Participants reported that many of the needs of the person with dementia increased as the course of the dementia progressed. Attention to the person with dementia as a human being and not just attending to their physical needs was deemed important, in particular talking with them. This was easier earlier in the course of dementia than later, and the attention towards the end of life focussed more on meeting their physical needs, for example, taking time to be gentle when changing them or swabbing their mouth. The most criticised care settings were hospitals, which were regarded as providing the least attention in all aspects of care; physical, personal, and communication.

Personalising care was also important to participants, not using a simple "one size fits all" approach to dementia. This became particularly problematic with medication and food. Care home staff were often not willing (or possibly not able) to deviate from set times to give medication and provide meals. But again, this seemed to be more problematic in hospitals, whereas care homes appeared to have tried their best to tailor their care. In particular 'good' care homes took notes of what residents liked or previous occupations and used this biographical information in their approach to care.

'Normality' might appear to be an inappropriate term to use when talking about death or disease; however, this was commonly used by participants when talking about care for their relative. This again developed over the course of the dementia, from initially meaning that they wanted their relatives to do as much as possible (as they had

previously in their life), in particular things that made them happy, through to simply fitting in with the family when they were in the later stages of the dementia.

One of the main aspects of 'good' care as discussed by participants focussed on the dignity of the person with dementia and providing them with what might be called respect (see page 235). This was a key concern of participants who were often worried about how their relative was being treated when they were not present. This was particularly so at the end of life, as care involved a great deal of personal care potentially compromising the person's dignity. When discussing dignity (see page 235) many participants brought the conversation back to their own struggle in providing personal care whilst maintaining their relative's dignity. This touched upon ways of ensuring that the person with dementia would still be treated as a person. Participants' description did not differ significantly from those of others, for example, the Royal College of Nursing's definition as:

> *'Dignity is concerned with how people feel, think and behave in relation to the worth or value of themselves and others. To treat someone with dignity is to treat them as being of worth, in a way that is respectful of them as valued individuals.' (Royal College of Nursing, 2008)*

In addition to these elements of 'good' quality care, participants also felt that many basic components of care were important. These included: compassion, maintaining the individual, pain management and comfort, and finally familiarity and continuity. Participants felt that with the application of these basic principles, 'good' care would follow. A core element of 'good' care could be described as empathy or compassion,

and participants made particular reference to when nursing staff failed to show such behaviour or emotion and examples of when they did, for example through showing sadness at the death of their relative. They appreciated a mixture of professionalism, but also a compassionate human side to the professionals' approach. Leaving a person naked on a trolley, or labelling someone "hopeless", was not seen as evidence of compassion or kindness. Participants felt there were a number of reasons for this, the nurses had changed role from their traditional 'caring' role, workplace pressure, or quite simply the wrong people in the wrong jobs.

Unlike other aspects of care participants felt there was something that professionals could do that had no medical role or aim; trying to maintain the individual and person. This mainly consisted of ensuring that the person still looked the same to the families, wearing their own items of clothing and wearing them the way they always had and being groomed in the way they had been. For example, one participant mentioned that the moustache of her father was shaved off for convenience and although she accepted this, it had initially shocked and upset her. However, appearance was simply one aspect to this, it was also about ensuring that their likes and dislikes were known, respected and encouraged. Some participants spoke about their relative liking an alcoholic drink in the evening, and they perceived that the good care homes would give their relative this pleasure. For others personal pleasures included beauty treatments, such as hairdressing or having their nails manicured. Familiarity for the person with dementia was also important. This included having the same staff caring for them, or being in their own room and environment. High levels of turnover of staff in care homes meant this was not always possible. This was more understandable to participants than the turnover of staff working in the community or of medical staff who knew the person.

They felt this was unacceptable and they could not explain why there was such high turnover.

The final element of basic care was potentially the most fundamental of all medical care for someone who is at the end of life, pain management. Many of the participants discussed how their relatives were comfortable at the end of life and pain free. However, there were some occasions when pain medication was not available either at weekends or due to what carers perceived as staff negligence. Pain medication was not the only relief from pain and the only way to improve comfort that participants discussed. Other examples of pain relief included the way in which care staff handled individuals when they had 'bed sores' and skin breakdown.

What constitutes good end of life care for the family carer?

The carers' wellbeing was often just as important as that of the person with dementia. Carers thought this was sometimes recognised by health and social care services; however, there were occasions when the carers considered themselves to be the forgotten piece within the care package. Some participants said they had never been asked how they felt.

Participants described a difference between caring for a parent compared to caring for a spouse. Adult children were generally younger than spouse carers. This demonstrated different difficulties between the two types of carer, with many adult children often having to balance caring for their relative whilst still caring for their family. Spouses, as they were often older, had challenges including difficulty with lifting and were

perceived by others as potentially not having the emotional strength to deal with the bureaucracy of caring.

The role of the carer was defined by participants in the interviews, and this encompassed a potential need for support on three levels: support with the care management including navigating systems, support with physical aspects of caring, and support with their own emotional needs.

Participants described a large proportion of their caring role as care management, even using the metaphor of their relative being a business and they the chief executive of their care. They were responsible for the daily running and co-ordination of care. It was often this aspect of care that participants resented having to do the most, as this was not perceived as something that should be the work of the family. Some, participants also resented other aspects of care such as physical care duties, including the personal care responsibilities. These physical aspects of caring that reached points that were unsustainable for the carers were often the trigger that led to a transfer of the person to a care home.

Finally, the role of caring for someone with dementia was depicted as both emotionally and psychologically draining. The caring 'journey' was extended over a long period of time and incorporated a series of demands. The 'journey' started with being in new territory and uncertainty, not just about what to do but also about the course of the dementia itself. Importantly, participants talked extensively about the loss of the person they once knew, not just physically but also psychologically, as the person seemed to 'fade away' from them. Many participants' discussions of the emotional and

psychological strains of caring were discussed in reference to Admiral Nurses. Not all families had access to an Admiral Nurse, but many thought they would have been useful to help with these concerns. Those who did have Admiral Nurses confirmed that emotional support for them was where they were most helpful. The Admiral Nurse was there to help the carer and the rest of the family, not directly to care for the person with dementia. Carers appreciated that someone was taking an interest in their welfare and well-being, which they often felt was lacking by many other professionals. This helped with feelings of stress, loneliness and isolation.

Place of death

Place of care and the place where their relative died were often important to participants, and they wanted the option to be able to choose where the person died. The opportunity to move them if they were not being cared for in that chosen place, was important. The preferred place of care for most was the person's home, and this was recognised as sometimes being the care home. Many of the participants felt very negatively about their relative spending their final days in and dying in hospital. This decision was often based on experiences gained earlier in the course of the dementia journey. Hospitals were not believed to be able to provide all the 'good' elements to care that have been discussed previously, including dignity and attention.

7.3   Discussion of findings with reference to the published literature

This section will focus on prominent themes and topics which recurred through the interviews and chapter six: clothing (as a manifestation of personhood), compassion and issues of nursing care, the role of a carer, relationship between professionals and carers, and discussions of end of life and death with the implications for advance care planning.

7.3.1 Clothing

Throughout the findings of this thesis concerns were often raised about the appearance of the individual with dementia. This was often in relation to individuals who were no longer being cared for primarily by their relatives. Carers were aware that often their relative was wearing someone else's clothes or shoes, for example. Carers placed high importance on maintaining the individual person with dementia. They wanted them to still be seen and treated as a person and not as "someone with dementia". The next section will discuss the importance of clothing in relation to personhood.

The importance of clothing to personhood

Carers talked about the individual's identification and how they were perceived by those around them, simply being a person, or as someone with dementia. There has been an array of work within this field of identity within the dementia literature for many years, dominated by Kitwood's description of what he termed personhood:

> *"A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being."* (Kitwood, 1997b, p.8)

Personhood is socially constructed and can entail how individuals are viewed by others. To be simply viewed as 'someone with dementia' or just a label would imply a lack of personhood and a reduction in their social status or standing. Brooker has stated that good dementia care at any point on the dementia trajectory involves maintaining an individual's personhood, typified by person centred care (Brooker, 2007).

There are many aspects of an individual which make up the person they are, or create the person. Typically in modern Western philosophy there has been a split between

cognition and body, with cognition having superior status to the body (Kontos, 2004), a long-standing argument favouring mind over matter. This leads to the argument that as the mind and cognitive abilities decline, for example with an individual who has dementia, their self also declines and 'fades away'. However, there has been movement in this line of thought over the past decade, with assertions that the self remains throughout the course of dementia and does not diminish as cognitive abilities decline (Twigg and Buse, 2013). Some have argued for some time against the Western philosophical emphasis on the importance of cognition, proposing that the self is more than simply the cognitive ability of an individual, and the body is also important to the self (Kontos, 2004). I would agree with this line of thought, that a decline in cognitive ability does not mean a decline in the self, because it moves us away from the once dominant medical model which only thought of the person with dementia as neurobiology and neuropsychology, often ignoring the psycho-social aspects of the disorder (Downs, 1997). This is reflected in the increased interest in psycho-social interventions seen in this field and the creation of groups such as INTERDEM[7].

Increased recognition of the psycho-social aspects of care and the importance of the social context and personhood, highlights the significance of social interaction for people with dementia (Twigg and Buse, 2013). A lack of social interaction can be as damaging to personhood as cognitive decline can be (Twigg and Buse, 2013).

With a focus on end of life care this thesis has explored the views of current and former carers of individuals who have described the times when the person with dementia's

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[7] INTERDEM is a pan-European network of researchers working on studies of early detection and psycho-social interventions in dementia (http://www.interdem.org/).

personhood is at one of its most vulnerable moments. They have been at a point where their relative's dignity, which was once controlled by themselves as individuals and hence intrinsic to the dyad, became reliant upon the actions of others and hence become extrinsic (Guo and Jacelon, 2014). This is the point at which the cognitive capabilities of the individual with dementia are at their lowest and, adopting a commonly used metaphor may be perceived as 'lost' and not a person. Chapter six of this thesis suggests that there are many elements of loss when caring for someone with dementia at the end of life (see quotes 048,18:20; 017, 37:2 on page 279 and 008A 008B, 34:18 on page 223 of chapter six). These covered the loss of what some believed to be the person they knew, and also the physical loss of the person when they died. Therefore what participants were describing was a gradual loss of the individual and the loss as they once had recognised them.

The symbolism of clothing

Clothing may be important for two related reasons. The first is the function of clothing to preserve personhood and sense of identity. The second reason relates to the benefit and comfort of the family, to retain some form of connection to and recognition of the person with dementia as they once were. Although this second point also addresses the identity and personhood of the person with dementia it is aimed more at the benefits to and the emotions of the carer, rather than the person with dementia.

Identification

Clothing can be seen as an extension of the physical body and therefore an extension of the self (Twigg, 2010). Items of clothing are themselves a physical entity and are placed upon the physical body (Twigg, 2010). As will be discussed below, clothing can act as a

bridge between the physical and cognitive aspects of the individual. In this sense clothing forms an important part of the formation and conceptualisation of personhood and of an individual's identity.

Clothing, in allowing for an expression of identity, represents an individual's personality, likes and dislikes, social status or class, race, ethnicity, age, gender and sexuality among much more (Davis, 1992, Holliday, 2001, Rolley, 1993, Tarlo, 2010, Twigg and Buse, 2013). It therefore acts as a form of social representation, and social identity (Twigg and Buse, 2013, Twigg, 2007). As Entwistle (2000) states, dress allows for social difference to be made concrete and visible (Entwistle, 2000). For example, if we see someone walking down the street with stained clothing which may be ill fitting and old, we may treat this person differently to someone who may be wearing a smart, pressed and well-fitted suit. The same applies to how a nurse or care worker may view a care home resident. A resident wearing their own smart and clean clothes compared to a resident who is wearing jogging bottoms (referred to in the literature as 'loungewear') Lee-Treweek (1994) as cited in (Twigg and Buse, 2013), which is soiled or dirty, could be viewed differently. This may lead to a difference in the care workers approach and attitude, for example the latter may be perceived as having a lower social status and not respected as much as the former. As McFarquhar and Lowis (2000) noted Western society and culture enforce the notion that people generally, but women in particular, need to be beautiful (McFarquhar and Lowis, 2000).

As Twigg and Buse (2013) show, much research within sociology has focussed on the role of clothing and identity in relation to gender and class (Twigg and Buse, 2013). Kontos provides a series of examples of how class can be established simply through

observations of peoples' clothing, accessories and posture. For example, Kontos describes Molly a resident wearing a silk blouse, pure white pearls, sitting in a polite manner with her legs crossed and hands in her lap (Kontos, 2004). Twigg argues that the ability for residents to maintain their previous dress, whether that be their silk blouse, suit and tie, or a pearl necklace, allows them to maintain their identity and self at an unconscious level (Twigg, 2010).

There is a lack of exploration of age, clothing and identity in the dementia literature (Twigg and Buse, 2013). In addition to expressing our status and position within society and acting as a social cue, clothing also allows for the opportunity for socialisation. In many cases, clothing can provide a way-in to social interaction, for example by commenting on an attractive garment. With social interaction being of importance for the maintenance of personhood and person-centred care, clothing may play an important role in promoting this. This may also be true for hair care and in particular hair dressing, which can be an important part of people's lives. A visit to the hairdressers can be seen as a social endeavour in which there is informal chat about everyday topics as well as personal discussion between the individual and the hairdresser (Ward and Holland, 2011). This was mentioned by some of the participants within this thesis, and how care homes were thought to be demonstrating elements of person-centred care by offering hairdressing (see quote 054, 21:15, on page 252 of chapter six). Research has shown that hair is important to maintain self-esteem, in particular for women, and this increases as they age (McFarquhar and Lowis, 2000).

Twigg explains that clothing is important for gender and elements of masculinity, for example fly fronted trousers are associated with male masculinity, but are often not

worn by men with dementia (Twigg, 2010). Older people with dementia are often placed in jogging bottoms with elastic waist bands for ease of care. Jogging bottoms are useful for times of emergency, such as help with toilet needs, and may be particularly relevant for people with dementia who are beginning to become incontinent. These simple examples show the large impact they have on the identification of the individual. Whether it is a change in what they wear or how they appear, as seen in the current findings (see quote 041, 11:93, on page 250), or the retention of their 'best' appearance which was discussed by carers in this thesis when care home workers dressed individuals smartly for special occasions such as Mother's Day (see quote 054, 21:15, on page 252)

Clothing allows the construction of identity on a daily practice with people selecting, managing and wearing clothes which are contextually appropriate for their life and social interactions (Weber and Mitchell, 2004, Guy et al., 2001). As dementia progresses we gradually see problems emerging about the ability to dress, in particular with the ability to recognise items of clothing and how they should be worn (Keady, 2005, Feyereisen, 1999, Bassett and Graham, 2007). This is when we begin to see issues such as those described above with the use of 'lounge wear' or convenience dressing. However, with this we are beginning to see a loss of the identity of the individual. The individuals are no longer being treated as individuals which Kitwood (1997a) and advocates of person-centred care argue they should be (Brooker, 2007).

Clothing as comfort for the family

Bamford and Bruce highlighted how the importance and desire for bathing and hairdressing remained among people with dementia (Bamford and Bruce, 2000), and

Kontos (2004) showed this was the same for clothing and general appearance, even in advanced dementia (Kontos, 2004).

As clothing has the potential to evoke strong emotional reactions (Ash, 1996) Cosley et al. (2009) have used clothes in reminiscence work as memory prompts, to evoke memories of past times (Cosley et al., 2009). The current study demonstrated how clothing also produced strong emotional reactions from the relatives of people with dementia (see quote 062, 24:13, on page 252 of chapter six). In this case however, it is the lack of their recognition of the clothing that evokes an emotional reaction, not its recognition. Work in this area has focussed on the effect and use of items of clothing and fashion as well as images for the person with dementia. Unlike the work on the use of clothing for reminiscence therapy, this thesis suggests clothing can also bring back memories of the individual for families, and this may offer them comfort and solace.

As Brooker suggests, good dementia care includes enabling people with dementia to keep their own clothes (Brooker, 2007), and carers in the current study also thought this was of great importance. This concurs the findings of Ward and colleagues who noted clothing and appearance were important for families' feelings of continuity (Ward et al., 2008).

One of the most distressing implications for the families was the failure of the individual with dementia to recognise them as their family. However, what some families described as more distressing at the end of life was their inability to recognise the individual with dementia. As physical changes occur towards the end of life, for example, weight loss and elements of frailty, the individual becomes less recognisable. This compounds the individual's already changed personality. It seemed to carers

therefore important to maintain their appearance as much as possible, such as clothing. This highlights how it is not just the person with dementia who is affected by clothing decisions. The ramifications are potentially far reaching for family members too and they may be emotionally affected by the loss of their family member and their physical characteristics. High and Rowles and the current findings suggest that care homes staff do not always take note of the preferences families have for belongings such as by enabling them to be dressed in their own clothing (see quote 050, 16:11, on page 250 of chapter six) (High and Rowles, 1995). A balance needs to be struck, as the families' wishes and concerns are important to incorporate into daily care, but families' wishes may not always reflect the individual's wishes and concerns if they could express them (Boyer et al., 2004). For example, carers may place a high level of importance on appearance and hygiene; but consider this more important than the person with dementia might (Bamford and Bruce, 2000).

Carers may therefore understandably become distressed when their relative is not wearing clothing that consistent with what they previously would have worn, or have a hairstyle which is different (Twigg and Buse, 2013). However, it is important to note that there may be a change in preference from the person with dementia as they not only progress through their journey of dementia but also grow older. For example, if the care home was having a 'beauty day' with nails being painted, they may opt for the colour that is not usually associated with them. This may not be distressing for families if they want to maintain the personhood of the individuals, but it may be distressing if the carer is starting to not recognise the individual.

The emotional reactions from clothing and other such personal items of dress can evoke strong emotions (Twigg and Buse, 2013) and this is evident in the present study. But this is not just important for use in reminiscence work or similar activities with the individual, it is also important to consider clothing's effects on carers.

7.3.2 Compassion

The findings in this thesis have highlighted dissatisfaction with nursing standards in hospital care. It was clear from the findings that the professionals that were of most disappointment to carers were not the doctors but the nurses, supporting previous work by Lawrence and colleagues (Lawrence et al., 2011). In the current study there was a perception that nursing standards were previously much better and that recent years had seen a decline in standards. In particular this related to the care and compassion that were not shown by the nurses.

Compassion was mentioned many times by those interviewed, replicating the findings of previous work. Lawrence et al. interviewed both bereaved carers and a mix of care professionals and found that compassion formed the 'crux' of family accounts about end of life care for people with dementia (Lawrence et al., 2011). However, compassion did not have a central focus in the findings of the study by Lawrence et al.

It is interesting to map compassion as conceptualised in the discussions of the participants compared to compassion as described in the policy literature. For example, compassion as discussed in the Francis report (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013) was later described by the Care Quality Commission (CQC) as a 'hard to describe' facet of care (Farenden, 2014). Earlier it was defined by the Department of Health as:

'how care is given through relationships based on empathy, respect and dignity – it can be described as intelligent kindness and is central to how people perceive their care.' (Department of Health and NHS Comissioning Board, 2012).

In the current study participants did not essentially deviate from this definition. Their discussions about nursing practice indicated a similar definition. Families discussed what could be termed compassion as being able to understand and appreciate the needs of others, and wanting to address these needs. However, time was often what families associated with professionals being compassionate. This was not as simple as just spending time with the person or with the family, it seemed more about what they did within that time. This mainly consisted of being able to demonstrate an emotional side to their personality and being able to demonstrate warmth, affection and empathy when connecting with individuals.

Exploring a lack of compassion

This section will explore the possible explanations for the lack of compassion which could be interpreted from the participants' responses in this thesis including; compassion fatigue, structure and organisational pressures on professionals, and malignant social psychology.

Emotional and psychological characteristics

The lack of compassion perceived by carers from nurses could simply be a case of widespread 'compassion fatigue'. Compassion fatigue has been described as:

'natural consequent behaviours and emotions resulting from knowing about a traumatizing event experienced by significant others – the stress resulting from helping or wanting to help a traumatized or suffering person' (Figley, 1995).

Nurses are at particular risk of compassion fatigue due to the nature of their work. Caring for vulnerable patients, who are often in pain and experiencing illness, can put professionals at considerable risk of being 'wounded by their work' (Stebnicki, 2000). Showalter (2010) has suggested that although health professionals suffer as a result of compassion fatigue both physically and mentally, they still provide care for their patients (Showalter, 2010). Not all nurses will suffer compassion fatigue. However, nurses will all be faced with the risk of compassion fatigue when caring for people at the end of their life, potentially more so when these patients have dementia, which may itself be distressing for nurses.

Nurses have been known to use various coping mechanisms to deal with or prevent compassion fatigue including: physical exercise, having supportive relationships and setting boundaries between themselves and patients (Melvin, 2012). The present findings suggest that at times these boundaries become too rigid and that as a consequence nurses appear distant and uncompassionate towards people with dementia. These boundaries offer a way of protecting themselves from becoming too emotionally attached to their patients (see quotes on compassion on page 241-250 of chapter six). This supports previous findings that care staff may 'distance themselves' from the emotional needs of the person, as they tried to balance their professional and personal feelings (Lawrence et al., 2011).

However, as this thesis shows, it would be inaccurate to suggest that all nurses put up boundaries. Clearly some nurses become emotionally involved in their patients as marked by their distress at the death of a patient (see quote 041, 11:67 of chapter six, page 249).

For some, however, their uncompassionate approach may simply reflect a lack of compassion and not compassion fatigue. There may also be those who are not in a role which is suited to them, emotionally. It has been argued that some people do not have the characteristics and personality to be able to show compassion in their approach (Crowther et al., 2013).

Structure and organisational pressures

The structure and organisational pressures of the health and social care systems which professionals, including nurses, face are an alternative explanation for perceived lack of compassion (Davies and Iliffe, 2014). In particular, palliative care services developed during the 1980's with the hospice movement, which grew outside the NHS, describing itself as breaking the rules and breaking down the boundaries between patient-centred care and protocol-driven care (Davies et al., 2014b). Palliative care is becoming increasingly integrated within the NHS, which is standardised and bounded by rules and structures. (Davies et al., 2014b).

A potential explanation for the dissatisfaction with nursing care is that nurses lack time. However, it is argued there is a lack of time to carry out duties in health and social care roles in general and this is not specific to nurses (Weeks, 2013) as noted in the Francis report (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013). This report

identified a general lack of resources, with insufficient doctors, nursing staff and support staff. The report furthermore described how reception staff were over-stretched and overworked. This leads to a question of 'why do they lack time?' Organisational pressures and time restraints, which are now being cited by nurses are having a direct consequence on their ability to perform their role and work load, resulting in a lack of time to perform the compassionate and empathetic parts to their role as a nurse and carer to the sick. In this thesis this has included the time to simply attend and talk to patients. The nursing role has changed from one in which they were there to perform the 'hands on' care for the ill to one which they are now becoming more 'paramedical' (interpreted as having more responsibilities previously associated with doctors), as a participant in the current study noted. As discussed by Mulhall (1998), nursing and medicine are beginning to overlap (Mulhall, 1998). The nurse's role is task-orientated, with a multitude of tasks, and hence this leads often to a lack of time to do some tasks which are not valued or seen as important. This was noted in a previous study, which is included in the systematic review of this thesis (Lawrence et al., 2011), whereby a psychologist and palliative care specialist emphasised how there was a risk of healthcare professionals becoming task focussed, which involved just thinking of the physical care tasks or practicalities and ignoring the emotional needs of the individual.

Malignant social psychology

Kitwood used the phrase 'malignant social psychology' to summarise the negative effects of social interaction, communication and the environment (i.e. social psychology) in people with dementia. This includes the negative behaviour of others which undermines the individual and the sense of personhood of someone with dementia (Kitwood, 1997a). Much of psychiatry and clinical psychology has previously

isolated the person with dementia and not considered the influence of the environment on them (Kitwood, 1993). For example, the advancing neurological impairments are noted, but the effects of others' behaviour around the person with dementia had not previously been considered. Kitwood used the term 'malignant' to emphasise that this treatment is culturally inherited, and not necessarily due to the evil intent of others.

Kitwood presents 17 elements to malignant social psychology which affect the person with dementia, most of which, were reflected in the present study (see table 7.1) (Kitwood, 1997a). Kitwood suggests that the examples of where professionals lack compassion are not always due to their evil intent or malice but simply due to some habits and behaviours which make up malignant social psychology. For example, some participants described how their relative was left naked or semi naked in public without thought for how the individual would have felt. Some were ignored by professionals when it came to discussions about medical decisions and treatment options. In Kitwood's 17 elements these appear to fit within the description of 'invalidation'. Kitwood describes this as ignoring the person with dementia's subjective state and experiences, not acknowledging their subjective reality. Alternative examples include professionals insisting on hospital admission despite this being against the previously expressed wishes of the person with dementia (see quote 025, 27:47 on page 221 of chapter six). People with dementia experience high levels of anxiety (Seignourel et al., 2008), they will become distressed with environments that are unfamiliar or for some that are too "clinical", such as a hospital setting (Waller, 2012). In the case of the current study it could be argued that professionals failed to acknowledge this, but further research would be needed to explore their decision making. Carers' views were that doctors did not always acknowledge the distress and anxiety it would cause to them

to be on an open ward with professionals in uniforms and other unfamiliar people around them (see quote 025, 27:47 on page 221).

Other elements of Kitwood's typology appear to fit within the experiences of participants in this thesis. There were some distressing portrayals from carers about the way in which care staff spoke to their relatives, sometimes raising their voices inappropriately, and accounts of swearing were rare but vividly recalled by carers. Intimidation is recognised by Kitwood as an element of malignant social psychology. However there needs to be caution with this element as Kitwood noted there is no evil intent, but it is difficult to conceive how this cannot involve some 'evil' intent on the part of the professional. It could be argued, however, that swearing is an odd form of maintaining normality.

Table 7.1 Kitwood's 17 elements of malignant social psychology (Kitwood, 1997a)

Element	Kitwood's description	Presence in data from current study
1. Treachery	Using forms of deception in order to distract or manipulate a person, or force them into compliance	Not reported
2. Disempowerment	Not allowing a person to use abilities that they do have; failing to help them complete action that they have initiated	"[…] But I said '[my husband] wouldn't know what a toilet was, he has to be taken to the toilet, he doesn't know the difference between a toilet, a bath, a sink, he doesn't know what a toilet is'. […] And she said [nurse], 'Oh,' she said, 'Not

		to worry,' she said, 'If he pees on the floor, that's okay' " (013 - 43:11)
3. Infantalization	Treating a person very patronizingly as an insensitive parent might treat a very young child	"[…] An occupational therapist […] she came bustling in one morning when my sister and I were there, she came bustling in and she went right up to my mother and sort of did this to her, you know, how you do. And she said, 'Oh hello K, I love to see your lovely smiley face.' And you thought, 'Any moment now you're going to get hit over the head woman,'" (060, 3:18)
4. Intimidation	Inducing fear in a person, through the use of threats or physical power	"[…] And this auxiliary nurse came, grabbed him by the shoulders and put him on the bed and said, 'Will you fucking stop moving?' And I just thought, and those were the words" (015, 46:45)
5. Labelling	Using a category such as dementia, or 'organic mental disorder', as the main basis for interacting with a person and for explaining their behaviour	"Treating the person as a person and not somebody with an illness. I think that's the most important thing. I mean they still have a personality even if they can't express themselves." (018, 23:20)

6. Stigmatization	Treating a person as if they were a diseased object, an alien or an outcast	"And she - they put her on to the acute ward, and it was from there that I realised that there's - the only word is 'discrimination', that people with dementia are discriminated against because everybody else in the hospital has no idea what they're dealing with. And I mean from consultant to floor worker" (036, 20:1)
7. Outpacing	Providing information, presenting choices, etc., at a rate too fast for a person to understand; putting them under pressure to do things more rapidly than they can bear	Not reported
8. Invalidation	Failing to acknowledge the subjective reality of a person's experience, and especially what they are feeling	"But I was also wound up by the kind of level of nursing care. And again, when I spoke to them, they didn't seem to think it was wrong. They thought it was alright for some guy to be lying naked in a bed rolling the sheet up, exposing himself" (002, 38:43)
9. Banishment	Sending a person away, or excluding them – physically or psychologically	Not reported
10. Objectification	Treating a person as if they were a lump of dead matter: to be pushed, lifted, filled, pumped or drained,	"[…] And everything about it was a thoroughly dehumanising experience

	without proper reference to the fact that they are sentient beings	because they would only help me change my mum when she'd wet herself […]" (008A 008B, 34:9)
11. Ignoring	Carrying on (in conversation or action) in the presence of a person as if they were not there	"[…] Then this doctor came in and he quite openly [in front of the person with dementia] was telling us that mam has this massive bleed and all this […]" (022, 4:22)
12. Imposition	Forcing a person to do something, overriding desire or denying the possibility of choice on their part	"[…] To put her to bed at a reasonable time. I mean she'd never gone to bed at six o'clock. Does anybody go to bed at six o'clock? So I had to fight for a long, long time, I think I had to wait for about eighteen months until somebody would actually agree to come at ten o'clock at night to put her to bed." (017, 37:3)
13. Withholding	Refusing to give asked-for attention, or to meet an evident need	"So I've had to go along to see the chief nurse and I've said, 'He's desperate for medication.' He looks at his watch and he says, 'Oh well it's not 2 o'clock yet,' or, 'He's not due his next door until 6.30.' And I want to say, 'Fuck the next...' You know, you look at the patient. Why are you being ruled by a

		clipboard? A clipboard is a tyranny" (006, 36:15)
14. Accusation	Blaming a person for actions or failures of action that arise from their lack ability, or their misunderstanding of the situation	"One of the nurses accused my father of being [trouble], you know, she was a - you know, if I ever see her again, I'll take a baseball bat to her face, I tell you! That's how strongly I feel about her. I will punch her lights out. **And was this the one that said your dad was...** *Trouble."* (015, 46:45)
15. Disruption	Intruding suddenly or disturbingly upon a person's action or reflection; crudely breaking their frame of reference	Not reported
16. Mockery	Making fun of a person's 'strange' actions or remarks; teasing, humiliating, making jokes at their expense	Not reported
17. Disparagement	Telling a person that they are incompetent, useless, worthless, etc., giving them messages that are damaging to their self esteem	"[…] And when he finally did get somebody to come and see him, he just looked at him at home and just said to me, 'Hopeless case.' […]" (031 – 26:8)

Kitwood asserts there is no malicious intent on the part of professionals, but instead malignant social psychology has become interwoven into the care culture (Kitwood,

1997a). As new nurses join the hospital ward, for example, they are trained by existing nurses within existing routines of practice. This encourages good practices from existing staff to be passed onto new starters. However, it also encourages the bad practice to be passed on, and hence bad practice or lack of care becomes interwoven into the care culture.

As demonstrated in the above examples and in table 7.1, it is possible that one explanation of the behaviour of the nurses identified in this thesis is caused by a background malignant social psychology (Brooker, 2007, Kitwood, 1997a), which causes carers to characterise the behaviour of the nurses as lacking compassion. Carers see the failings, not their source.

An alternative to malignant social psychology is to focus on strengths of the person with dementia rather than their deficits, in an approach known as person centred care (Kitwood, 1997a, Brooker, 2007). Brooker has built on the work of Kitwood and states that the outcome of person-centred care for people with dementia is to maintain their personhood in the face of declining mental powers (Brooker, 2007).

Why are only the nurses to blame for a lack of compassion?

Although there are some accounts of other professionals (in particular doctors) who lack compassion when caring for people with dementia (see quote 031, 26:8, on page 242 of chapter six), it was nurses who bore the brunt of criticism within these interviews. There could be many reasons why nurses were seen as the ones who lacked compassion and received more criticism than doctors.

The role of the nurse is suggested to have both empathy and compassion at its core, with compassion and concern often drawing people into the nursing career (Wentzel and Brysiewicz, 2014). Therefore when this is seen as sometimes lacking by families and their expectations of care are not met these unmet expectations and lack of perceived compassion may impact upon their views and opinions of their experiences. In a recent article from the professional journal Nursing Times, it was found that nurses felt that patients and carers had unrealistic expectations of nurses and health services (Ford, 2012). It could therefore potentially be that families have unrealistic expectations of the nursing role and the care that they are able to provide at the end of life. This leaves the nursing role as somewhat ambiguous, and the changes in the nursing role have left citizens ill-informed about their roles and tasks. However, the same could be said about expectations of doctors, relating to the old saying that doctors cure or treat and nurses care. There is no cure for dementia, and it is a progressive degenerative illness. However, expectations of cure are not placed on doctors from relatives of people with dementia; nevertheless 'good' care is still expected from the nursing staff.

A study of professional boundaries found that one of the key distinctions between nurses and physicians was time spent with patients (Walby and Greenwell, 1994), with nurses spending more time. In this sense nurses are seen as 'frontline' and often the 'face' of the NHS. They are the ones that families will see delivering the care and therefore the ones that are likely to be judged by families. They will also be better placed to become involved in the daily emotional aspects of care and make connections with families and patients. This emotional bond and relationship may make them easier to criticise, for what families may see as lacking compassion.

7.3.3   The role of a carer

The term carer

The participants described many difficulties that they had gone through in the dementia 'journey' with their relative. One of the key struggles was around their own identity, in particular the ambiguity of their role as not only a relative but also a carer. It appeared that some family members went from being a relative to being a carer overnight.

As discussed in chapter three there are some arguments that the term carer is no longer an appropriate term to use, as it restricts the role of the individual classified as a 'carer', and gives them a presumed burden (Molyneaux et al., 2011). Additionally the term 'carer' also implies a sense of care for one another in the same sense that the term 'loved one' implies that the individuals love one another, which may not always be the case (Pilgrim, 1999). Sanders and colleagues also described what they termed the 'disengaged caregiver' (Sanders et al., 2009). As noted in chapter three, this is a 'carer' who has relinquished not only physical responsibilities but has also removed themselves emotionally from the individual.

Definitions of 'carer' can be unclear (O'Connor, 2007). For example, what does it actually entail or mean and how is it different when one feels a responsibility to care for a relative anyway? Alternative terms have been suggested including 'advocate', or using their specific familial relationship title, such as son or daughter (Pilgrim, 1999, Molyneaux et al., 2011). Many of the participants in this thesis when describing their role, in particular with regards to the care management side of their role, described it as advocating for their relative.

As in other studies, participants in this study did not simply adopt the term carer for themselves, rather there was some socially constructed process to this adoption (O'Connor, 2007). This was, for example, through conversations with health and social care professionals or other 'carers' (see quote 004, 33:68, on page 263 of chapter six).

This adoption of the term carer implies that their relationship between the 'carer' and the person with dementia has also now changed. Molyneaux and colleagues caution using the term carer as this implies that a previous relationship is now lost (Molyneaux et al., 2011). Many participants accepted their role as a carer and did not have any problem identifying as a carer (see quote 030, 14:36 on page 264 of chapter six). However, some did not appreciate this term and found it difficult to be identified and 'labelled' as a carer (see quote 004, 33:68 on page 263 of chapter six). The present findings support this, suggesting that for many of the participants they simply felt it was a responsibility that they had already as the daughter or son, for example (see quote 041, 11:90, on page 264 of chapter six) (Cleary et al., 2006). O'Connor suggests that the lack of identification with the role of carer and the expression of it as being part of the familial relationship is possibly due to the inability of the 'carer' to step back and assess their new role. Instead they are preoccupied by the duties within this role, whilst also failing to recognise a loss of relationship (O'Connor, 2007). Others however, appeared happy to adopt the role of 'caring' but did not see this as a responsibility of being a relative. Therefore the use of an additional 'label' such as carer allows for clear boundaries between what they may perceive to be different roles. This highlights once more variation in carers' views.

As discussed earlier much work has focussed on exploring and maintaining the personhood of the person with dementia, and maintaining their personhood (Kitwood, 1997a, Sabat and Collins, 1999, Kontos, 2004). Little has considered the perspective of the families who go on to become the carer of the person with dementia and maintaining their personhood. Kitwood alludes to this (Kitwood, 1997a) by asking: 'does anyone consider their anger, inadequacy and guilt?' The quotes (004, 33:68 and 045, 19:6, on pages 263-264 of chapter six) from this study appear to support a report from the National Council for Palliative Care, which suggested that there can be a loss of identity of the individual who has now become 'the carer' (National Council for Palliative Care, 2013). As discussed in the previous section, many things make up an individual and the self. People are identified in many ways, for example dad, brother or son. However, it may be that caring strips this away from those who are caring for people with dementia. Further research would be needed to explore this idea further.

Transition to role of carer

A new 'carer' has to adapt to their new role and the demands that come with it. These demands include the physical care for the person, the psychological and emotional impact of caring, and balancing the 'normal' aspects of their life as much as possible. For example, many carers described how they now needed to provide personal care which was something they had never done before (see quote 011, 35:25 on page 238) or the difficulties of balancing work and caring (see quote 057, 17:19 on page 262). Sanders and Power discussed the experiences of husbands caring for their wives with dementia or other chronic conditions and emphasised the change in roles and relationship that occur (Sanders and Power, 2009). In particular Sanders and Power described how husbands felt their role had changed to become one of protector of their

wife. The husbands had always felt an element of their role was to protect, but this protector role was now in relation to their wife's self-esteem, personhood and dignity. Their roles also changed in simpler terms, from handyman in the home to undertaking duties that had traditionally been their wife's role, such as laundry. It was not just their role that changed, but also their relationship with their wife, as she progressively deteriorated. Sanders and Power noted how they were forced to develop a new level of intimacy and closeness, recognising the finality of the relationship (Sanders and Power, 2009).

In the early stages of dementia there may not be much of a change in families roles and the term 'carer' may only be for administrative purposes, such as financial benefits. As Molyneaux and colleagues noted the term 'carer' opens a gate to services (Molyneaux et al., 2011). The caring role could be argued to be in a constant state of transition with some points more obvious than others, for example the diagnosis of dementia, or the moment mobility starts to become a problem. As discussed in chapter three, Lindgren (1993) has described caring as a career with three stages: the 'encounter stage', 'enduring stage', and finally the 'exit stage' (Lindgren, 1993). One of the most visible changes is the phase in which the person with dementia may move to a care home. Galvin et al. highlights how the role of carer may change at this point, becoming an ambiguous role of carer/visitor (Galvin et al., 2005). This mirrors the earlier transition of role discussed above, from wife, husband, son or daughter, for example, to carer. For someone at or approaching the end of life, being cared for at home promotes further changes in the carer role. In particular participants described how the increasing number of professionals (for example, district nurse, GP, care workers, occupational therapist) which may visit the person with dementia at home. These need coordination and some

form of management, which may become more difficult as the symptoms develop. End of life symptoms such as incontinence, difficulty swallowing, multiple infections, and skin breakdown (Mitchell et al., 2009) can be distressing for the carer to deal with on their own.

Personal care and toileting can be particularly stressful components of the caring role, especially for adult children of their parent who has dementia. Many adult children expressed their discomfort with these aspects of care, in particular, and this was not restricted to the adult children of the opposite sex to their parent (see quote 015, 46:30:34, on page 239 of chapter six). As suggested by Sanders and Power, who investigated this with husbands caring for their wives found this was often a catalyst for relinquishing caring duties to professional services (Sanders and Power, 2009).

Professionals' views of the role of carer

It is not just carers who feel that their role is ambiguous and struggle with identity. Twigg described how social care organisations or agencies also struggle in conceptualising their relationship with family or informal carers (Twigg, 1989, Twigg and Atkin, 1994). Within the social care system carers are also perceived as having an ambiguous position. Twigg illustrates how carers lie on either side of the margin of the social care system. On the one hand, carers are within the remit of the care being delivered, part of their concern and responsibility, on the other, they are beyond the remit of the social care system, they are not the responsibility of the social care system and are taken for granted (Twigg and Atkin, 1994). Twigg suggests that the social care services group carers into one of three categories or frames; carers as resources, carers as co-workers, and carer as co-clients. Subsequently Twigg added a fourth frame of the

superseded carer (Twigg and Atkin, 1994). There are several close links with what Twigg proposes and the findings from this study. The carers within the current study recounted stories which match each of the frames. Twigg comments in her paper how she focuses on the social care sectors/agencies, but this may equally apply to the health sector. The findings in the current study suggest how these frames do indeed apply to the health sector, and exist despite policy acceptance of carers' right to services (Department of Health, 2008b).

Carers as a resource

The first frame of carer as resource comes with the understanding that the majority of care at first is informal (i.e. not provided by professionals) and will subsequently be followed with more formal elements of support and care. This is particularly true of people with dementia, with the majority of care for people with dementia provided by family carers (see quote 028, 31:31, on page 275 of chapter six), without whom the formal care system would be likely to collapse (Alzheimer's Society, 2013). Therefore carers are resources and health and social care services are increasingly recognising this (Department of Health, 2008b). Some participants described how professionals did not seem to listen to their view or 'expertise'; however, many of the participants in the current study showed a reluctance to receive any formal form of support. Nevertheless, towards end of life an increase in formal support is generally accepted to be necessary.

Twigg describes social care services or agencies within this model as acting as a supplement rather than a substitute to the care from the carers, only stepping in when care is not available or not enough. Within this frame carers form the background of care and are therefore not considered a priority. Twigg argues that any conflict of

interests between the carer and the person with dementia will be ignored by professionals (Twigg, 1989). However, as reported in this study, the wishes of some carers were questioned when professionals perceived these not to be in the best interests of the person with dementia (see quote 045, 19:10, on page 227 of chapter six).

Within this frame of carer as resource, carers are separated from the care that is available from formal services, and may now become somewhat isolated and potentially unsupported in their duties. In the current study it was common for participants to feel unsupported after the initial diagnosis of dementia (see quote 042, 9:18, on page 220 of chapter six). They felt that much of the support on offer did not arrive until later. As discussed in chapter six, carers' main anxiety was often around the care management tasks the role of carer encompassed, and feeling unsupported in this (see quote 033, 15:2, on page 269 of chapter six).

Viewing carers as a resource also has potential consequences for the carer's individual health and well-being. If carers are simply seen as 'a given', they may become 'part of the furniture' of the care and not a receiver of care. This model or frame for viewing family carers has the potential to neglect the carer and lies behind current policy to improve carers' support (for example, the National Carers Strategy (Department of Health, 2008b) and the Care Act 2014 (Department of Health, 2014)). The policy indicates the risks of undervaluing the importance of carers' abilities and knowledge, whilst simultaneously being reliant on their abilities and knowledge.

If the carer is seen as separate to the person with dementia, as this 'carer as resource' model suggests, the individual needs of the person with dementia and the carer may not

reach the eligibility criteria for support. However, hypothetically their combined needs may reach the criteria. Several carers within the current study did not meet criteria for certain levels of support such as palliative care, for example. Combined as a carer and person with dementia, however, they did meet these criteria (see quote 004, 33:30 on page 262 of chapter six). Fortinsky suggests in his work of triads (person with dementia, carer, and professional) that rarely does a person with dementia come alone (Fortinsky, 2001). Similarly, some have suggested that there is not a dichotomy of 'carer' and 'cared-for' (Keith, 1992) but instead that a caring relationship is reciprocal (Williams and Robinson, 2001).

Carers as co-workers

The second frame focuses on carers as co-workers and aims for family carers and professionals to work in parallel. This framework integrates the carer within the care service, as a co-worker rather than someone who simply acts as the backdrop to care and separate (see quote 003, 42:43, on page 270 of chapter six). This optimally allows for the input from two experts of very different types; the professionals who are experts from training and education, and carers who are the experts through experience (see quote 035, 35:15, on page 266 of chapter six). This theoretically means that the person with dementia should be receiving the best care possible, from those who know them well (the family carer) and those who know the disease well (the professional).

Additionally, this means that the welfare of the carer may be better maintained as they are now part of the care system. This was seen within the current study when carers were offered respite care. Carers in this study, however, often declined this offer as they felt they did not require this (see quote 060, 3:14, on page 272 of chapter six). Some

research has suggested that carers find difficultly letting their relative go into a care home, for example, due to guilt (Nolan and Dellasega, 2000). Although some relatives find it difficult to take on the role and be known as the 'carer' for their relative (see quote 004, 33:68 on page 263 of chapter 6), some also find it difficult to relinquish this role. As Stewart et al discussed, a sense of control can be important for the families at the end of life (Stewart et al., 1999). They referred to control as control and autonomy over caring. This ranged from choices being available to them, for example, scheduling appointments, to control over the whole dying process and dying on their terms, in particular terms of treatment. Many in the current study who had been caring for their relative at home for many years, suddenly found that they were no longer the primary carer on the move of the person with dementia to a care home. For some this was a difficult transition and one with which they struggled. They felt they had lost the element of control and the ability to be the individual's advocate (see quote 022, 4:31, and 030, 14:5 on pages 271-272 of chapter six). Unlike the first frame of carer as resource, professionals in this frame intervene before a crisis point is reached.

Carers as co-clients

The third framework focusses on the carer as a co-client. Twigg suggests it is most applicable to an elderly couple, with age and disability of the spouse carer defining them as a co-client, also in need of care. In many cases the aim of this model is that of reducing the strain and stress of the carer. This assumes that carers are now the concern of the services, they are not co-workers which can be worked with and assist in care duties, nor are they something to be exploited as resources solely caring for their relative with dementia.

This frame would seem more applicable to the older carer groups within this thesis, such as the spousal carers. Many had needs themselves, in particular health needs including the need for psychological support (see quote 043, 063, 22:17, on page 281 of chapter six). Adult children however, also had high levels of needs and could require an element of support themselves, for example practical support to balance caring duties and 'normal' working life. Meuser and Marwit (2001) showed that there is a difference between the way adult children and spouses react to caring for a relative with dementia, with levels of stress, strain, guilt and grief being experienced differently at different time points (Meuser and Marwit, 2001). Adult children generally also have less time, as demonstrated by Forbes and colleagues (Forbes et al., 2000), and highlighted in chapter three. They are often trying to care for their relative with dementia whilst maintain a job and possibly a family (see quote 057, 17:19, on page 262 of chapter six). Not all adult children will have these competing interests and their priorities will be different. Campbell (2010) demonstrated that sons who were never married gave caring a more central role within their life (Campbell, 2010). For example, in the current study one participant was an unmarried male who left work to care for his mother full time.

The frame of co-client should be treated with caution, in order to ensure that the care does not focus on the carer only at the end of life, taking attention away from the priorities of the patient (Barnes, 1997). Within palliative care, attention may move from the dying individual to the carer, focussing on bereavement and survival without the person (Harding and Higginson, 2001). This shift of focus could begin even sooner for carers of people with dementia, with the potential for prolonged pre-grief (Chan et al., 2013, Kiely et al., 2008). Fortinsky previously warned that the involvement of the carer can lead to the person with dementia being "pushed out of the picture" (Fortinsky,

2001). This was particularly noticeable around the discussion of the Admiral Nursing service. This service was focussed on the carer and not the individual, for example see quotes 043, 063, 22:17 on page 281 and 005, 32:4, on page 282, of chapter six.

Superseded carer

The fourth and final frame, Twigg described a superseded carer as one who is not to be supported but displaced (Twigg and Atkin, 1994). This can take one of two approaches. In the first approach, the main concern is to increase and maintain the independence of the person being cared for. In this approach the aim is not to benefit the carer. This approach would not be applicable for people at the end of life with dementia as they are becoming more and more dependent upon others. The second approach is to focus on relieving the burden placed on the carer through increasing the independence of the cared for person.

This is potentially an approach that some professionals take towards carers of people with dementia towards the end of life, when it may become apparent that carers are struggling and in need of support. In particular, it was often shortly before this stage that carers described making decisions about relocation (see quote 025, 27:52, on page 208 of chapter six). As Twigg suggests support for the carer may involve them giving up the caring role and becoming once again the relative. This is very different to the other frames of thought introduced by Twigg, as this sees the family as relatives and not as carers.

7.3.4   Relationship between professionals and carer

Many of the elements of 'good' quality end of life care that are described in chapter six describe relationships between participants and health and social care professionals and

the characteristics of staff. This reinforces importance of professionals that was highlighted previously in chapter three. Many of the examples from chapter six of 'good' relationships with professionals that participants discussed were where they had developed a rapport and understanding with one another. This was particularly the case for those who had the support of Admiral Nurses. However, there were many examples of 'poor' working relationships and a lack of rapport. The discussions regarding compassion, respect, and dignity, and the blame participants attributed (particularly to the nursing staff), epitomised poor relationships. Poor relationships were also cited when participants felt unsupported within their role of completing care management tasks, and struggled to communicate effectively with professionals.

In the next sections I will discuss: 'battles' with professionals, why relationships are important, what carers want from their relationships with professionals, and anger with professionals.

'Battles' with professionals

Conflict and the description of fighting were briefly mentioned within chapter three, when some carers' felt they had to fight doctors about treatment for their relative. Descriptions of struggles and the use of military metaphors such as 'battle' were also used in the current study in relation to services, professionals and the health and social care systems as a whole. When participants discussed battles with professionals in the current study, sometimes these 'battles' were 'won', and these were usually about how to proceed with treatment. However, there were several occasions when participants described a 'constant battle' with no sense of winning or losing (see quote 012, 48:27, on page 261 of chapter six). It was apparent from the interviews that there was some

anger felt by carers, when battles were lost or professionals were thought to be being unreasonable (see for example quote 045, 19:10 on page 227 of chapter six).

This description of 'battles' in the current findings is a contrast to the use of metaphors to discuss the disease itself, as in other illnesses, such as cancer (McCartney, 2014). In her article in The Guardian (Granger, 2014), Dr Kate Granger's discussed her discomfort with the use of military language such as 'battle' and 'fight' in relation to a person's 'journey' with cancer. The implication of discussing battles in relation to a terminal disease is that the person 'fighting' the disease will inevitably loose. This may leave people with the disease feeling inadequate and foster an element of self-blame (Lane et al., 2013).

This discussion of 'battles' in the current study with services and professionals as opposed to the disease, means the battle is being faced by the carers and not the person with dementia, who has the disease. In cancer the 'battle' refers to the individual with the disease or at least includes the individual and their family 'fighting'. In dementia however, carers are battling the services and advocating for their relative.

Why relationships are important

The use of such 'battle' language and military metaphors clearly illustrated the often broken relationships between professionals or services and carers at the end of life, seen from carers' perspectives. It is easy to say that relationships between professionals and families need to be improved, but what is it about the relationship that is important, or needs to be improved? As demonstrated in the literature review of this thesis in chapter three, little research has been conducted with or about carers at the end of life for people

with dementia (Davies et al., 2014a). We know little about supporting relationships which will enhance the caregiving experience (Davies and Nolan, 2008).

As noted in previous chapters, carers of people with dementia are needed to help communicate with professionals about the individuals needs because of the declining communication abilities of the individual with dementia. The lack of ability to communicate with the person with dementia at the end of life is challenging to many professionals (Davies et al., 2013). Because of this the nature of the relationship is one in which the professionals and the carer work together in partnership with one another. This allows for an exchange of information, skills and knowledge. Some have proposed a model of 'carer as expert', in which family carers' expertise is recognised, (Nolan et al., 1996). Many problems often need a collaborative relationship between professionals and carers for their solution, in particular, pain management and other symptom control, and place of care (Raymond et al., 2014b). Carers are the liminal figure between the private world of the person with dementia and the public world of the health and social care systems, acting to build relationships with professionals, and act often as mediator (Galvin et al., 2005).

A 'good' relationship between carers and professionals is important at the end of life because carers are often in completely uncharted territories and lack the skills and knowledge to care for someone with dementia. They need the confidence and encouragement from professionals to provide 'good' quality end of life care. However, this will not be available if there is a lack of trust between the professionals and carers. As Brooker states, for person-centred care relationships between all people in the care

environment should be nurtured (Brooker, 2007). These relationships will include the relationship between carers and the professionals.

What carers want from their relationship with professionals

When reflecting on elements of 'good' care, Admiral Nurses were often seen by participants as setting the 'gold standard' for professionals. Although the Admiral Nursing role is not for the direct benefit of the person with dementia (at the time of this study) any benefit to the carer could be seen as an indirect benefit to the person with dementia.

Participants described how it was important for professionals to have a relationship not only with the person with dementia, but also their family and carer. Innes and colleagues found that developing a positive interpersonal relationship between service providers and the carer was important (Innes et al., 2005). In Innes et al's study these relationships were likened to a friendship, with the use of 'banter' and loving relationships with professionals being important for a positive experience. Innes et al. described how participants considered loving relationships to be when professionals went above and beyond their call of duty. This may have included spending extra time unpaid and offering lifts. This type of relationship was often described in the current study when participants spoke about the relationship they had with the Admiral Nurse. In some participants' reports of their relationship with Admiral Nurses they appeared to talk about how professional boundaries were somewhat blurred, with the nurse showing some of their non-professional, 'normal', human side. Participants were able to have a more connected and personal relationship with the Admiral Nurses, for example having a chat about life in the local pub (see quote (043, 063, 22:17, on page 281 of chapter

six). This was appreciated by the participants as they felt that the professional was acting with more compassion, concern and genuine interest in their case. This resonates with how palliative care began as a movement which was not governed by professional rules or strict guidelines, and was set up outside the NHS (Davies et al., 2014b).

Admiral Nurses are specialist mental health nurses by background and therefore have knowledge about the health and social care systems (Manthorpe et al., 2014). They offer a bridge between the often disjointed health and social care systems and the carer. Dementia UK has described Admiral Nurses as there to focus on supporting the families (Dementia UK, 2014). They do this through providing psychological support, advice, reassurance, confidence, and simply being a point of contact.

As discussed in chapter six, emotional and psychological support is not the only assistance that carers require. There are elements to the role including the physical aspects of care which Admiral Nurses do not provide (Maio et al., 2014). Admiral Nurses as currently organised are therefore not the solution to all the problems of caring for someone with dementia. Similarly they are not there to provide care management, even though many of the participants reported that the Admiral Nurses helped them with some of these tasks.

It was not just the Admiral Nurses described in this study that were able to offer such support. In particular community care experienced by participants was often provided by care workers who knew the whole family unit, including the person with dementia. This was a stark contrast to the acute units and this was an indication of better care, as suggested by Galvin and colleagues (Galvin et al., 2005).

Anger with professionals

As suggested in the discussion above and in chapter six, carers often felt disappointment with and even anger towards professionals about the care that they delivered at the end of life for people with dementia. In some cases carers felt there was not enough done to increase the comfort of their relative; however, others felt there was not enough active treatment provided, thus highlighting the spectrum of treatment seen as appropriate demonstrated in both the study findings and chapter three.

This anger at professionals, however, could be interpreted as anger towards the dementia itself, and how it takes away the person they once knew. Participants may have felt that they could not express their anger at the dementia, so instead sometimes they channelled this anger towards the nearest person whom they could blame: health and social care professionals. For example, the lack of ability to know when end of life was approaching can be a consequence of dementia (as seen in chapter two), which at times was channelled into blaming professionals for this (see quote 050, 16:18, on page 220 of chapter six). Many of the participants became emotional or angry at several points during the interviews about periods of time in which were distressing for reasons pertaining to the disease itself. The move of their relative to a care home was a particularly distressing situation for many of the participants (see quote 043, 063, 22:20, on page 277 of chapter six). As discussed, the reasons for care home moves were often due to increasing physical needs due to the degenerative nature of dementia. At this point dementia was beginning to take away who they saw as their relative, but it was also taking from the carer their ability to care for their relative. As discussed in the clothing section of this chapter, dementia had only left the physical part of the person, and carers sometimes became upset at professionals for not maintaining the way they

looked, (e.g. quote 050, 16:11 on page 250 of chapter six). There are many changes to the body of the person with dementia towards the end of life, including weight loss, which are uncontrollable (Mitchell et al., 2009). Clothing is to some extent controllable and therefore they were able to channel the anger they have at those who were responsible for and have control of this.

Similarly, many discussed the lack of dignity given to people with dementia, which was once controlled by the individual but is now in the control of others. This is again something which dementia itself has stripped from the individual and not the professionals themselves. However, there were examples when professionals were said to have done little to assist in the restoration and maintenance of dignity. An example was the description of flannels to wash an individual whilst they stood naked (see quote 004, 33:20 on page 237 of chapter six).

Many occasions were discussed by participants in the current study where professionals were reported not to be providing 'good' quality end of life care. However, it is possible it is not the professionals, but the consequences of dementia that give rise to blame for carers' views of 'poor' care. Nevertheless anger is still directed at professionals.

7.3.5   Discussions of end of life and death

At the beginning of this chapter I discussed the participants' understanding of the terms 'end of life care' and 'palliative care'. I also alluded to the level of ease with which participants discussed the topic of end of life and death. Previous findings regarding such 'difficult conversations' as well as the review of literature in chapter three, have suggested that the person or the family are not ready to have them (Hirschman et al., 2008, Davies et al., 2014a). The findings from the current study both confirm this

statement and also disagree with it to some extent. Some families are ready and do want these conversations, and many of the participants suggested it is not families who are not ready, but professionals.

As reported in chapter three, some participants who did not accept their relative was dying and wanted to pursue all the treatment possible (Davies et al., 2014a). There appeared to be a subtle but albeit noticeable difference between carers' emotional and intellectual acceptance of death. Many understood that their relatives were dying; however, emotionally it was often not until the very end (or sometimes never) that they accepted this (see quote 045, 19:10, on page 227 of chapter six). Therefore discussions regarding such topics remained difficult for them.

In addition to the findings indicating that carers were not always ready to discuss these topics, recruitment also suggests this. Although recruitment for the study was successful in general, recruiting 47 family carers, only one carer of someone who had recently received a diagnosis was recruited. This may indicate that carers are not ready to have conversations earlier in the course of the dementia. Successful recruitment of people who were currently caring and also those who were bereaved indicates that they may be more willing to talk about these topics later.

This goes against the recommendations to have these conversations early in the course of dementia (Department of Health, 2009, National Council for Palliative Care (NCPC), 2009). The one interview with a carer of a recently diagnosed person with dementia tended to cover other issues that the family were experiencing, for example, related to

the diagnosis or to behavioural problems. Despite encouragement to discuss end of life topics, the conversation did not easily lead in this direction.

The content and flow of the other interviews also demonstrated some discomfort with these discussions. Despite participants being invited to participate in a study which was described as discussing end of life, many veered away from this topic. The interviews often took a biographical approach. The participants discussed the person's life and took me through their journey stage-by-stage, leading to end of life discussions. Yet as discussed for many end of life was what they were always talking about, it was not simply the final part of the journey, but began after the diagnosis and in the earlier stages of the illness. However, discussion of the specific, finer details of end of life care was difficult and sometimes not always possible. For example, discussing artificial nutrition and hydration, or withdrawal of treatment, was particularly difficult. Some would simply become too distressed at this point, or simply lacked knowledge about end of life care.

Many have described how professionals can be reluctant or find it difficult to discuss end of life care and have the 'difficult conversations' (Robinson et al., 2013, Cavalieri et al., 2002). Professionals are often told by research studies and policy reports, that they simply need more training and need to feel more comfortable about having these conversations (Cavalieri et al., 2002, Lacey, 2005, Harrison-Dening et al., 2011, Lawrence et al., 2011). However, it is not always skills and training they need to develop but the confidence to have these conversations (Davies et al., 2014b). The National Council for Palliative Care has produced guides aimed at helping professionals to have these 'difficult' conversations (National Council for Palliative Care, 2011). It

provided useful tips about when and how to engage in conversations about end of life, possibly enhancing some level of confidence for professionals.

Both the reluctance amongst professionals and the difficulties of families to discuss these topics creates a complication for the current policy initiatives in England to increase advance care planning (ACP) for people with dementia (Department of Health, 2008a, Royal College of Physicians of London, 2009, National Institute for Health and Care Excellence (NICE), 2004). ACP has been defined by Henry and Seymour (as discussed in chapter two) on behalf of the Department of Health as:

> *'a process of discussion that usually takes place in anticipation of a future deterioration of a person's condition, between that person and a care worker'* (Henry and Seymour, 2007).

ACP can include a 'do not attempt resuscitation order' (DNAR), advance decisions to refuse treatment (ADRT), statement of wishes, and lasting power of attorney (LPA) arrangements.

The literature suggests that there are many perceived difficulties and barriers to ACP in dementia (Robinson et al., 2013). In particular both Froggatt and colleagues (2009) and Stewart and colleagues (2011) have highlighted the difficulty of integrating ACP into routine practice (Froggatt et al., 2009) and the legal ambiguities of ACP, including different components of ACP such as an advance decision (legally binding statement refusing certain treatment) and an advance statement (statement of general wishes and beliefs) (Robinson et al., 2013, Stewart et al., 2011). The findings here suggest that it

takes time to come to terms with the diagnosis and disease. This makes it difficult to have conversations early in the course. This is in line Bunn et al.'s suggestion that families may push for a diagnosis and are key to instigating it, but not all are always ready for the diagnosis (Bunn et al., 2012). This leads to questions about the appropriateness of having conversations regarding end of life, at an early stage. There needs to be a careful cost benefit consideration, with a cost of causing possible distress to the individual weighed against their family's distress and a benefit of receiving end of life care which is in line with their wishes. However, Finucane and colleagues found a difference between patient and carer concerns. Family carers were concerned about the level of distress talking about ACP would have on the individual, but no distress was shown by the person with dementia before or after such conversations (Finucane et al., 1991).

Robinson found that professionals working with people with dementia found it difficult to know when to discuss ACP. They felt that after diagnosis, it was too early; however, once the dementia was advanced, it was too late (Robinson et al., 2013). However the literature suggests it is not just professionals that find this difficult: Sampson and colleagues found that older people do not engage in ACP despite attempts to engage them (Sampson et al., 2011b). The current study supports this finding, with participants reporting it difficult to discuss in-depth specific aspects of end of life care and associated treatment. This was particularly true of those currently caring for a person with dementia.

Further concerns about planning arise from this thesis when adopting a perspective that it is possible to identify 'good' care for the person with dementia and 'good' care for the

carer. Carers may have conflicted needs and ideas which may not always be the best interest or wishes of the person with dementia. This could potentially lead to carers' needs and wishes being prioritised over the person with dementia, as previous research has cautioned (Molyneaux et al., 2011, Harrison-Dening et al., 2011).

All these complications lead to questions about how far ACP should go. There is some evidence that ACP has reduced the amount of emergency admissions to hospital among people with dementia (Robinson et al., 2012, Caplan et al., 2006). However, Robinson and colleagues cautioned that there needs to be a reflection about whether ACP is a true indicator of 'good' quality end of life care (Robinson et al., 2013).

Although the current findings suggest caution may be needed about when to begin ACP and end of life discussions, this study does highlight the need for such conversations. There was a lack of consensus among participants when discussing the type of treatment carers would like their relative to receive and so such conversations need to be taken seriously. There were many factors that appeared to influence carers' decisions about treatment options, including the level of information that they had received and their resulting understanding of dementia. This is in line with previous findings from Forbes et al. who found that a lack of understanding and information of the disease meant family carers were unprepared to make decisions (Forbes et al., 2000). These uncertainties highlight the need for such discussions.

7.4   Methodological strengths and limitations

7.4.1 Study design

As discussed previously in chapter two it is difficult to provide an accurate prognosis for a person with dementia. Therefore, to get a more rounded experience of end of life

care for dementia, bereaved relatives were deemed to be the most relevant to interview, taking a retrospective approach. The use of a retrospective or follow-back mortality design eradicates the challenge of determining who is at the end of life and their inclusion within a research study, for example. Studies that have adopted a prospective design have shown difficulties in respondent burden and non-response (Wenger et al., 1994). However, recruiting only bereaved relatives does not give the opportunity for those who are currently experiencing end of life care the opportunity to voice their opinions and perceptions. Therefore, this study adopted a mixed design using both a retrospective sample and a prospective sample of participants who self-selected as carers of people with dementia receiving end of life care. This enabled the study to avoid the problem of deciding when an individual was at the end of life. The three groups of carers interviewed in this study offer a unique insight into caregiving. However, as noted in the findings, some were unclear as to when 'end of life' began.

A further strength of the study was the use of in-depth interviews as opposed to standardised questionnaires or quantitative measures. The method was chosen to allow for a more detailed exploration and discussion of the participants' experiences. As discussed in chapters one and two, there are many measures or instruments to examine quality of care; however these measures often assess outcomes not applicable to end of life care, such as recovery and death rates. Although there are increasing numbers of measures used in end of life care, many commentators have raised concerns about their use and sensitivity (Stiel et al., 2012), as detailed in chapter one.

In-depth interviews as opposed to semi-structured interviews allowed for a more detailed exploration of the participants experiences, matching the aim of this study. As

discussed in the methods chapter of this thesis, in-depth interviews have been compared to conversation (Lofland and Lofland, 1995). In this sense there are fewer set questions which the interviewer asks and as such a more informal environment for the participant is created. In the current study this was desirable due to the potentially distressing and emotional topic of the interviews. This also placed more control in the hands of the participants for them to discuss the topics about end of life care that they felt were important. I probed for further details and clarification as and when needed. Finally, this also reduced the influence of my assumptions as a researcher being imposed upon them and biasing their answers, through letting them take the lead and talk.

7.4.2 Sample and recruitment

One risk of bias to this study was the source of recruitment for the sample. The participants were recruited from a network of family carers within the charity Dementia UK. The network consists of those who wish to be involved in research activities and other activities such as public speaking. Several of the participants had spoken about their experiences with other people either at conferences, training days, or for research purposes. This meant that at times some of the conveying of their experiences appeared to be somewhat rehearsed. As a rehearsed story they sometimes lacked some of the emotion that would be expected when recalling these experiences for the first time with a stranger.

As members of a network which is responsible for sharing carers' experiences and lobbying, it is possible that many of the members of this network, and hence my participants, would represent 'extreme' cases, whereby they will either have experiences which are 'very good' which they would like to express, or experiences which are 'very poor', creating a further potential sample bias. Previous work from Van der Steen and

colleagues found that families were more likely to participate in research if they had positive experiences to report (van der Steen et al., 2012a). However, the study from Van der Steen only used a retrospective sample of bereaved relatives, whilst the current study has used both a prospective and retrospective sample. Other studies have indicated that there may have been a selection bias towards those with negative experiences (Thuné-Boyle et al., 2013). However, within the current study both positive and negative experiences were reported.

Participants were recruited for this study by Dementia UK using email. This introduces an additional potential source of bias for the sample. This recruitment strategy restricts those who do not have access to the internet, and those who are not able to use a computer. This may have excluded older carers who could be less likely to have computer access. However, email was the suggested method to contact participants by Dementia UK, as most of their carers from their 'Uniting Carers' network had email addresses.

A further potential sample limitation is the possibility of participant recall and attention bias. This may be particularly true of the retrospective sample, as they may not remember with much clarity some experiences within their dementia journey. Although due to the emotional nature of the situation participants would be expected to have better recall; however, improved recall may relate to specific details, and could potentially miss other important contextual details (Christianson, 1992, Christianson and Loftus, 1987). Finally, we know, from Schwarz and Clore (1989) that emotion can affect our judgement, which may have been a confounding variable in the participant's

view of whether their relative received 'good' quality end of life care (Schwarz and Clore, 1989).

It is important to note that the time since death varied amongst the bereaved participants. Some were recently bereaved (but not less than three months), and some had been bereaved for up to ten years. This increases the variety in the sample and reduces potential overall memory recall bias.

As the findings section of this thesis divided 'good' quality end of life care for the person with dementia and 'good' quality end of life care for their carer, it is important to consider the reliability of carer's reports of the person with dementia's view. There is some evidence to show that carer reports do match that of the patients in some domains such as functional abilities; however, they also disagree in areas such as perceptions of pain, with carers over-estimating the amount of pain (McPherson and Addington-Hall, 2003). Higginson demonstrated that families were accurate in the retrospective recall of service provision (Higginson et al., 1994). Many of the findings in this thesis are discussing service provision and how symptoms were managed as opposed to medical symptoms. This would suggest that discussion in this thesis focussed on what Donabedian would term the processes and structures of care (Donabedian, 1966, Donabedian, 1988). Therefore, based on evidence from Higginson, the participants' reports in the current study appear valid.

Due to the nature of the topic of the research, recruitment of carers as participants was challenging. This is a distressing topic to discuss as it is covers dementia which is often stigmatised and end of life care and death, which are still seen by many as taboo. A

strength of this study is the number of participants recruited, with 47 participants and 46 interviews in total, which is large for a qualitative study. However, there was little variation in ethnicity, with the majority of participants being White British. Furthermore, there were no carers from same sex relationships, who may have had different experiences of care (McGovern, 2014).

A further strength of the sample was the numbers of male carers recruited. There are fewer male carers in the population than females (Robinson et al., 2014) and therefore an expectation that it would be difficult to recruit them; however this study successfully recruited and interviewed ten male carers. Although this number is small compared to the total sample of 47, this is a reasonable number given that men are underrepresented in the literature on caring in general, and even more so in dementia care (Mc Donnell and Ryan, 2011).

7.4.3   Method of analysis

Thematic analysis was used to analyse the interviews for the current study, and this was discussed in the methods chapter of this thesis, alternative methods of analysis appropriate for this data were also noted. Many of the discussions with participants were highly emotional, with many participants becoming upset in the course of the interview. They also demonstrated other emotions such as happiness and humour when reflecting on their dementia journey and caring experience. With a thematic analysis it can sometimes be difficult to emphasise these points. Thematic analysis generally focusses on the content of the data (for example what participants have said); however, it does not explore nuances of the data, such as the type of language participants use or how they have expressed what they have said. However, I have tried to allude to this during the discussion within the findings chapter.

In the next section I will discuss two alternative methods of analysis which were considered for this study: narrative analysis, and thematic framework analysis. I will describe their method of analysis, and the disadvantages of applying them to the data from the current study.

Narrative analysis

Narrative analysis is an approach of re-telling the story of the interviewee, making it into a readable format which is understandable to the reader (Reissman, 2008). Many opt for this method as narratives are the basic way that people make sense of the world. In particular it focusses on chronological order which makes it different from other forms of data analysis. The chronology will normally include the past, present and the future. In addition to the chronology the analysis may also develop themes to accompany it. The themes can be used to create the structure of the story. Attention should be taken to the language used, taking particular note of emotive language and expression of feelings.

Narrative analysis would have portrayed experiences of 'bad' or 'good' end of life care for people with dementia in a well-ordered and interesting format for the reader. However, it does not adequately answer the research question of this thesis, which is to highlight the aspects of 'good' or 'bad' quality end of life care. Narrative analysis is too descriptive and does not offer the level of analysis which was required for the current study. The findings are better shown in themes as opposed to a story of an experience, where a reader may become lost or confused. A narrative analysis would concentrate more on how the story/experience is being told; focusing on how the narrative is constructed. Due to the large number of interviews in this study, to describe each

interview in a narrative form would be too extensive and detailed. Only a selection of interviews could have been presented as a narrative in the thesis. This could potentially have meant placing too much emphasis on individual cases rather than collective experiences, and leading to the possibility that some participants' answers will not be discussed or considered.

Thematic Framework Analysis

Thematic Framework Analysis was developed in the 1980s by the National Centre for Social Research (Ritchie and Spencer, 1994), in an effort to help manage data which is unstructured and make the analysis process transparent allowing for external scrutiny. It is a matrix based analysis method which allows for a transparent approach to the analysis of the data and allow the researcher to move along the hierarchy of data analysis from raw data through to explanatory account. The method involves the development of a thematic framework which is applied systematically to all the data. The researcher summarises in their own words abstracts of the coded data in charts/matrices.

There have been some criticisms of the methodology which led to this method not being adopted for the analysis in this thesis. The Framework Approach is much more labour intensive than a thematic analysis. With this in mind, the amount of time spent on the data analysis could lead to a focus on the process of the data analysis as opposed to the outcome of the data analysis, which is the purpose of conducting the research. The Framework method takes a deductive approach to the data which does not match the aim of the study. The current study had an explorative aim, whilst the thematic Framework Approach is commonly used by health researchers when investigating

policy. Within policy research a clear set of aims and a direction for the research is agreed at the beginning of the research (Pope et al., 2006), in contrast to explorative research such as this study. The thematic Framework used in this method is developed from these aims and often the topic guide used by the researcher in the interviews is more structured. In contrast the topic guide used in this thesis was much less structured. For these reasons thematic framework analysis takes a more deductive approach and does not allow easily for the emergence of themes and concepts from the data. Therefore, Framework Analysis does not match my position of using a mix of both deductive and inductive processes, with an emphasis on inductive processes. Freedom of the interview and iteration of questions seemed important for the voice of the carer to come through in the results of the data.

The summarising of the data into charts and matrices is done quite soon in the process of Framework Analysis. This early approach moves away from and potentially loses sight of the raw data soon on in the analysis, reducing the voice of the participant in the results, which again goes against the exploratory aim of the current thesis.

7.4.4   Trustworthiness and rigour

Guba and Lincoln (1981) suggested four main areas of concern for thinking about the trustworthiness of findings; truth value, applicability, consistency, and neutrality (Guba and Lincoln, 1981).

In discussing the truth of the findings Guba and Lincoln are referring to the credibility of findings. The results of the current study have been presented at three separate workshops. The audiences of these workshops varied, including: carers, health and social care professionals, and researchers. This allowed for some form of member

checking, helping to ensure the credibility of the results (Barbour, 2001, Mays and Pope, 2000).

Applicability refers to what would be understood as the generalisability of findings, in quantitative research. However, with qualitative research the aim is not to generalise findings or aim for representativeness, instead the aim is for transferability of findings and reflect diversity in the population (Barbour, 2001). The findings within the current study will not be generalised to all, however, they will be transferable to other similar contexts and experiences. This study used purposive sampling to recruit a range of different carers and therefore although it was not seeking generalizability the recruitment process sought to maximise the range of experiences to explore and discuss.

Consistency has been defined as the dependability of findings, in other words how likely that the findings would be replicated by others. In quantitative research this would be referred to as reliability. This study took several measures to ensure that there was rigour within the methodology and findings. In particular, a strength of this study is the detailed methodology chapter within this thesis (Mays and Pope, 1995). It provides a detailed and clear explanation of the stages of research from recruitment through to data analysis. Details of recruitment and sampling with reference to breadth of the sample have been discussed previously. One of the main methods of ensuring rigour within this thesis was through the approach to analysis of the data. All interviews were recorded and transcribed verbatim using a professional transcriber. All transcripts were checked for errors whilst reading and listening to the original recording. As part of the analysis, some interviews (n =5) were independently coded by more than one researcher and checked against a code list, using an iterative approach. This independent coding

has been referred to by others as inter-rater reliability in quantitative research or multiple coding in qualitative research, used to enhance rigour in findings (Mays and Pope, 1995, Barbour, 2001). Throughout the period of coding and the development of themes there were several meetings among all members of the analysis team which again ensured rigour within the analysis phase (Mays and Pope, 1995).

Neutrality refers to the bias of the researcher on the data. It is well acknowledged within qualitative research that the researcher's own predispositions may influence the participants and hence the findings. In this thesis I have reflected on my experience of conducting the interviews and have outlined my theoretical stance within the methodology of this thesis. Furthermore, analysis was conducted within a team with peer debriefing to test interpretations and ideas, minimising researcher bias from any individual researcher.

7.5   Future research

This is one of the only studies within UK to explore the views of carers anticipating or reflecting upon the end of life for a person with dementia (Davies et al., 2014a). This study has identified several areas which are appropriate for future research. These include:

1. This study highlighted debate over the use of the term 'carer', supporting previous findings (Molyneaux et al., 2011). The ambiguity of this term and the role of a family member as a carer is in need of further exploration. This study suggests that the role is unclear and both the individual carer and professionals potentially do not understand the expectations and duties a carer has placed upon them. An exploration

of role demarcation may be required. In particular, carers within this study noted the need to act as a case manager on several occasions. Clarity is required on how much carers should be responsible for this and if not then who should be conducting this work.

2. An exploration of the channelling of anger about dementia through blaming professionals is required. This is an interpretation based on the quotations included in this thesis and impressions from the interviews. Future qualitative studies should investigate this in more depth.

3. Exploration of the effect of emotions on recall of memories, McPherson and Addington-Hall have suggested also that future work should measure the mood states and psychological health of carers to establish the effect this may have on the accuracy of recall of events (McPherson and Addington-Hall, 2003).

4. This thesis did not explore the impact of socio-demographic characteristics on being a carer; for example, the difference of caring as a son compared to that as a daughter, husband or wife. However, from the findings of this study further investigation of this may be warranted. As McDonnell and Ryan (2011) note, little is still known about male carers and even less of the son's role as a carer (Mc Donnell and Ryan, 2011).

5. Work is needed to establish how best to incorporate carer perspectives such as those in this study, in the development of new guidelines for end of life care for people with dementia. I am intending to study the inclusion of carers' views in future guidelines and tools as a development from this thesis, through an Alzheimer's Society grant (awarded October 2014).

7.6   Implications for policy and practice

7.6.1   Advance care planning

As discussed in chapter two and earlier in this chapter advance care planning is being encouraged for people with dementia as early as possible (Department of Health, 2008a, National Council for Palliative Care (NCPC), 2009). As Harrison-Dening and colleagues note, the threshold for decision making capacity means that meaningful planning needs to be done early in the course of dementia (Harrison-Dening et al., 2011). This current study supports this and argues that planning is important with families ready to do this. However, professionals who are responsible for care planning with the person with dementia and their family need to be aware that not everyone is able to do this. This study concurs with current recommendations that a tailored approach should be taken to planning (Department of Health, 2008a). Approaches to planning should incorporate different individuals' abilities to have difficult conversations and take the time the individuals' need to be able to have these conversations. This means it may not be appropriate to have these conversations within the first few months of diagnosis.

A tailored approach should also be used to include those details of identity and personhood which this study has identified. The care plan is not simply about medical treatment or religious faith/spiritual concerns; it is also about the individual preferences of the person with dementia. This means that when the person is no longer able to express themselves, the plan should provide adequate information for the professionals caring for the person with dementia. For example, this could be about the foods they like. More importantly, from the carers' perspective, it should give an overview of their biography. This may include their previous occupation, family role and even the way they used to dress. A care plan needs to be thought of as much more than a medical plan

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for care in the future. This study has shown that conversations about medical treatment were particularly difficult. To make this easier those professional engaged in planning should start with biography and the likes and dislikes of the individual, this may allow a natural progression into the more distressing topics of withdrawing/refusing treatment, for example. This was reflected in the approach taken in the interview style in this study, starting with life history and then moving on to end of life care topics.

Finally, this study has emphasised the importance of the dyad in approaches to care. It is worth encouraging discussion of both the needs of the carer and the person with dementia on separate occasions in the planning stages. These separate discussions may allow for care for the person with dementia and care for the family carer to be discussed separately. This may reduce the needs of the carer to dominate the care of the person with dementia, which this discussion cautions against. A separate discussion for carers may also make them feel more valued by the care professionals. This is discussed within the National End of Life Care Strategy with reference to carers' assessments (Department of Health, 2008a); however, this needs to be used in conjunction with the ACP for the person with dementia.

7.6.2   Carers as advocates for the person with dementia

Some of the participants in this study described their annoyance about being assumed to be and labelled as a 'carer'. They described how assumptions were placed upon them as they were now assumed to be the 'carer'. However, in discussing these assumptions they also described their 'caring' role. They often associated this as taking the role of 'advocate'. The use of the term 'advocate' instead of 'carer' removes the ambiguity around the role of the carer, which was described and discussed in research from O'Connor (2007).

The current study and the use of the term 'advocate' has highlighted the importance of remembering that the carer is often an integral part of the person with dementia's life. Professionals both in policy development and practice need to listen to their voice and encourage them to talk about what they think should happen at the end of life. This has implications for developing individual care plans which have been discussed and recommended in the aftermath of the LCP (Neuberger, 2013). However, as discussed in chapter two, definitions of what is meant by a care pathway or plan vary, and firm definition of this would be needed first (Samsi and Manthorpe, 2014). Furthermore, it also has implications for the development of future guidelines and recommendations such as the National Dementia Strategy which comes to an end in 2015 (Department of Health, 2009).

7.6.3   Admiral Nurses

The support from Admiral Nurses given to carers was described in this study by participants on several occasions. As the numbers of people with dementia continue to rise, so too will the number of family carers (Alzheimer's Society, 2014). This study has noted that carers need support as part of 'good' quality end of life care. To receive adequate support for these increasing numbers of carers there may need to be increasing numbers of Admiral Nurses or similar professionals. Therefore in addition to listening to the views and experiences of family carers as advocates, professionals, in particular commissioners need to be aware of carers' needs for support. Many participants in this study described how they did not have one available to them, but thought they would have found this helpful.

7.6.4 The call for 'specialist palliative care'

This study questions the speciality of end of life care for people with dementia. Many of the 'good' aspects of end of life care were basic elements of care, including pain management and paying attention to the individual and their needs. Sampson and the authors of the National Dementia Strategy have described poor access to specialist palliative care and hospices (Sampson, 2010, Department of Health, 2009). However, as Sampson suggests, these basic needs do not need to be fulfilled by a specialist palliative care team (Sampson et al., 2011a), although some individuals may require a specialist approach. Some people with dementia may have difficulties with swallowing which require specialist attention or some may have complex pain experiences. The findings in the current study suggest recommendations to tailor the care to the individual, assumptions should not be made that all people with dementia will have needs which require input from specialist palliative care teams.

7.6.5 EAPC recommendations for optimal palliative care

This thesis has built on the recommendations from the EAPC which has defined optimal palliative care for people with dementia, as discussed in chapter two (van der Steen et al., 2014). The current study supports the adoption of a palliative approach and the emphasis that specialist palliative care should be available for people with complex problems but is not required for all. I would agree with the EAPC that person-centred care is important, however, I would suggest this domain needs to be more specific and include issues found in this thesis such as the importance of clothing and appearance. However, the EAPC also suggests that planning for end of life should be begin as soon as possible and potentially as soon as a diagnosis is made. As discussed I would suggest a tailored approach as not all will be ready to discuss end of life care after diagnosis.

Finally, the EAPC have highlighted the importance of family carers in end of life care as found and emphasised in this thesis.

7.6.6 Conceptual model of quality of care

Many of the findings from this study fit those of the conceptual framework from Stewart et al. (1999) discussed in chapter one. The key features of quality end of life care described in this study fall within the structure and process aspects of care. This would support what Stewart and colleagues suggest using as indicators for good quality care. For example the themes 'compassion' and 'the importance of relationships between professionals and carers' found in this thesis fall within the category of interpersonal and communication style with patient and family in the framework. This study suggests the model from Stewart and colleagues is potentially an appropriate one to consider when identifying indicators for quality end of life care for people with dementia.

7.7 Conclusion

What are the features of 'good' and 'bad' quality end of life care for people with dementia from the perspective of family carers? This was the key question explored within this study. This study has made a substantial contribution to this field of research, by beginning to clarify some of the uncertainties behind this question. It has demonstrated the challenges of synthesising the views of carers. There was a strong variation in their views, not only shown in the interviews with participants but also in the review from chapter three, which is important to reflect in future policy and guidelines.

Many of the aspects of 'good' quality end of life care for people with dementia were what carers perceived to be basic elements of clinical, nursing, and social care. These included pain management and giving attention to the individual. The views of carers who felt that they were the experts suggested that they did not feel that care at the end of life needed to be complex. Many of them had not received specialist palliative care support and reflecting on their experiences, they did not feel they had required specialist palliative services. This raises questions about how to improve care for people with dementia at the end of life. Carers also often still associate palliative care with cancer and do not recognise its potential use as part of end of life care for people with dementia.

This study provided examples from carers' perspectives of 'poor' care and failings at times on the behalf of professionals. However, carers often see the failings and not the source of the problem. For example, in this chapter I have shown that carers often blamed 'poor' care on nursing, feeling that often nurses lacked compassion. Not surprisingly, carers did not delve into the details about why they believed there was a lack of compassion. The explanations of compassion fatigue and organisational pressures tentatively explored in this thesis, suggest that the high expectations carers place on professionals may be unattainable.

A common and often emotional consequence of dementia is that the individual no longer identifies those around them, including their family or carer. The current study found that this is not only restricted to the person with dementia. As the dementia progresses and the disease demonstrates its physical affects, families also begin to not recognise the individual.

Carers are exceptionally important in end of life care of people with dementia. Recognition of this importance is vital to maintain 'good' care and working relationships with all those involved in the care. The care is not just of the individual with dementia, but also the care of the carer. This thesis highlights the importance of the dyad.

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Appendix 1: Participant Information Sheet

Informed Consent

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title: **End of life care in Dementia – Lessons from Family Carers**

Name of Researchers: **Steve Iliffe and Nathan Davies**

This study has been approved by the UCL Research Ethics Committee (Project ID Number): **3344/001**

Thank you for your interest in taking part in the study. Before you agree to take part please ensure you have fully read the information sheet that will have been given to you by the researcher.

If you have any questions which have arisen from the information sheet or are unsure about any aspect of the research, please do not hesitate to ask the researcher before you decide whether to take part.

You will be given a copy of this consent form together with the information sheet for you to keep and refer to at any time.

Participant's Statement:

I   ………………………………… have read the notes written above and the
    Information Sheet, and understand what the study involves.

- understand that my participation is voluntary and if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.

Research Department of Primary Care and Population Health, University College London, Royal Free Campus, Rowland Hill Street, London, NW3 2PF

- consent to the recording of my personal information for the purposes of this research study.

- understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

- agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

- understand that my participation will be tape recorded and I consent to the use of this material as part of the project.

- agree to be contacted in the future by UCL researchers who would like to invite me to participate further in this study.

- understand that the information I have submitted will be published as a report and I will be sent a copy if I want one. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.

Participants Signature: …………………………   Date: ………………………….

Researchers Signature: …………………………   Date: ………………………….

1 copy for participant, 1 copy for researcher

Research Department of Primary Care and Population Health, University College London,
Royal Free Campus, Rowland Hill Street, London, NW3 2PF

APPENDIX 2: Information Sheet

Carers Information Sheet

You will be given a copy of this information sheet.

Title of Project: **End of Life Care in Dementia – Lessons from Family Carers**

This study has been approved by the UCL Research Ethics Committee (Project ID Number): **3344/001**

Name of researchers: **Nathan Davies and Steve Iliffe**

Work Address: **Research Department of Primary Care and Population Health, University College London, Royal Free Campus, Rowland Hill Street, London, NW3 2PF**

Contact Details: **020 7433 0060 ext. 34141**
                            Nathan.davies.10@ucl.ac.uk

We would like to invite you to participate in this research project.

We are currently studying family carers' experiences and expectations of end of life care for persons with dementia. This research is being carried out by University College London, as part of a European project in five countries.

We are keen to get a better understanding of how to improve end of life care for people with dementia, starting from the experiences of family carers. We hope that your experiences and expectations can help to improve palliative care for persons with dementia.

As part of the study we would like to interview you at a time that is most convenient for yourself. This would take no more than one hour. The interview will take place in your home or elsewhere if you prefer, and someone can accompany you if you wish. The interviews will be tape recorded, then transcribed and the tape destroyed after transcription. You will be given the opportunity to read the transcript and make comments if you wish to do so.

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All your answers during the interview will be kept strictly confidential. After completion of the study we are happy to provide you with a final report of the overall findings, if you would like to have one.

If you would like to take part we would ask you to contact the researcher Nathan Davies on the above contact details. We would then contact you to in order to arrange a time which is convenient for you for the interview.

Please discuss the information above with others if you wish. You can contact us on the above address and contact details to ask us if there is anything that is not clear or if you would like more information.

It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part you are still free to withdraw at any time before, during or after the interview and without giving a reason.

All data will be collected and stored in accordance with the Data Protection Act 1998.

Research Department of Primary Care and Population Health, University College London, Royal Free Campus, Rowland Hill Street, London, NW3 2PF

APPENDIX 3: TOPIC GUIDE

3.1 Initial topic guide

3.2 Final topic guide

Appendix 3.1: Initial Topic Guide

This is the topic guide that was initially used which is more detailed.

Carers Interview Topic Guide

Thank you for your time and agreeing to talk to me about end of life care for people with dementia. I work on a European project which is looking at ways to improve palliative care for people with dementia and cancer. My role is focussing on dementia and I think it is important to include the opinions of families in this process. Because of this I would like to learn about your experience of caring for someone with dementia and in particular I would like to focus on the quality of care.

1. *Narrative from the carer:*
    a. When did you start caring for X?
    b. What is your relationship to X?
    c. Would you call yourself a carer? What is your opinion about using the term 'carer'?
    d. Could you tell me a bit about your time caring for X?

2. *Understanding of Palliative Care and End of Life Care:*
    a. Can you tell me what you understand about End of Life Care/Palliative care?
    b. Would you think X is getting or needs end of life/palliative care?
    c. What are your views on EOLC?

Can provide below definitions if needed (use own words):

Palliative care is 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.

End of life care may be used synonymously with palliative care, end of life is understood as an extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of their illness.

In the end of life care strategy for example in England, end of life care is defined in terms of the last 12 months of life. It is becoming increasingly used within the UK as a

term to move away from the notion of palliative care being specialist and only for cancer patients.

3. *Opinion:* Tell me about the care X is receiving from others such as:

   a. GP

   b. Nursing staff

   c. Specialist teams – palliative care team, Community psychiatric team

   d. Home teams

   e. Care home

   f. Hospital

4. *Judge:* Can you tell me what led you to that opinion about the quality of care?

   a. What is it about it that makes it good/bad?

   b. What particular processes or things happen within the care home/home/hospital/hospice that make it good/bad?

   c. Can you think of a particular time or event that made you think... 'yes that's good quality care or not poor quality care'?

   d. How could it be improved?

   e. What things are important to you when you think about the care you would like X to receive?

   f. What would make you consider a care home? Or make others consider a care home if you would not consider a care home?

   g. If or when you were looking for a care home for your relative what where you looking for or

   h. What would you look for now with the experience you now have?

5. *Summary:* So bearing in mind what you have just said, could you say in one sentence what good/high quality of care is?

6. *Information:*

   a. What information have you received to date? (i.e. information about advance care planning, lasting power of attorney, nutrition, symptoms,

prognosis, mental capacity act 2005, guidance on helping people with decision making)

b. Has someone spoke to you about EOLC – this is what to expect, this is what we can provide?

c. How did you receive this information? (i.e. conversation with doctor or other medical professional, leaflet/booklet)

d. Where did this come from? (I.e. primary (GP, care home) or Secondary (hospital staff).

e. Was this enough information or would you have liked more – if so, what other information would you have liked to have received?

7. *Out of hours and emergency services:*

a. Have you or someone else had to call paramedics for x? If so what was the situation and what was the result of this (i.e. where they transferred to hospital or treated at home)?

b. Have there been any occasions where you have needed to access medication out of normal working hours? How did you find this?

c. Have you had any experience of out of hours nursing care or out of hours GP visits? If so how was this?

8. *Communication:*

a. How well do you think communication works within and between social services and health services?

b. How good (or bad) is communication between out of hours and day time/regular services?

c. How good (or bad) is the communication between yourself and the doctors/nurses/other professionals you see?

9. **Place of care:** This topic will discuss whether the patient moved between different settings, for example from home to hospital and the benefit and effects of this on both the carer and the patient?

a. Where would they like to die?

b. Where would you like them to die?

c. Have they spent time in hospital?

10. *Patients' wishes*:

    a. How well are/were X's wishes met?

    b. Are/were X's wishes clearly known to the health and social care teams?

    c. Was there or how much advanced care planning has happened? Is this care plan being followed?

    d. How do you think others plan for EOL?

11. **Pain management and treatment:**

    a. How well is X's pain managed?

    b. Would/how would you expect an infection to be treated? Antibiotics?

    c. How about bed sores?

12. **Positive aspects:** Are there any aspects we have not talked about that you have experienced and feel are good?

    a. What bits have you been particularly pleased/ impressed with for example?

    b. Can you think of a specific example or time?

13. **Negative aspects:** Are there any aspects that you have not been pleased with, that we have not yet talked about?

Finish with a summary of what you have got from the interview and thanking the interviewee for their time.

Appendix 3.2 Final topic guide

After using the initial topic guide it was decided this was too long and details and was

not required for the interviews. A shorter and less detailed topic guide was developed.

Carers Interview Topic Guide

1. *Narrative from the carer*: who are they caring for, where, how long?

2. *Understanding of Palliative Care and End of Life Care:* can give explanations if needed.

3. *Opinion:* GP, Nursing staff, *Specialist teams – palliative care teams*, Home teams, Care home, Hospital

4. *Judge:* Can you tell me what led you to that opinion about the quality of care?

5. How could it be **improved**?

6. What things are **important** to you when you think about the care you would like 'X' to receive?

7. What would make you or do you think make others **consider** a care home?

8. *Summary of journey so far/or had.*

9. *Information*

10. *Out of hours and emergency services*

11. *Communication*

12. **Place of care**

13. *Person with dementia wishes*

14. **Pain management and treatment**

15. **Comorbidities**

16. **Positive aspects**

17. **Negative aspects**

APPENDIX 4: Outputs from Study

4.1 Peer reviewed Publications

4.2 Conference Presentations

4.3 Blog Posts

4.1 Peer reviewed Publications

Articles

Davies, N. (2015). Talking with family carers about end of life care for people with dementia. *European Journal of Palliative Care, 22(1),* 6-8.

Davies, N., Maio, L., Rait, G., & Iliffe, S. (2014). Quality end of life care for dementia: What have family carers told us so far? A narrative synthesis. *Palliative medicine, 28(7),* 919-930.

Conference Abstracts

Davies, N., Maio, L., Rait, G., & Iliffe, S. (2014). Quality end of life care for dementia from a family perspective: A narrative review. *Palliative medicine, 28(6),* 746.

Davies, N., Maio, L., Rait, G., & Iliffe, S. (2014). The experience of living with and caring or someone with dementia at the end of their life. *Palliative medicine, 28(6),* 673.

Davies, N., Rait, G., & Iliffe, S. (2014). Is end of life care at home for people with dementia possible? Views of family carers. *BMJ Supportive and Palliative Care, 4(1), 110-110.*

4.2 Conference Presentations

Poster presentations

Davies, N., Maio, L., Rait, G., & Iliffe, S. (2014). Quality end of life care for dementia from a family perspective: A narrative review. 8th World Research Congress of the European Association for Palliative Care, Lleida 2014.

Davies, N., Maio, L., Rait, G., & Iliffe, S. (2014). The experience of living with and caring or someone with dementia at the end of their life. 8th World Research Congress of the European Association for Palliative Care, Lleida 2014.

Davies, N., Rait, G. & Iliffe, S. Is end of life care at home for people with dementia possible? Views of family carers. Marie Curie Annual Palliative Care Research Conference, RSM, London 2014.

Davies, N., Rait, G., & Iliffe, S. Family Carer Perspectives of Quality End of Life Care for Dementia. 13th World Congress of the European Association of Palliative Care, Prague 2013.

Oral presentations

Davies, N., Rait, G. & Iliffe, S. Quality end of life care for people with dementia: What can family carers tell us? Margaret Butterworth Care Home Forum, King's College London, 2014.

Davies, N., Rait, G. & Iliffe, S. Quality end of life care for someone with dementia: The families' voice. Admiral Nurse Forum, Dementia UK, Stratford Upon Avon, 2014.

Davies, N., Rait, G. & Iliffe, S. Quality end of life care for someone with dementia: The families' voice. Alzheimer's Society Research Conference, Nottingham, 2014.

Davies, N., Rait, G., & Iliffe, S. Interviewing about a taboo within a stigma. Society for Academic Primary Care (SAPC), Cambridge 2014.

Davies, N., Rait, G., & Iliffe, S. Interviewing about a taboo within a stigma. UCL Qualitative Research Conference, London 2013.

4.3 Blog Posts

Davies, N. "What do you want, sorry?" – talking about end of life care for people with dementia. European Association of Palliative Care (EAPC), July 2013.

Davies, N. Another transition in the NHS – another difficulty in recruiting people to take part in research? Social Care Workforce Research Unit (SCWRU), December 2013.

Davies, N. Can we really recruit family carers of people with dementia who have recently been diagnosed? INTERDEM, June 2014.