Dementia: What care do patients and informal carers need in the last year of life and time surrounding death?

An Exploratory Qualitative Study

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Doctor of Philosophy

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CONTENTS

Chapter 3: Methodology   *67*

Tables and figures:

ABSTRACT

Background: The incidence and prevalence of dementia is increasing in the UK as the aged population increases. It is currently high on the national agenda. The National Dementia Strategy for England and End of Life Strategy advocate both living and dying well with dementia. Recent media attention has resulted in greater public interest in what can be a debilitating, unpredictable condition affecting those around the person with dementia and not the sufferer alone. This is at a huge cost to the economy and predicted to increase. Research suggests this group receive different levels of care and treatment at end of life than those cognitively intact experiencing different life limiting illnesses. This study sought to explore needs of people with dementia and their informal carers in the last year of life and surrounding death.

Aims: The main aim of this study was to explore experiences of this group identifying their underlying needs at this time.

Methods: Qualitative methodology was used to explore these differences. Interviews informed by narrative were conducted with bereaved informal carers of people with dementia on one occasion to access their experiences and views. Field notes were kept by the researcher to supplement interpretation and analysis.

Analysis: Interviews were recorded digitally and transcribed fully by the researcher. Analysis was informed by the Grounded Theory approach.

Results: A total of 41 participants were interviewed. These were mainly siblings or spouse and came from a range of backgrounds ranging from 21-86years in age. Most participants were female (31), death occurred in various 24 hour care environments including district general hospitals, nursing and residential care homes (specialist EMI and non-specialist). A small number (4) experienced death within the family home. Five themes were derived from within the data, carers as experts; kindness; humanity and compassion in care; the hard work of caring; living and dying with dementia in the face of uncertainty and communicating in a world of chaos and unpredictability. The latter being the underpinning theme in the data. Informal carers want to collaborate and be included in all aspects of palliative and end of life care for their loved ones. Issues separating dementia from other life limiting illnesses and provision of palliative and end of life care are: disease course, uncertainty and unpredictability over long periods of time and the role of informal carers as experts with a group whose communication skills are compromised.

Discussion: If palliative and end of life care for this group is to mirror that currently provided for other terminal illnesses, the development of knowledge, confidence and communication skills amongst the workforce is crucial. In order to be successful, multi agency working, flexible and creative ways of delivering palliative and end of life care for this group are essential.

DECLARATION

This thesis is the result of my own work. Material contained in this thesis has not been presented, nor is currently being presented, either in part or wholly for any other degree qualification.

I was solely responsible for all data collection and analysis.

ACKNOWLEDGEMENTS

DEDICATION

This piece of work is dedicated to my wonderful father in law Iain Paton. Iain was a kind, generous, independent, strong and truly inspirational person. He was always so immensely proud of everything I had achieved on an academic and personal basis, including my running quests and crazy races and events I endured all because I could.

Iain was diagnosed with advanced prostate cancer as I embarked upon the PhD journey. On learning the topic of my study, he took great delight in referring to me as "Dr. Death", despite not having completed my period of study or being awarded the higher degree, a measure of his eternal optimism, great faith in my ability and for that I truly thank him, wherever he may be.

Sadly, Iain lost his battle with cancer in May 2011 after much suffering on an emotional and physical level as the wrath of cancer took hold and stripped him of all he was. He knew he would be unable to see the completed work but thankfully was aware of this dedication.

Rest in peace my lovely Iain, fondest memories always, much love,

Dr. Crowther

Chapter 1: Introduction

1.1 Background to Study

There has been increasing interest, attention and increased public profile of dementia generally over recent years. A possible contributing factor is increased media attention due to a number of high profile cases being openly reported, these include: Terry Pratchett, John Suchet, Fiona Phillips, Ronald Regan and George Melly. Dementia is now recognised as high priority nationally within governments in the United Kingdom. Publication and proposal of government directives and strategies across the UK focusing specifically on dementia and end of life across life limiting illnesses have also influenced the rise in attention and profile of the disease.

Dementia is a term used to describe a syndrome which may be caused by a number of illnesses. Within these there is a progressive decline in multiple areas of functioning including, declining memory, reasoning, communication skills and ability to carry out daily activities independently (DoH 2009). Individuals may also develop behavioural and psychological symptoms such as psychosis, depression, aggression and begin to walk about, seemingly aimlessly with no purpose, or engage in searching behaviour alongside cognitive symptoms described earlier. The latter non-cognitive symptoms, which may or may not occur at any stage of the illness, can cause problems themselves which further complicate care issues for all involved in care. Causes of these illnesses are not well understood to date but they all basically result in structural and chemical changes in the brain leading to death of brain tissue (DoH 2009). Most common types of dementia are: Alzheimer's disease, vascular dementia, mixtures of these two pathologies otherwise known as "mixed dementia" and more rare types including Lewy body dementia, dementia in Parkinson's disease and fronto-temporal dementia. They all share the same

devastating impact upon those affected and their informal carers. Dementia is no respecter of age, gender, ethnicity or social class. Whilst still predominantly a disease associated with older age there are approximately 15,000 people under the age of 65 years across the UK living and dying with dementia (DoH 2009). All adults of working age can be affected by the disease and people with learning disability are particularly at risk of developing a dementia. It is one of the most common, severe and devastating disorders faced by society today with prevalence and incidence predicted to rise as the global population increases. It can be the source of many ethical dilemmas (Nuffield Council on Bioethics 2009) as the disease progresses and people with dementia become increasingly reliant upon others to make decisions on their behalf and in their best interests.

Unveiling of the national dementia strategy for England (DoH 2009) catapulted dementia further into the spotlight. This is a comprehensive, visionary, ambitious five year plan with a budget of £150 million to be released to Primary Care Trusts over a two year period. It is estimated additional costs of implementing the strategy over a ten year period will be £1.889 billion although this does not include all potential costs. Further details of costs are due to be released later in 2011. It is anticipated implementation of the strategy is to be funded largely through efficiency savings re-directed to other areas i.e. reducing unnecessary use of acute hospital beds for people with dementia would enable more funds to be directed to development of services concentrating on earlier diagnosis and interventions. Implementation and success of this strategy remains to be seen. Since its introduction there has been a change in government with proposed changes for the health care system in the UK and disestablishment of Primary Care Trusts. Despite this there appears to be continued commitment to improving dementia care. Other parts of the UK (Wales,

Scotland and Northern Ireland) have unveiled similar proposals, plans and strategies in an attempt to manage predicted increase in numbers experiencing the disease and improve service delivery.

The main focus of all these plans and strategies is; "Living well with dementia". This includes improving early identification, assessment and diagnostic services, raising awareness and reducing stigma, improving care in hospitals and care home environments and educating the workforce. Maintaining well-being and affording people dignity and respect in care at all stages of the disease process are key elements of these directives. All focus on measurable outcomes for people with dementia and their informal carers and strive towards meeting challenges and objectives contained within them. These initiatives were all developed from a number of consultation exercises with key stakeholders including people with dementia and their carers. Interestingly, the National Dementia Action Plan for Wales (Welsh Assembly Government 2009) has at its heart development of communities actively engaging in dementia care and support whereas the other documents have a tendency to focus on provision of professional oriented services and care.

Minimal attention is paid within the strategies to dying with dementia. A criticism in early consultations of the draft dementia strategy for England (DoH 2009) was the omission of any objectives pertaining to end of life care. This resulted in one of the 17 objectives identified in the final document addressing this problem. It is envisaged the End of Life Strategy (DoH 2008) and the National End of Life Care Programme (DoH 2004), which encompass the full range of life limiting illnesses, including dementia would address any issues identified and encountered. As a result, any further details pertaining to end of life in the actual dementia strategy were not required. The dementia strategy (DoH 2009) pays particular attention to both living

and dying well with dementia, with emphasis being more on living well whilst the End of Life Care Strategy (DoH 2008) focuses on dying well across disease areas.

Along with increased attention and interest in dementia generally, the UK has also witnessed changes in relation to development and improvements in supportive, palliative and end of life care. Provision of this has also been the subject of media attention over recent years. Historically the focus of end of life care has been within the discipline of oncology. There is now acknowledgement other illnesses such as heart disease, chronic renal failure and dementia also limit life expectancy of those experiencing these. As a result more attention needs to be paid to developing services related to palliative and end of life care for these groups enabling them and those who care for them. The objective being to enable people to live as well as they can and have good quality of life until they die.

The End of Life Care Strategy (DoH 2008) built upon the National End of Life Programme outlining plans for improving provision of end of life care for people in England regardless of diagnosis. Central to the strategy is increase in availability of services in the community and development of skills amongst health and social care staff. A commitment to funding such proposals included the allocation of £286 million between 2009 and 2011. The National End of Life Programme (NHS 2004) supports implementation of the End of Life Care Strategy. It collaborates with health and social care staff who work in any capacity with those nearing or at end of life facilitating improvements in end of life care.

Also influential in end of life care was the Darzi report (DoH 2008). In this the necessity to provide greater dignity and respect at end of life was identified. Central to this was provision of 24 hour palliative and end of life services. This led to

requests for each Strategic Health Authority to produce vision documents for eight clinical pathways one of which was end of life care. As part of that process Primary Care Trusts were charged with planning processes to identify and allocate resources over a period of time to end of life care (Public Accounts Committee 2008-9). It remains to be seen how this will or may change in light of changed government and their plans for the NHS in general.

Unnecessary admissions into hospital at end of life and focus on facilitating care and dying in a persons' preferred place are key elements of the strategy and programme. Establishing preferred priority and place of care for those experiencing life limiting illness may be crucial to facilitating and contributing to a good death, although this may not always be achievable. Whilst many people express a wish to die within their own homes this does not always happen with up to 58% of people dying within a hospital environment (NAO 2008). Preferred place of care is an issue in itself that can create some confusion. Preferred place of care may not necessarily be preferred place of death for someone approaching death it is important to establish it there are any differences. Agar et al (2008) suggest two conversations are required in this respect in order to establish and record any differences. Brazil et al (2005) also identified differences amongst informal carers and care recipients as to what individuals wish for regarding places of care and death. They discovered care recipients expressed more desire to be cared for and die at home. Their informal carers however, felt they needed formal support and expressed preferences for care and death in hospitals and care homes. With regards to people with dementia and their informal carers this potentially makes having and recording these difficult conversations more urgent in earlier phases of the disease process to ensure people's wishes are carried out. The National End of Life Programme (2011) has

published guidance for professionals and formal carers in an attempt to guide them with this.

A number of documents and guidelines have been produced aimed at professional and formal carers advocating best practice regarding end of life care and treatments. These range from being generic to more focused on dementia. The General Medical Council (2010) published guidelines for medical practitioners to guide them with regards to end of life care. These include such emotive issues and topics as withdrawing and withholding treatments. This document is very specific about what constitutes treatment as end of life approaches. Frequently one of the ethical dilemmas faced in dementia as the disease progresses is the withholding and withdrawing of treatments, including nutrition. This can become an ethical issue for informal carers of people with dementia as death approaches resulting in emotive, uncomfortable choices having to be made at difficult times.

The Royal College of General Practitioners produced their own End of Life Care Strategy (2009) outlining how they would lead the way in defining, enabling and pioneering good practice in end of life care reflecting the crucial role they felt they played both now and in the future. More recently the Royal College of General Practitioners (2011) have in partnership with the Royal College of Nursing published an end of life charter for patients. This outlines all they (GP's) intend to do in an attempt to care for their patients to the best of their ability until the end of their lives, considering their patients wishes. It is anticipated this document will eventually be prominently placed in all GP practices for patients to see.

The National End of Life Care Programme (2010) released a framework targeting social care personnel. This framework advocates living and dying well across social

care and identifies specific targets and means by which to achieve this. These include integrated health and social care at end of life, commissioning strategies to support a good death, care and support planning, education of the workforce and improving experiences of service users and carers. This is a generic framework and not illness or diagnosis specific.

The National Institute for Clinical Excellence (2006) produced more specific guidelines pertaining to dementia care in general. Contained within this document is guidance on delivering supportive, palliative and end of life care to people with dementia. Informal carers and supporting them is also integral to this guidance. This guidance was amended in March (2011) in order to reflect changes in prescribing recommendations for treatments licensed specifically for dementia.

From a European perspective Bamford (2010) described the UK as being pacesetters across Europe regarding dementia care and strategies for its management. Within European plans diagnosis is again the main focus, beginning rather than end of the dementia journey being discussed and compared. The rate of this appears to range considerably between countries as such it is therefore difficult for many nations to know the scale of the challenge they face. Bamford (2010) also advocates caution in applying any one strategy or directive on dementia care across whole populations. France are now on their third dementia action plan as a result of not considering initially what influenced certain aspects of each plan they implemented. Bamford (2010) argues this illustrates need for policy makers and politicians to unpick the cultural, social systems, structures and norms that frame dementia. It should never be assumed features of one strategy are readily transferrable to other areas and countries for this very reason. This is possibly one reason why parts of the UK have chosen to develop and adopt their own strategies,

plans and directives. There may still be problems encountered in the multi cultural society of the UK. Increase in migration may also affect implementation and success of individual strategies as diversity of individual communities increase.

Within England the Carers Strategy (DoH 2008) outlines plans for supporting carers across a range of illnesses, contexts and situations. Acknowledging contributions unpaid informal carers make to society and the need to collaborate, develop partnerships and respect expert knowledge is integral to this. Payne et al's (2010) work was more focused and considered challenges faced by unpaid, non-professional, family carers in Europe across life limiting illnesses identifying challenges and priorities. They looked at contributions this group made to palliative and end of life care for people nearing death. They explained why their contributions are significant, vital to palliative and end of life care and identified limitations to continuing this long term.

Up to 500,000 people a year die in England following a period of life limiting illness such as cancer, heart disease and dementia (NAO 2008). Several organisations such as the National Council for Palliative Care, Alzheimer's Society and Alzheimer's Scotland, Help the Hospices have begun to undertake research specifically focused on end of life care and dementia. The UK has one of the best systems for provision of end of life care internationally performing well on issues related to obtaining pain relief and quality of support provided. However, there are still gaps in service provision, inequalities in end of life care and in particular for people with dementia and their informal carers.

All the above, how they are influencing dementia care at end of life will be referred to in the literature review and throughout this piece of work. These directives support need for research such as this exploring personal experience.

1.2 Developing the research question

Being mindful and having an awareness of recent policy and guideline developments regarding palliative and end of life care in general and pertaining to dementia, all helped develop and inform the research question. The need to extend these into life limiting illnesses other than cancer has been identified. Literature presented and discussed in chapter two supports the research question further. In this a gap in the literature was identified pertaining to qualitative methodologies in relation to palliative and end of life needs for people with dementia and their informal carers. Current literature mostly focuses on quantitative and mixed method approaches used to establish answers to research questions researchers felt needed answering, rather than approaching informal carers themselves in order to ascertain what they perceived and interpreted as their, needs, wants and wishes. There is little in the current literature prioritising the "voice" of informal carers of people with dementia in this specific topic area.

1.3 Aims and Objectives

In order to explore the research question, the following aims and objectives were identified:

   Aims:
- Explore and identify impact of experiences of caring for a person with dementia in last year of their life and time surrounding death

- Explore and identify needs as interpreted by informal carers themselves based upon these experiences

- Explore and establish any similarities/differences amongst the group in order to identify unmet needs and potential barriers to support at this time

Objectives:

- Explore literature on palliative and end of life care for this group and provide a description of current understanding of experiences

- Identify an appropriate methodology and sample to facilitate exploration of experiences of this group considering others that may influence this

- To communicate with informal carers supporting concept of inclusion not exclusion

- Propose a model based on the data that can be used to inform practice, policy and service development on local and national levels

- Critically review the study and identify further research areas and topics that will address the needs of others in a similar situation in the future

- Develop research skills and produce thesis for examination

1.4 Outline of thesis

Chapter two commences with definitions of dementia, its' stages, palliative care, supportive care, terminal and end of life care in general. This is provided in order to help set the context of this study and how these concepts relate to dementia and end of life. It then explores the literature considering the above aims in order to support the background to this study.

Chapters three and four describe and justify methodology and methods chosen that have been drawn upon and informed this study. Important areas of study design, framework for evaluating rigour and ethical considerations are all presented here.

Chapter five presents, explores and discusses results. It commences with demographic details of study participants and an introduction to them individually. This helps set the scene and individual contexts of participants, supporting greater understanding of situations and circumstances. Results are then presented and discussed as individual themes and sub themes, arising from the data. There were thirteen sub themes in total, indicating the complex nature of caring for someone with dementia in the last year of their life and time surrounding death.

Finally, in chapter six conduct of the research is critically reviewed using the framework identified. Strengths and limitations of this study are also discussed in relation to what they add to the literature. Findings are considered in light of the original research question and discussions from chapter five expanded upon and results related to models, theories and literature. This chapter concludes the thesis identifying and discussing the catalytic utility of this study in relation to clinical and policy implications. In addition to this areas for future research identified from this study are presented and discussed.

Chapter 2: Literature review

2.1. Introduction

The impact a diagnosis of dementia can have on people with the disease and their informal carers has received an increasing amount of attention in recent years and has been addressed in the preceding chapter. In order to understand the context of the study it is necessary to outline what is meant by some of the terms found in the literature including dementia and its' stages, palliative care, supportive care, end of life care, terminal illness and terminal care. The strategy employed for search and review of the literature will be presented initially followed by a general description of the above terms. Following on from this a review of literature to date in relation to dementia and palliative, supportive and end of life care will be presented. Communication and communicating in a world of chaos is the underpinning theme within the data. Due to this the researcher felt it was necessary to re-visit literature on communication, this has also been included in this chapter.

2.2. Literature Search

The study has been informed by grounded theory methodology (Glaser & Strauss 1967, Charmaz 2006). This methodology has not been applied in this study in the purist sense, the exact approach and rational are outlined in the methodology and methods chapters. The literature review and point at which this is undertaken in grounded theory has long been disputed and misunderstood (Charmaz 2006). Disputes and debates range from delaying it until after analysis, thus avoiding development of what is often referred to as "received theory", to taking a critical stance towards earlier theories prior to commencement of data collection. The latter enabling discovery of how characteristics are lived and understood in the real world, not as given in text books and papers (Charmaz 2006).

Considering the aims and objectives of the study, background of the researcher and ethical approval required it was considered appropriate to conduct a literature review prior to commencement of data collection and at other points as the study progressed.

Electronic databases were searched using combinations of key terms relevant to the study. An example from the search strategy, terms used with one of these (Medline) are in table 1 below.

Table 1: Example from search strategy

Searches	Terms used on Medline	Results	Type of search
1	Informal carers	105421	Advanced
2	Formal carers *or* paid carers	216031	"
3	Family carers	17566	"
4	Caregivers	204321	"
5	Palliative care	5013546	"
6	Terminal illness	4821369	"
7	End of life care	3611029	"
8	Long term conditions	224709	"
9	Advanced dementia	215509	"
10	Dementia	2293167	"
11	Pain	6239910	"
12	Nursing care *and* dementia	3023506	"
13	Hospital care *and* dementia	4112416	"
14	Supportive care	6324664	"
15	3 *and* 9	209	"
16	5 *and* 9	112	"
17	9 *and* 10 and 11	321	"
18	3 *and* 5 *not* cancer	102	"
19	3 *and* 9 *and* 10	341	"
20	3 *and* 5 *and* 9	256	"
21	3 *and* 5 *and* 7 *not* cancer	325	"
22	5 *and* 7 *and* 14 *not* cancer	203	"

Other data bases searched using the same terms included: Psychinfo, CINHAL, Cochrane Database of Systematic Reviews (CDSR) NHS Library, Scopus and PubMed. Similar results and duplications were found in most of these. Table 1

demonstrates how one search yielded an unmanageable amount of literature. Boolean operators such as "and" "not" and "or" facilitated a reduction in these. Initially, abstracts from these were located and read. Decisions regarding inclusion, exclusion and quality assessments were made based upon relevance to this study and the following guidelines:

- Did articles describe important clinical problem addressed via a clearly formulated question?

- Was appropriate methodological approach used?

- How were setting and subjects selected?

- Researcher's perspective and whether taken into account?

- Data collection methods, descriptions of these and detail.

- Analytical methods used, measures for quality control and whether implemented.

- Credibility and clinical significance of results.

- Conclusions drawn, whether justifiable by results?

- Transferability of findings to clinical settings.

    (Greenhalgh 2001)

The search commenced prior to data collection, November 2008 - February 2009. Literature was re-visited at intervals throughout the research process as data analysis progressed. A final search and review of literature was conducted on completion of data collection, October 2010 to May 2011. In addition government, related documents and reports from the Department of Health were identified and obtained from the internet. Charitable organisations such as Alzheimer's Society and Aged UK that host websites were searched. The search engine Google was used on occasions to access lay information including information accessible to patients and

carers. Alerts were activated, Pro-Quest, (Nursing and Allied Health Source) using the terms "dementia and palliative care". A "snowballing" approach was employed to collect other source material. This included using a series of other contacts including universities, libraries and references from key articles and books. References were also obtained from colleagues and student peers working in a similar area and during conference attendance. As identified in an earlier chapter, dementia is a national priority for the coalition government it is widely covered in the media at present which was another source of information and material.

2.3 Dementia

Dementia has been described in chapter one. It is progressive in nature meaning symptoms will gradually get worse. How fast dementia progresses is dependent upon several influencing factors including type of dementia a person has. Every one experiences the illness in different ways.

Common types of dementia include: Alzheimer's Disease, vascular dementia, fronto temporal dementia and dementia with Lewy Bodies. Rarer types of dementia include: progressive supranuclear palsy, posteria cortical atrophy, HIV/AIDS related, Korsakoff's syndrome, Binswangers disease and Creutdfeldt Jakob disease (CJD). Some people with motor neurone disease, multiple sclerosis, Parkinson's and Huntington's disease may also develop dementia as the disease progresses.

There are three identifiable stages/phases.

Stage 1: Mild dementia: the person will be aware of some of the problems
they are encountering, mostly related to poor short term memory. Others
around and close to them will be aware of some of their difficulties.
Reluctance to seek help and covering up of problems, where possible

may be evident. Activities of daily living are maintained.

Stage 2: Moderate dementia: difficulties with short term memory worsening, problem solving and planning difficult, recognition of people may be an issue, communication may be impaired, increasing reliance upon others for support with activities of daily living and safety. Transfer into 24 hour care may occur at this phase depending upon level of support required.

Stage 3: Advanced or terminal phase: person is totally dependent upon others for all activities of daily living. Characterised by minimal verbalisations, significant weight loss, swallowing difficulties, inability to ambulate or sit without assistance, the person is prone to multiple secondary infections i.e. urinary tract infections and pneumonia.

2.4. Palliative care

Historically the palliative care model and services were initially developed and provided to support cancer patients as they approached death. It was founded by Dame Cicely Saunders in 1967 and introduced into the hospice movement at that time. From then onwards the hospice movement has grown immensely internationally and hospices are the most public manifestation of palliative care. Palliative care is care that improves quality of life of patients and their families facing life-threatening illness. Particular attention is given to prevention, assessment, and treatment of pain and other symptoms, and to provision of psychological, emotional and spiritual support.

There appears to be no single agreed definition of palliative care. The World Health Organisation defines it as follows:

"*The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount*" (WHO 1990)

The Department of Health (2003) offers a more lengthy definition stating:

Palliative care is holistic care by multi-professional teams for people, their families and carers whose illness may no longer be curable. It enables them to achieve the best quality of life during the final stages of their illness. The care may be provided in a number of settings, at home (with support from specialist staff), in a hospice or palliative care unit, the hospital or at a hospice day centre. Services provided include family support and bereavement services. Palliative care was first developed in the UK by the voluntary hospice movement but is increasingly being provided within NHS hospitals and palliative care centres in the community. It is now a recognised and integral part of health service provision and the principles and practice apply equally across all conditions and in all care settings.

Whichever definition one alludes to, it is clear palliative care is not only intended for the person with a life limiting illness, but also for families of such people and others who may be close to them. It is guided by the following set of principles:

- Affirmation of life and regard for death as a normal process so that death should never be hastened nor postponed.

- Provides relief from distressing symptoms

- Integrates the physical, psychological, social and spiritual aspects of care

- Offers support to dying people enabling them to lives as actively as possible until death.

- Offers support to families coping with the person's illness and their bereavement. (Hughes et al 2000)

It can be said palliative care forms a spectrum (Addington-Hall 1998). At one end lies palliative care supportive in nature which makes use of the principles outlined above whilst the other end of the spectrum specialist palliative care focuses on more complex cases. Between these two lies palliative interventions including, radiotherapy, chemotherapy and surgical techniques which are normally delivered by health care professionals other than palliative care specialists.

2.5. Supportive care

Supportive care is another term similar to palliative care which has a number of different definitions. The working definition suggested by the National Council for Hospice and Specialist Palliative Care Services (2002) is cancer focused. Despite this it is applicable across a wide range illnesses and is provision of multi-disciplinary holistic care to patients with serious and life limiting illnesses and their families. It can begin around time of diagnosis and continues through treatments aimed at cure or prolonging life and into the phase acknowledged as palliative care. It can be defined as care given to improve quality of life of patients and their families who have serious or life limiting illness. The goal of supportive care is to treat as early as possible symptoms of a disease, side effects caused by treatment of a disease and any psychological, social and spiritual problems related to a disease and its treatment (Karabos 2009). Supportive care is not a distinct speciality it is the responsibility of all health and social care professionals delivering care. It requires a broad spectrum of competence ranging from foundations skills to highly specific expertise and experience. Sensitive and open communication is fundamental alongside good co-ordination within and between organisations that will facilitate a smooth progression between services for patients and their carers.

The above definitions of palliative and supportive care present us with our first conundrum in relation to dementia. If palliative care is defined in a narrow way, being only about pain and other symptom control, then supportive care may include palliative care as well as a range of other care that could be provided to "support" a person with a life threatening disease and their family. However, if palliative care is defined in a wide ranging way, then it may be described as being in two parts, one part being about pain and other symptom control, the other part being supportive care. Secondly, in relation to palliative care and dementia one could ask the question, when does palliative care commence in dementia? Symptoms are apparent from onset of the disease and are usually the rational for seeking help/attention. Frequently these will require a clear management strategy for a long indefinite period of time, is this then supportive or palliative care?

Hughes et al (2010) recommend the model of supportive care for people with dementia for a variety of reasons. Including its roots being strongly embedded in palliative care and compatibility of the supportive and person centred care models. The person centred model (Kittwood 1997) has informed thinking and practice in dementia for a number of years and is strongly associated with and recommended in the care of people with dementia and their families.

2.6. End of life care

End of life care is an important part of palliative care, and usually refers to the care of a person during the last part of their life, from the point at which it has become clear the person is in a progressive state of decline (Watson et al 2005). End of life care is usually a longer period than the time during which someone is considered to be "dying". In the UK it is mainly health care professionals who use the term end of life

care. Patients and families are more likely to refer to terminal illness and terminal care. The time at the end of life is different for each person, and each person has unique needs for information, support and for care.

2.7. Terminal Illness & Terminal Care

Terminal care is care provided for a patient in the terminal, or end phase of their life. But how do you know when this end phase has been reached?

In the same way there are many different definitions of palliative and supportive care, there are also many different definitions of terminal care. Some people define terminal care in the same way as the definition of end of life care given above, so effectively they consider it another name for end of life care. In the UK many patients and families will refer to someone being terminally ill when they regard them, and indeed they may have, many months or even years to live.

Alternatively, terminal care is sometimes defined as care provided for someone who is "dying". But how do we know when someone is dying? Some people take the view everyone effectively starts to die from the day they are born. The reality of course is, it is never known exactly when someone is going to die from a life-threatening disease and prognostication is very difficult. Taking this approach of equating terminal care with "dying", some medical organisations define someone as being terminally ill when it is expected there is only a short period of time, perhaps a few days or weeks, or at most a month or two, before the person is expected to die. Finally, some define being terminally as when they have reached a certain medical condition which is usually specific to the disease they have.

2.8. The literature

As demonstrated above, the definition of palliative care and other terms outlined is provision of holistic care and support to people with life limiting illnesses and their families. Although dementia is clearly one such illness (Wolf-klein et al 2007) and can be argued is comparable to incurable meta-static cancer or end stage heart failure, (Tonks 2009) historically palliative care has not addressed the needs of people with dementia and their carers.

There is general consensus in the literature supportive and palliative care services should be delivered, as far as possible, where patients and carers want them including in the home, care home, hospice or hospital. Patients, their families and other carers should play a central role in deciding where and how this should be. Hughes et al (2005) advocate provision of this for people with dementia and their carers via specialised units with outreach and liaison services integral to this service. Lloyd-Williams et al (2005) suggested is was time palliative care services look beyond cancer care in order re-dress the balance and in an attempt to meet the needs of people with dementia and their carers that are often overlooked.

Although some areas have excellent levels of care, treatment and support for people with dementia and their families as death approaches, generally it is believed to be poor and suboptimal than that provided to those cognitively intact. In advanced stages of the disease, people with dementia are often transferred to acute hospital settings with episodes of acute illness where they may undergo burdensome and often aggressive interventions whilst receiving totally inadequate care for their cognitive and functional problems, the consequences of such resulting in problems with delirium, anxiety, constipation, and pressure sores (Hertogh 2006). Mitchel et al

(2007) suggest society's attitudes need to change in general in relation to dementia and dementia care. This is supported by the dementia strategy (DoH 2009) with specific objectives pertaining to raising public awareness of the dementias and the kinds of issues involved including those at end of life.

As noted earlier, the impact a diagnosis of dementia can have upon the person with dementia and their informal carers has received an increasing amount of attention over time. Elements of this have focused on economic impact faced by a nation with a predicted increase in the incidence and prevalence of dementia (DoH 2009). There is also a wealth of literature on psychological impact of such a diagnosis, again, for both the person with dementia and their informal carers (Takano, Arai 2005, McDaid, Sassi 2001, Charlesworth 2001, Donaldson et al 1998). Dartington (2008) wrote a personal account of caring for his wife who had dementia until her death at home describing the whole journey and problems they encountered to the end.

The use and application of the Mental Capacity Act (DoH 2005) in relation to people with dementia and their carers, across the disease trajectory, not solely pertaining to end of life, is evident in the literature. This Act was implemented in England and Wales and is enshrined in statue common law and best practice principles. Scotland has its own mental capacity legislation which has been in force since 2000. These acts outline key principles, procedures and safeguards for vulnerable groups including those with dementia and their carers. One of the principles of this act enables people with dementia and their informal carers to make decisions about health care and treatments in a formal capacity. It allows people to specify care they want and treatments they do and do not wish to receive in certain circumstances. To supplement the act, Hutchinson & Foster's (2008) work, commissioned by the Social Care Institute for Excellence, produced further practical guidance on best interests at

end of life with a particular focus on decision making and care planning as death approaches.

For those who lack capacity to make their own decisions, including people with dementia, who do not have a surrogate carer to act in their best interests, a review of the act (DoH 2007) saw the recommendation and implementation of the Independent Mental Capacity Advocate (IMCA) in England and Wales. This person acts as advocate regarding making choices in the best interests of the person with dementia in the absence of any other identified person able to do this.

Those who may loose capacity can document and record their choices and preferences for health and welfare in the form of Advanced Care Plans and Advanced Decisions to Refuse Treatments. These issues are also addressed in the literature review.

Personal stories and narratives of individual journeys through dementia (Davies 1989, Sterin 2002, Holst & Halblberg 2003, Cheston et al 2004, Cottrell & Hooker 2005) also feature in the literature. These are increasing in numbers as the profile of dementia is raised in the hope stigma attached will be acknowledged and reduced.

2.8.1. Life expectancy and dementia

One of the many challenges faced in dementia care is prediction of life expectancy once a diagnosis is finally made. It is extremely difficult to predict how long someone will survive with dementia as there are many variables influencing this for example age, physical health, gender, socio-economic status and environment (specific details on the length of time people with dementia lived after diagnosis in this study

sample can be found in table 5 (chapter 5). It is even more problematic to predict when someone starts dying with dementia and stops living with it. Shuster (2000) suggest the end stage of dementia may in some cases last as long as two to three years.

Life expectancy is increasing globally as a consequence numbers of people affected by dementia is estimated to double every twenty years (Hertogh 2006). In order to accurately predict economic cost to health, social systems and society in general our understanding of causes, course and consequence are of key importance (Jing et al 2008). A frequently raised question in clinical settings is the impact of dementia upon life expectancy. This is harder to answer and predict than it is for other life limiting illnesses. People with dementia have markedly decreased survival rates than those cognitively intact (Waring et al 2005, Fitzpatrick et al 2005, Freels et al 2002) and are two to four times more likely to die at any given age than those without dementia (Guehne et al 2006, Dewey & Saz 2001). There have been numerous studies, (Fitzpatrick et al 2005, Dewey & Saz 2001, Knopman et al 2003) including cohort and case series in various settings investigating the median survival time of people with dementia, they estimate this to be between three and nine years from the time of diagnosis. Factors associated with variation in times of survival include age, sex, socio-demographic characteristics, initial severity of dementia, type of dementia, existing co-morbid conditions and genetic characteristics.

With regards to exploring life expectancy for this group, Jing et al (2008) conducted a large multi centre, longitudinal, prospective population based epidemiological study of cognitive function and disability in the UK. Participants were subjected to a range of assessments, interviewed and re-interviewed over a 10 year period and followed up for mortality at 14 years. This study concluded among those who had died at 14

year follow up period (81%) females were likely to live longer. The estimated survival time after estimated onset of dementia was 4.6 years for women and 4.1 for men. Survival was influenced by age, sex and level of disability prior to onset. Accommodation, marital status and self reported health were not associated with survival in this study. An estimated survival after onset of dementia may be a useful measure for individuals, families and society especially when faced with having to provide some sense of how long a person with dementia may survive. This kind of information would also contribute to prediction of potential economic costs in relation to formal care provision. However, there is often a delay in recognition and formal diagnosis of dementia which clinician's need to be aware of when using best estimates in individual cases. This study's findings may be limited as exact timing of onset of dementia was unknown an estimate was used as midpoint between interviews. As a result participants who died rapidly after onset were not diagnosed and could therefore not be included in the final survival analysis. This could have led to an over estimate of survival times. Individuals who dropped out or refused follow up during the study are reported to have impaired cognitive ability and higher mortality. Some of the study's findings seemed self evident but could be useful when considering survival times for people with dementia and thinking about when someone may be likely to start dying from dementia in terms of time.

2.8.2. Palliative care and dementia

Predicting life expectancy in people with dementia presents us with challenges on different levels. We are all individuals and as such experiences of the disease process and variables influencing the outcome are different and unique. Two thirds of all people with a diagnosis of dementia in the UK reside at home. A third resides in care homes and two thirds of all those in care homes have some form and degree of

dementia (DoH 2009). A large number of people with dementia will end their lives in 24 hour care environments, this maybe nursing/residential care homes or acute wards in district general hospitals. It is not surprising much of the research to date on palliative, supportive and end of life care for this group has been undertaken within this type of environment.

Powers & Watson (2008) conducted a mixed methods study exploring meaning and practice of practice of palliative care for nursing home residents experiencing dementia who were approaching end of life. This random sample was recruited over a one year period from three nursing homes in America. Inclusion criteria included a diagnosis of dementia and residency of at least one year. The quantitative element of the project collected data on symptoms, trajectories and life prolonging treatments. The qualitative element focused on interviews and observations of care staff and families of residents. Content analysis was used to derive themes from qualitative data. The focus was on last year of life in nursing homes and experiences of this. It concluded, as there is no precise definition of end of life and various definitions of palliative care, this further compounded difficulty experienced in predicting end of life and initiating palliative care for this group. Discrepancies were uncovered between what professionals and public perceive as palliative care. These perceptions were affected by experiences of the relentless and unforgiving nature of dementia related diseases characterised by a long course and uncertain trajectories. Prognostic indicators of when life will end being less pronounced than for other life limiting diseases. The residents' course fluctuated between curative and comfort care, a notable increase in symptoms occurred just before death and most died from complications relating to dementia. Families found care decisions difficult as a result of the uncertain disease course. Due to imprecise definitions of palliative and end of

life care discussed earlier, this study advocates palliative care is what should be offered to residents admitted to nursing home environments from admission onwards. This should not be a model of care introduced as an alternative approach to care when the person is in a precipitous state of decline from which they are not expected to recover. Mahon & Sorrell (2008) counter argue this advocating palliative care should commence from the outset for people with dementia and not just applied at end of life as has been the tradition in cancer care.

Differing definitions of end of life and palliative care are again highlighted by Mahon & Sorrel (2008) as one of the problems in this area. End of life being defined by the Hospice movement as the last six months in cancer care. They advocate inclusion of people with dementia and their carers in end of life discussions from diagnosis enabling the person with dementia to be included. This raises the issue of ethics in palliative care with people with dementia, the usual medical ethics being hard to apply as a result of cognitive impairments and capacity issues. If the person with dementia is included in these discussions from an early point in the disease process they and their carers can define what is morally and ethically right for them in their circumstances. Mahon & Sorrel (2008) conclude access to end of life care for people with dementia is problematic and will continue to be so whilst there is little agreement as to what constitutes this time frame or period.

The Liverpool Care Pathway (Ellershaw et al 2003) is another tool advocated by different organisations (DoH 2008, NICE 2004) to support end of life care. It consists of a set of documents that support the process of identifying needs in the last days or hours of life. It is implemented by formal carers when they are reasonably certain this time has arrived or is approaching. The documents include an information leaflet

about the pathway for informal carers of those who maybe subject to its' implementation as end of life approaches.

The LCP has been the subject of controversy in recent years and source of criticism within the media (Irvine et al 2009, Warner 2009). This appears to be as a result of misunderstandings and inappropriate use of the pathway. This aroused a great deal of concern, fear and anxiety it may be a way of introducing euthanasia via the back door (Warner 2009). Since its' inception this tool has been developed over the years. Following controversy and criticism which arose, version 12 (Marie Curie Cancer Institute 2009) has been produced. This version now has safeguards built into regarding frequent, regular review and re-assessment hopefully reducing the risk of people being placed on the pathway without review, thus remaining on it for longer than was originally intended.

As with all tools and assessments, the above are only as good as those charged with the responsibility of implementing them. They require well developed communication skills, knowledge and training including regular updates on changes or any issues identified with their use.

When considering the disease trajectory of dementia and how we might predict death approaching, prognostic indicators, discussed in chapters one and six, that are an integral part of the Gold Standards Framework, as outlined in the End of Life Strategy (DoH 2008), include ones applicable to dementia. These highlight specific symptoms one may observe that could indicate the person with dementia is nearing end of life. These can then be used to implement end of life care plans and good quality care that would hopefully, support a good death. Birch and Stokoe (2010) described dementia as having three stages. They suggest various symptoms occur

at different stages in the disease trajectory. During the last stage, if clinicians are knowledgeable about symptoms to be alert for, the prognostic indicators in the GSF (DoH 2008) are easier to consider and apply hopefully resulting in improved end of life care.

Ashton et al (2009) undertook an evaluation in the North West of England exploring whether these two initiatives (GSF, LCP) were applicable and relevant to people with advanced dementia nearing the end of their lives in 24 hour care environments. Four care homes and one NHS mental health ward were included in the evaluation. They all adopted the Gold Standards Framework and Liverpool Care pathway as models of care for the person with advanced dementia nearing the end of their life. This was a mixed methods study utilising focus groups, survey and semi-structured interviews. The survey element of the project consisted of online and postal questionnaires and included the multi-disciplinary team, care staff and GP's from care environments included in the project. Family members of people with dementia who had died in the care settings were also interviewed. This study concluded confidence increased for care staff in working with people with dementia at the end of their lives following training in use of the tools. The numbers of inappropriate admissions to hospital for this group as the end of their life approached also decreased. It is suggested this was mainly as a result of training in using these tools which resulted in increased confidence of care staff. This led to reduced emergency calls to Primary Care and out of hours services which often resulted in hospital admission being the outcome, all be it inappropriately. This was a small scale evaluation and there is no information available about how or why individual environments were selected. Larger scale projects are required to establish whether or not these initiatives are of true value to this group of people and their carers. Sustainability of benefits reported need to be

studied and monitored in these environments which would support continued use and extension of the models with this group. The Hawthorne (Franke, Kaul 1978) effect is also something to be aware of when considering sustainability. This is the beneficial effect of an interview or other encounter and can occur during the course of a research project. This effect cannot be attributed to content of the interview or result of any specific act or treatment but is the result of indefinable personal factors present in the interaction (Mosby 2009). It is suggested paying attention to and measuring output results in changes in subjects behaviours that are primarily caused by an awareness of being studied. Chiea and Hobbs (2006) reject this claim purporting the Hawthorne effect has no useful place in discussion of research findings as there are so many other variables influencing outcomes. They go on further to criticise the Hawthorne effect as a term coined over 50 years ago based on work two decades prior to this. As such, they suggest it has been discounted and original experiments this term was based on out dated and of little relevance in the current research arena. Despite this, there still needs to be monitoring of sustainability and continued use of such initiatives as the Liverpool Care Pathway and the Gold Standards Framework in a range of care environments and illnesses.

One of the objectives of the Dementia Strategy (DoH 2009) is to reduce inappropriate hospital admission for this group. Efficiency savings are required to fund these proposals. Results of this project would indicate use of these models of end of life care and training in these would support this. However, further work is required to establish the exact economic benefit and any efficiency savings incurred and sustained as a result of implementing the models.

Seven family members were approached in this study to be interviewed about their experiences of end of life care in the establishments included. Four of these agreed,

there is no information or details about why three declined. All family carers interviewed reported positive experiences and outcomes for their relatives including a pain free death and dying in their "home" (the care setting) where people knew them. This was an interesting result as the literature would suggest people with advanced dementia often have pain unrecognised and untreated primarily due to communication issues and being unable to communicate their needs (Buffum et al 2007). Reynolds et al (2008) purport pain in cognitively impaired nursing home residents is under recognised. As a result pain relief for this group is prescribed on an as required basis when regular medications would be more appropriate. This North West of England study was on a small scale and as identified, further work is needed. It is difficult to draw any conclusions from this work and caution should be exercised in making generalisations about results, in particular the carer interviews as this was a very small sample.

As noted earlier, palliative care has been historically linked with cancer and cancer care. There is limited understanding of symptoms and care in last few months of life for adults dying from causes other than cancer (Burt et al 2010, Sampson et al 2005). Currently there is a focus on applying this model and provision of this kind of service to a wider range of life limiting illnesses including neurological conditions such as dementia, heart failure and chronic renal failure.

Burt et al (2010) undertook a study in England amongst community dwelling older adults dying from cancer and non-cancer (organ failure and dementia) diagnosis comparing differences in last three months of life. This was a two phase retrospective cross-sectional postal survey of bereaved relatives (n=3,040). It formed part of the national evaluation in England of a Department of Health led palliative care education programme for district and community nurses. Data was collected

before and after launch of the programme. They report no statistical differences between phases and data was therefore combined for the report. Response rate to questionnaires was low across the two phases combined this was 1266 (41.6%). They associated response rate with informants gender (males were less likely to respond than females) and relationship to the deceased. Highest response rate came from sons and daughters compared to spouses/partners, other relatives and friends. Variations in response rate were also observed according to age of deceased and may reflect different informant/decedent relationship patterns across decedent age bands. Analysis and data presented excluded people who remained in a nursing home or in hospital in the last three months of life and there is no explanation of this. This study concluded there are important differences in experiences of older adults dying from cancer and non-cancer causes in the last months of life independent of age. Variations in symptom incidence, treatment received and quality of care suggest, whilst cancer patients may have a higher symptom burden, non-cancer patients are less likely to receive effective symptom control. Non-cancer patients were less likely to receive care from specialist palliative care teams reflecting the historic focus of specialist palliative care on advanced cancer. This is an issue that, as identified earlier, is currently being addressed. Non-cancer patients were also less likely to receive input from district nurses. This could be accounted for in terms of differences in symptom experiences. However, there was a disparity in satisfaction with quality of district nursing service which cannot be attributed to this. Participants caring for non-cancer patients appeared to be less likely to feel fully supported and informed and less likely to have found looking after their loved one rewarding. Burt et al (2010) suggest an overall picture emerged of cancer patients receiving more health and social care services in the last three

months of life and of these services being more satisfactory from perspectives of carers. This was a large population based survey with a low response rate to questionnaires. The questionnaire used, Voices of Informal Carers – Evaluation of Services (VOICES, Addington-Hall et al 1998) is a large multi faceted questionnaire used mainly in studies evaluating satisfaction and focusing on policy and service improvements. It is time consuming to complete this could be a contributing factor to low response rate. The population under study would have included older carers who may have required assistance to complete this. There is no indication if this was offered this may have impacted upon confidentiality/anonymity issues if it had been. Although a recent publication, this is older data collected between summer 2002 and winter 2004. As such, the situation may have changed with increasing pressure to explore whether the palliative care model can be applied with the same or similar success to cancer to a wider range of life limiting illnesses.

A more recent piece of work, a survey of family carers of people with dementia by the National Council for Palliative Care (2009) invited people to answer a range of questions related to their perception of the most important aspects of palliative and end of life care. This was an internet based survey with a range of options in answer to questions. Questions prompted answers and these were rated according to what was most important to the person completing the survey. Space was also available for information of a qualitative nature to be inserted. This facilitated thematic analysis of this data and development of themes, these then supported quantitative elements of data. Themes derived from data carers identified as important included, right support to help with physical needs, co-ordination of support, choices in relation to place of care and practical help and support. These are included in the aims and objectives of the dementia strategy (DoH 2009). It also identified, from the carers'

perspective, difficulties with knowing when the end of life is for a person with dementia, the unpredictability of the illness being the issue. Carers reported a preference to be informed of this rather than not. This internet survey selected people from key organisations such as the Alzheimer's Society and For Dementia. It was a self selected sample, access to the internet was required to participate (n=224). This was not a particularly large sample considering potential numbers of carers available within these organisations. One respondent was a person with dementia, whose voice also needs to be heard, however, it may have been difficult to report this individual response and maintain anonymity and confidentiality. Whilst access to and familiarity with the internet is increasing amongst the older population the internet based nature of this work excluded a large group of people who may have other wise participated. The socio-economic background of the group included may have also influenced responses for similar reasons outlined above. Families and older carers from a poorer more disadvantaged background may not have been included. It does however form the basis of much more work needed to establish needs of this group at this time and will help to inform future projects regarding design and methodology.

Ahronheim et al (2000) undertook a randomised controlled trial of palliative care in advanced dementia. This was an American study focusing on people with advanced dementia who were hospitalised with acute illness. The intervention group received recommendations from a palliative care team with the goal of enhancing patient comfort. The control group received care as usual without these recommendations, 99 people were recruited over a three year period. Dementia status was evaluated using the Functional Assessment Staging Tool (Sclan 1982). This is reported as a valid reliable observational tool for assessing and measuring functional deterioration

throughout the course of Alzheimer 's disease and other types of dementia. The aim of the project was to establish if a palliative care service for this group was appropriate in the acute hospital care environment. It was a dedicated hospital palliative care team that delivered the intervention. Although not a dedicated palliative care in dementia team, the team were reported as having extensive experience of working with patients with advanced dementia and their families. The control group were treated by usual hospital staff. The study failed to demonstrate a palliative care intervention by the research team could have any impact on specific treatment plans in patients with advanced dementia who were hospitalised. Patients in the intervention group were discharged significantly more often with the intention to initiate a palliative care plan. Interventions whilst outside the hospital were not measured. One patient who was re-admitted had their palliative care plan abandoned in the hospital and there is no reason given for this. The lack of impact on specific treatments was attributed to a number of reasons. Numbers were small and there was a trend towards forgoing certain treatments amongst the intervention group. Larger numbers may have revealed differences in certain treatment categories. Patients were randomised into the trial usually having already spent a week in hospital and influencing a well established care plan at this time may have been difficult. Half of the intervention group (n=48) had only one acute hospital admission, mostly as they died during admission or shortly afterwards. In these cases measuring sustainability of the intervention of hospitalisation survivors would have been difficult due to small numbers. Selection bias is another possible reason for lack of measurability. Surrogates or proxies were used to consent people into this study. Theoretically, a family that agreed to hospitalise a relative with advanced dementia may be less likely to agree to a palliative care plan feeling this indicated a

loss of hope for any kind of recovery for the person with dementia. Contacting families of people on an ongoing basis to discuss care options proved difficult limiting ability to interact with them in the intervention group and was seen as a possible obstacle to developing alternative care plans. Continuity of care for both groups by physicians was a problem. Few cases had the benefit of the same physician prior to or after hospitalisation. As a result temporary physicians had less time and commitment to follow recommendations made by the research team. There is also the issue of withdrawing or forgoing life sustaining treatments in parts of the USA. This study was based in New York where law requires patients without capacity have written evidence provided. In the absence of formal written advanced directives physicians were reluctant to withdraw or avoid life sustaining treatments or other aggressive manoeuvres (Ahronheim et al 2000). It is important to be aware of international differences in statute when considering applicability of others work within the United Kingdom. This particular study is useful for alerting us to issues faced in delivering palliative care to people with dementia in the acute hospital environment.

2.8.3. Making end of life decisions for people with dementia:

Using proxies to inform end of life decisions for people with dementia may be fraught with difficulty and ethical dilemmas. Making of end of life decisions for both people with dementia and their caregivers is a frequently encountered issue as serious medical co-morbidity becomes significant as dementia progresses (Lee et al 2006). Apart from cognitive ability, multiple other things influence end of life choices including psychosocial and cultural factors. Undoubtedly personal preferences of decision makers would have a direct effect on their choice of end of life decisions for people with dementia (Lee et al 2006). Physical condition, mood disturbances,

religious orientation, social support and cultural background are all potential factors that may influence choice in relation to end of life decisions for oneself and relatives. Advanced directives (DoH 2005) provide the opportunity to arrange one's affairs before mental deterioration occurs. This is particularly relevant with dementia when prolonged process of cognitive deterioration affects ability to make personal judgement and decisions (Lee et al 2006). In most circumstances, medical professionals and carers are involved in proxy decision making processes. Advancing cognitive impairment and psychological disturbances may influence decision-making and end of life perception in people with dementia.

Lee et al (2006) conducted an interesting study amongst Chinese elders on the subject of proxy decision making exploring attitudes of people with dementia to end of life decision-making. This included two groups, those with a diagnosis of mild dementia (n=26) and those without (n=30). Severity of dementia for the groups was rated using the Clinical Dementia Rating Scale (Morris 1997) a clinical interview rating six areas of functioning. Those scoring 0 represented normal cognition and those scoring 1 represented mild impairment. Cognitive status was evaluated using a Cantonese version of the Mini Mental State Examination (Chui 1994) and a battery of screening assessments not identified. They looked at attitudes of these groups in making end of life decisions based on three case scenarios they were given to consider. These formed part of a two part questionnaire adapted from one used in a study designed to evaluate the attitude of people with dementia and their carers after making proxy end of life decisions for the person with dementia. The first part collected demographic information and the second part consisted of three hypothetical scenarios concerning end of life decisions for people with dementia with different medical co-morbidities. These were read aloud to participants for them to

consider. Due to the progressive nature of dementia it is assumed patients with dementia loose the ability to make personal decisions and as such are unlikely to participate in their own end of life decisions. Lee et al (2006) found attitudes towards life and sustaining life amongst the mildly demented group did not deviate much from the cognitively intact group. A positive attitude towards use of life supporting therapy was demonstrated amongst the group with dementia. One could assume this group would not endeavour to prolong their life or would not be able to make decisions due to intellectual impairment. On the contrary, a similar preference for further invasive treatments if supportive therapy failed was apparent. More than half the group with dementia agreed they should be treated with all methods available compared to one third of the cognitively intact group who "highly disagreed" with being saved aggressively. This positive attitude in the group with dementia may reflect a genuine motivation for life (Lee et al 2006).

Those in the mild dementia group were observed to make choices in the scenarios as if choosing for a "friend" and needed to be reminded to choose as if deciding for themselves. This typically resulted in a change in decision. Decisions were more positive and active when faced with acute treatable, surgical interventions. Decisions and choices were more conservative, emotional and pessimistic when faced with the scenario involving advanced dementia and serious medical problems combined. Participants in this study were recruited from social centres and care homes, numbers from each were not stated. However, they do state most resided in care homes. In Chinese culture placing a relative or loved one in a care home has negative connotations and may be an indicator of poor family relationships and happiness within families affecting the choices made by some. Those living with family or children may have a more optimistic and active outlook on life. There is no

indication of how many from each group so it is hard to establish how this may have affected the positive responses to scenarios and overall results. Most participants were female, differences in attitudes between genders therefore hard to establish. Elderly men may have a more antagonistic outlook on invasive treatments sustaining life and have a preference to die comfortably without intervention.

For family members the decision to place a loved one into a care setting is fraught with several adaptive challenges often accompanied by feelings of guilt. They have to cope with loss of proximity of their loved one and relinquish their caregiver responsibility, entrusting their loved one to others who are usually total strangers. Alongside this, the progression of dementia confronts them with difficult moral and ethical decisions to make with regards to end of life (Hertogh 2006). Caron et al (2005) suggest these decisions are made more difficult not only due to lack of information with regards to specific decisions to be made but also with regards to the natural course and progression of the disease which can make the future even more difficult to anticipate for them. Faced with a situation in which limited knowledge regarding the disease trajectory is available, occasional contact with physicians who do not know the person with dementia well, it is not surprising that healthcare proxies often insist on hospital admission in cases of acute illness (Herogh 2006).

Making decisions regarding future care, treatment and expression of any wishes regarding end of life is something the wider population should be considering. The Mental Capacity Act (2005) is a legal framework which offers the opportunity for people who may need to make decisions on behalf of someone who lacks capacity to do so independently, to legally do so and act on their behalf and in their best interests. This framework covers health, welfare and financial aspects of decision making on someone else's behalf. It enables people with dementia and their informal

carers to consider formalising their wishes with regards to declining certain treatments and care. It gives an individual the opportunity to express their desired health care wishes should they be unable to speak for themselves, due to illness or injury (Meller et al 2009). Formalising one's wishes via advanced care plans (ACP) can facilitate good care and care one would want should a particular situation arise. Advanced care plans can facilitate decision making and reduce stress regarding difficult end of life decisions.

Meller et al (2009) conducted a piece of work in Australia exploring the implementation and use of ACP in nursing homes. It is importance to note the legal framework for such is different in Australia to that in certain parts of the UK. Despite this, there are similarities and lessons to be learned. The residents included were those with advanced dementia and their families. They developed an advanced care planning service within these environments in partnership with General Practitioners, specialists and nursing home staff. The aim of the service was to put in place a process whereby treatment options for residents who had lost their decision making ability, could be considered in advance of any further episodes of ill health. This was a ten step plan and included educational sessions for all those who may be involved including families, care home staff and General Practitioners. Community based educational sessions were also requested and provided in an attempt to raise awareness of the need to plan ahead for such circumstances. Information on roles and responsibilities of professionals, carers and individuals were included in these sessions. This was an interesting study with issues such as when is the best time to have conversations about advanced care plans, how to approach families in aged care facilities about these, who is the best person to act on someone else's behalf, implementation of these and legal aspects were all raised with a recommendation

further work is required. This study concluded advanced care planning is an important component of care for residents experiencing advanced dementia in this kind of care environment. It provides a conduit between acute and palliative care by focusing on current and any anticipated clinical need. It does this within a supportive legal context allowing families and clinician's to act in residents/patients best interests. They go on further to suggest this approach to care needs to include open and honest discussion of all the options and positive alternatives to letting someone else decide.

Sampson et al (2010a) undertook a similar pilot study in acute hospital care environment. The aim was to pilot a palliative care and advanced care plan intervention. It considered feasibility of implementing a two component intervention to improve end of life care for people with advanced dementia. Patients in the study had undergone emergency admission to hospital. Patient participants (32) were all elderly, in the advanced stages of dementia and physically frail. The intervention consisted of a palliative care assessment which then informed an advanced care plan discussion with the carer who was then offered the opportunity to write an advanced care plan. Carer patient dyads were randomised to "care as usual" or intervention group. Several carer related outcome measures were used at baseline, six weeks, six months and three months post bereavement. If the person with dementia died the carer was asked to complete the Satisfaction with End of Life Care in Dementia Scale (Kiely 2006).

Phase one consisted of preparatory work to develop the intervention utilising the Medical Research Council (MRC 2000) guidelines. The study states qualitative work was undertaken with 20 principal carers of people with dementia, however there is no detail regarding what this actually entailed, one has to assume it was either one

to one interviews or focus groups. They interviewed 21 health care professionals from a range of disciplines, experience and care settings including acute hospital, nursing home and primary care. Framework analysis was used to identify five main themes from this data. This aspect of the work enlightened them to poor levels of awareness and knowledge of the terminal nature of dementia amongst both carers and health care professionals.

Phase two involved using data collected in phase one to design the two component intervention. Palliative care needs assessments for patients and framework for the discussion of advanced care plan with carers. The intervention was delivered by a senior nurse experienced in dementia and dementia care who also received palliative care training. Carers proved difficult to recruit during hospital admissions and 33 patient and carers entered the study, 22 were randomised to the intervention arm and 11 to the control, care as usual group. There is no information about randomisation process or how this was achieved. The palliative care needs assessment drew upon a structured clinical approach and lasted 30 minutes. This covered a range of domains including, dementia severity, presence of delirium, communication, pain, pressure sore risk, nutrition, hydration, feeding and swallowing. A management plan was formulated using the results of these assessments and documented in clinical notes. Findings were also used to inform subsequent discussions with carers. Discussions with carers consisted of four consultations. These were initially attempted within the hospital environment. However carers were difficult to engage with at this time and patients often rapidly discharged. Discussions and consultations took place in the community following a review of protocol.

This was an interesting study which demonstrates problems with recruitment in the acute hospital care environment for people with dementia and their carers. Authors describe this environment as challenging in terms of recruitment. Recruitment targets were not met in this study and fell well below what were expected. The researchers were hoping for 40 carer patient dyads in each group and only 32 were recruited overall again, suggestive of difficulties with the environment chosen. Two carers dropped out after the first consultation regarding advanced care plan and there is no information regarding reasons for this. Three patient participants died before advanced care plan discussions were completed and of 17 carers who took part in advanced care plan discussions only seven made one. There were a number of reasons given for this such as complex and conflicting family dynamics and a general unwillingness to address end of life care issues. The most difficulty was with accepting what was going to happen in the future and again an unwillingness to make decisions about what were viewed as hypothetical future scenarios.

It is difficult to measure effect and outcome of the intervention based upon numbers of people willing to make an advanced care plan in this study. Carers who did not make an advanced care plan reported benefits from discussions and receiving information they would not otherwise have been in possession of including being alerted to the terminal nature of dementia. This was a small scale study due to the recruitment issues it is difficult to generalise and apply the results. It is another study indicating the latter stages of dementia and when someone is experiencing acute illness is not necessarily the best time to approach the issue of advanced care plans. It is useful in guiding future work of this nature and in informing of us of potential methodological issues when developing similar projects which are needed if ACP is

to become accepted as the "norm" and utilised more efficiently in today's aging society.

In contrast to those with cancer and other advanced chronic disease, most people with severe dementia will have profound cognitive impairment and will lack capacity required to make decisions about their care and treatment (Sampson 2010b). People with dementia are significantly less likely to have an advanced care plan compared to those with cancer, although uptake of the process in cancer remains variable. Ideally, advanced care planning should be attempted in earlier stages of dementia when a person is still competent to make decisions and express their values and preferences. In current UK clinical practice, it still remains rare for a person with advance dementia to have an advance care plan (Sampson 2010b).

No participant in the current study reported having had a written, formal advanced care plan in place. However, some participants described tongue in cheek, flippant conversations about illness, treatments, care and end of life wishes had taken place whilst the person with dementia was still alive. As a result some choices made on behalf of the person with dementia as end of life approached and upon death, were made based on these conversations.

The study discussed by Lee et al (2006) enlightens us as to how people with mild dementia may engage in decision making pertaining to end of life and invasive treatment choices. The question to ask in relation to advanced care planning for this group is: do we, or will we ever know, if those choices made and documented at an earlier stage of the disease process change or may change over time?

A person experiencing any other form of life limiting illness will be able to re-visit the advanced care plan if they so desire, at regular intervals and make their changed

wishes known. This may be more difficult for a person with dementia and will need facilitating. Decisions made on their behalf and in their best interests may not necessarily reflect their wishes at that moment in time. These may change over time as the disease progresses and changes could reflect a more positive outlook than was previously recorded.

2.9. Communication theories, styles and types

Communication is the process of exchange of ideas, views, opinion, understanding, emotions, facts or information between two or more persons by any sources or medium. With every interaction, whether active or passive, we find ourselves communicating with other people. Even our silence connotes some intention, which others may interpret at their discretion. Whether by artefact or by attendance, every human being constantly participates in the process of communication. Communication has existed since the beginnings of life with theories and models of communication evolving over time. Whilst the field of communication has evolved and changed considerably over the last few decades earlier theories and models (Shannon 1948, Katz 1957) have stood the test of time and are still referred to as baselines in teaching communication theories and models in many disciplines today (Foulger 2004). Shannon's (1948) model provides early information about the process of communication. It includes the information source, the message, transmitter, signal, channel, noise, receiver and destination. Like all communication models, this is a minimalist abstraction of the reality it attempts to reproduce. The reality of most communication systems is more complex. Most information sources (and destinations) act as both sources and destinations. Transmitters, receivers, channels, signals, even messages are often layered both serially and in parallel such that there are multiple signals transmitted and received, even when they are

converged into a common signal stream and a common channel. Shannon's model is a useful abstraction identifying the most important components of communication and their general relationship to one another (Foulger 2004).

More in depth study of the process of human communication commenced in the 20th century (Littlejohn et al 2008). Serious study of communication began with the advent and development of communication technologies and has continued to grow. The field of Communication Theory now exists at a crossroads of Psychology, Sociology and Anthropology borrowing heavily from each. Psychology is the study of human behaviour, sociology is the study of science and social processes and anthropology is the study of communication as a factor which develops, maintains and changes culture (Littlejohn et al 2008). Communication studies focus on communications as central to human experience. This involves understanding how people behave in creating, exchanging and interpreting messages. It illuminates a process that defines what it is to be human (Littlejohn et al 2008).

Recent communication model terms used by Rothwell (2010) are similar to those of Shannon (1947) but also refer to things such as decoder, encoder, feedback and message. From these terms we begin to form an understanding of the process of communication, what it involves and what it means. Using the above terms Rothwell (2010) describes three models of communication:

1). *Linear Model:* a one way model to communicate with others. It consists of sender encoding a message and channelling it to receiver in presence of noise. Disadvantages of this model includes the assumption there is a clear cut beginning and end to communication and no feedback from receiver. Examples include: lectures, email, text message or letter.

2). _Interactive Model:_ two linear models placed on top of each other. Sender channels a message to receiver and receiver then becomes sender channelling a message back to the original sender. Feedback is also contained in this model indicating communication is not a one way but two way process. Field of experience is included here which includes cultural background, ethnicity geographic location and general personal experiences accumulated over the course of a lifetime. Disadvantages of this model include feedback not being simultaneous. Examples include instant messaging. An instant message is sent to receiver, original sender has to wait for message from original receiver to react. Another example is a question/answer session, you ask a question, wait for question to be understood and then receive an answer.

3). _Transactional Model:_ Assumption is made people are connected through communication: they engage in transaction. It recognises each is a sender-receiver, not merely a sender or receiver. It also recognises communication affects all parties involved, communication is fluid/simultaneous which is the process of most conversations. It also contains ellipses that demonstrate how you interpret information you are given. An example is talking and listening to friends. Whilst a friend may be talking, constant feedback is given on what you think via facial expression and verbal feedback. This is done without necessarily stopping the person from talking.

An additional working definition of communication was considered by Lanham (2003) and as far back as Goffman (1959). This was a progression on earlier attempts to define communication that revolutionised into the constructionist model. Constructionists believe the process of communication is in itself the only messages

that exist. The packaging cannot be separated from social and historical context from which it arose. Therefore the substance to look at in communication theory is style for Lanham (2003) and presentation and performance of self for Goffman (1959).

Having considered and discussed some aspects of communication theory and models, attention will now focus on communication styles, types and skills.

As identified earlier, communication can occur via various processes and methods depending on channel used and style of communication there can be various types. Based on channels used for communicating, the process of communication can be broadly classified as verbal communication and non-verbal communication. Verbal communication includes written and oral communication whereas non-verbal communication includes body language, facial expressions and visuals, diagrams or pictures used for communication.

Communication styles and behaviours that may be involved in these styles and types are outlined in the table overleaf.

Table 2: Communication Styles and Types:

Communication styles/behaviours	Communication types:
Assertive: Most effective and healthiest style, natural, confident expression of self. Creation of mutually satisfying solutions Communicate needs clearly and forthrightly	**Verbal:** Spoken word, exchange of words and conversations
Aggressive: Involves control, manipulation, anger and intimidation	**Non-verbal:** Body language, movements, positioning
Passive: Based on compliance, avoidance of confrontation at all costs Minimal questioning	**Formal:** Written communications, Conference presentations, meetings, written memos

Foulger (2004)

Although it is difficult to sectionalise communication Hargie (2006) identified what he viewed as nine core communication skills:

- non-verbal communication

- questioning

- Reinforcement

- Reflecting

- Explaining

- Self-disclosure

- Listening

- Humour

- Laughter

- Persuasion

Hargie (2006) proposed the above as "core" skills as they occur to a greater or lesser degree in most interactions. Whilst none of these are mutually exclusive, they are all important components of communication. Good communication skills are fundamental to communication and require a high level of self-awareness. Communication is a vital component of any health care including that surrounding death (Newton 2010). Omitted from this list are bargaining and negotiation skills. The researcher feels these are also important communication skills to possess.

Few areas of academic study have attracted so much attention as that of interpersonal communication, in recent years there has been a deluge of research studies in this topic area. Reasons for this were aptly summarised by Wiemann (2003) who purported our ability to create and sustain our social world largely depends upon how well we communicate with others. Social skills are crucial to our

well-being both individually and collectively. The importance of understanding skilled behaviour in all its complexities cannot be overstated. Studies have shown a clear positive relationship between effective interpersonal skills and a range of benefits such as greater happiness in life, resilience to stress and psychosocial problems, and enhanced academic and professional achievements (Hargie & Dickson, 2004). There is a wealth of literature and research considering communication and interpersonal skills in health and different disease areas, Done et al (2001), Regnard et al (2007), Moore et al (2006), Godwin et al (2009), Hasson et al (2010), Newton (2010).

Regarding the professional domain, as society developed and became more complex, need evolved for a greater number of what Ellis (1980) termed, 'interpersonal professionals'. These are people who spend a large part of their working lives in face-to-face interaction with others. Such professionals include doctors, teachers, speech therapists, physiotherapists, occupational therapists, social workers, psychologists, nurses, careers advisers, counsellors and business executives, to name but a few (Hargie 2006). Historically, training of many of these professionals focused almost entirely upon acquisition of specialised knowledge. However, more recently centrality and importance of interpersonal communication in their work has been recognised and catered for in training (Hargie 2006).

Hargie (2006) suggests competence in most types of professions involves implementation of the following three main sets of skills.

1). *Cognitive skills:* Pertains to knowledge base of profession, that which characterises it and sets it apart from others i.e. doctors need to understand human anatomy.

2). *Technical skills***:** Specialised practical and manipulative techniques essential to a profession i.e. surgeons ability to use a scalpel skilfully, nurses ability to dress wounds.

3). *Communication skills:* Professional must have ability to interact effectively with clients, patients and other professionals.

Traditionally, education and training of most professional groups focused mainly on the former two sets of skills at the expense of interpersonal skills. This is somewhat surprising as it has long been recognised the ability to communicate effectively is a pre-requisite to success in many areas of life (Hargie 2006).

Increasing attention has been devoted to the entire spectrum of socially skilled interaction (Hargie 2006). The obvious observation some individuals are more socially skilled than others has led to formulation of systematic investigations into the nature and function of social skills. This has been in the context of development, remedial and specialised social skills. Relationships are an important part of life, they define who we are and are a fundamental, undeniably integrative force in our whole existence Hargie et al (1997). Relationships can be taken for granted as a major influence in life, relationships matter, we all know they do (Foley et al 2006).

2.10. Summary

There is an increasing interest and focus on dementia generally more specifically over recent years end of life issues for this group have begun to receive significant attention. This appears to be borne out of curiosity to establish whether historical models of providing palliative, supportive and end of life care for people experiencing cancer can be transferred and applied to this particular group in a range of care environments.

As has been demonstrated in this review the majority of literature has a specific focus on formal (waged) carers and 24 hour care environments i.e. nursing/residential care, acute hospital care. Hennings et al (2010) undertook a systematic review of family carers views of end of life and dying with dementia in care homes, this is one of few examples from the literature to focus on informal carers perceptions of this time frame.

Studies investigating views and perceptions of formal carers have a tendency to rely upon such methods as structured interviews, internet surveys, questionnaires and focus groups. This indicates a research agenda investigator led and does not offer opportunities for carers to relay views and perceptions in an open, honest storied manner. Whilst this type of work is valuable for identifying some element of need it is in danger of not establishing fundamentals such as why, how, where, when or whom in relation to different end of life care models and their applicability to this group.

A common theme across the literature is the unpredictability and nature of dementia in terms of life expectancy and being able to prognosticate when someone with dementia actually begins to die with it. This is one of the challenges faced with investigating whether existing models of end of life care can be applied to this group

in what way or how these may need to be adapted. Finally, the literature on communication was re-visited in preparation for considering the underpinning theme in the results chapter.

This review of the literature has identified a gap with regards to informal carers and their personal experiences of the last year of life and events surrounding death for a person with dementia. This study enabled informal carers to relay their story of events during this time frame with minimal interference from the researcher ensuring issues of importance to informal carers and not professionals are the focus. This will contribute to the dearth of literature available.

Having identified and critiqued some of the literature on palliative, supportive and end of life care for people with dementia and their informal carers, the next chapter will outline the methodology from which this study drew upon.

Chapter 3: Methodology

3.1 Introduction

This chapter describes the philosophical, methodological and ethical underpinnings of the study. It aims to provide the reader with information regarding the philosophy and epistemology in more detail in order to facilitate a greater understanding of its choice and demonstrate and explain how it has guided and influenced the study. Differences in research approaches will be outlined along with philosophical and epistemological underpinnings of the study, chosen methodology, it's historical perspectives, it's evolution and interpretation of this selected in order to help achieve aims and objectives of the study. Finally, ethical considerations and evaluative framework are discussed.

3.2. Rationale

The phrase qualitative enquiry can be viewed as an imprecise and umbrella term referring to widely divergent terms including grounded theory, phenomenology, ethno-methodology, ethnography and philosophical inquiry (Sandalowski 1986). The study adopted a qualitative approach informed by the philosophy of phenomenology and drawing upon Grounded theory as a methodology (Glazer & Strauss 1967, Strauss & Corbin 2008, Charmaz 2000, 2006). This was identified as the most appropriate approach to engage with considering aims of the study which were to explore the experience and interpret what, from informal carers perspectives, theirs and the person with dementia's needs are, during the last year of life and surrounding death. Definitive cause and effect relationships, as with quantitative work, were not the aims or objectives of the study, nor will they be provided but it does serve to raise awareness and insight into human experience.

A quantitative approach is not appropriate for the purpose of obtaining the kind of data required for this study. By definition quantitative approaches deal with quantities and relationships between attributes. It involves the collection and analysis of highly structured data in the positivist tradition. Quantitative approaches are more appropriate in situations where there is pre-existing knowledge which will permit use of standardised data collection methods (i.e. questionnaires) and in which the aim is to document prevalence or test a hypothesis (Bowling 2002).

Demographic information of a quantitative nature on all participants was collected. This was done to facilitate a description of the participants and to help contextualise the study.

3.3. Philosophical underpinning and epistemology

Phenomenology is an umbrella term encompassing both a philosophical movement and a range of research approaches. Applied to research, phenomenology is the study of phenomena, its nature and meanings. Focus is on the way things appear to us through experience or in our consciousness, the aim being to provide a rich textured description of lived experience. As such different methods can be utilised in an attempt to meet aims and objectives of a study.

Phenomenology as a philosophical stance is concerned with meaning of something to an individual and how that meaning is constructed. It begins with acknowledgement of a gap in our understanding and clarification or illumination will be of benefit to all stakeholders. This study drew upon phenomenology as a philosophy rather than research methodology as it studied experience of the last year of life and subsequent death, of a person with dementia and experiences of their carers during this time.

Phenomenology has evolved overtime with philosophers such as Husserl (1952) and Heidegger (1962) contributing to its development, interpretation and understanding. It is considered to be located within the "interpretive" research paradigm characterised by ontological assumptions reality is complex, holistic and context dependent (Racher & Robinson 2002). Focus is on human experience and subjectivity rather than objectivity. Phenomenological approaches are based in a paradigm of personal knowledge and subjectivity and as such emphasise importance of personal perspectives and interpretation. It can be extremely powerful in understanding subjective experience, gaining insights into people's motivations and actions and cutting through the wealth of taken for granted assumptions and conventional wisdom (Lester 1999).

It is argued phenomenology offers the opportunity of understanding the world other research methodologies may not (Lester 1999). Phenomenological research adopts what is known as emergent designs. It can be difficult to follow a linear pattern as with other approaches, and the question under investigation, if there is one, may change as research proceeds and data is analysed. Husserl (1970) suggests pure phenomenological research seeks to describe rather than explain and commences from a perspective free from hypothesis or pre-conceptions.

Heidegger (1962) a student of Husserl, refuted the possibility of commencing without pre-conceptions or bias suggesting this was almost impossible for the human mind. Emphasis is on making it clear how interpretations and meanings have been placed on findings. To achieve this, the researcher needs to be visible in the frame of research as an interested and subjective participant rather than a detached, distant and partial observer (Stanley& Wise 1993).

Husserl was educated as a mathematician and developed a strong interest in philosophy (Hunter 2004). He believed there was a real world accessible to body and senses which was constantly presented to us whether or not we were always aware of it. He described this as the world in which he found himself or natural world about him which was always present. This world includes the individual, but is also inhabited by others and in order to live together individuals must set up common objectives as the world about us is there for us all and to which we all belong (Husserl 1969). This shared world of fact and interpretation he described as "the intersubjective world about me" (Husserl 1969). He believed much more could be known and asserted about the natural world than logical positivism would allow and developed what was later seen as an unrealistic model of inquiry (Hunter 2004). Husserl (1969) believed it was possible for the skilled researcher to achieve "pure consciousness" or "transcendental consciousness" by "bracketing out" the individual's experience contaminated by culture, societal pressure and history. His concept of phenomenological reduction required the researcher's experience of the natural world be set aside. Perceptions and interpretations are eidetic in their character and require bracketing out when interpreting human experience. What would remain in the researcher after this process would be an understanding of the "essence" of the experience (Hunter 2004). Husserl (1969) purported through this method of transcendental phenomenology in which bracketing out occurred, pure consciousness was able to identify the true nature or essence of experience. What he did was to re-create subject/object differentiation later seen to be a problem with logical positivism. This method of transcendental phenomenology pioneered by Husserl (1969) may seem problematic in what is asked of the human mind is almost impossible. Despite this, his reflections on the functioning of the human mind and

way in which humans attribute meaning to experience have been foundational for qualitative research methods.

Martin Heidegger was a student of Husserl who developed an interest in phenomenology. Unlike Husserl, whose training was in mathematics, his background was theology. This drew him towards a synthesis of phenomenology with hermeneutics on occasions referred to as hermeneutical phenomenology. Hermeneutics meaning interpretation, or the art of theory of interpretation was originally derived from the interpretation of bible scriptures (Koch 1995).

Heidegger's (1962) primary focus was on the structure of "being" and for him the task of hermeneutics was to understand the mystery of being. For Heidegger humankind was a being towards death, time being the constraining horizon of being. The conundrum for hermeneutics was humans have being but meaning of their being was not immediately apparent and potential for misunderstanding was great (Hunter 2004). This also has potential for misunderstanding as some may interpret this as an assumption man is more easily accessible as an object of knowledge, physical or psychological than are non human subjects. The contrary is true, man is the most difficult object encountered in the cognitive process. Man is aware of the structures which make cognition possible: he lives in and acts through them. They are immediately present to him for they are he himself (Hunter 2004).

The experience of "being there", Dasein, was the starting point for Heidegger's hermeneutical method/circle: Dasein was the being of the enquirer (Heidegger 1962). Heidegger's hermeneutical circle was located in "lived experience" of interpreter rather than in the mind and world of the author. In order to assess this cycle of meaning and interpretation, one must endeavour to leap into the circle

wholly. The interpreter (researcher) does not stand outside of the circle and analyse existence from an objective, external perspective. It is the very fact of participating in the structures of being that enables the interpreter to understand it. Heidegger articulated the position that pre-suppositions are not to be eliminated or suspended and as such rejected the transcendental approach of Husserl (1969). His concept of "being in the world" necessitated a view the person and the world are co constituted, an indissoluble unity. A person makes sense of the world from within existence and not while detached from it (Koch 1995).

Phenomenology for Heidegger was a way of approaching objects for philosophical research and he applied hermeneutics as a research method founded on the ontological thesis lived experience is an interpretive process. Heidegger believed nothing can be encountered without reference to a person's background. Understanding and interpretation is based on that background, in its historicality. Understanding is a reciprocal activity and present may only be understood in terms of past and past in terms of present. The part and whole are similarly understood through a reciprocal relationship. Heidegger devised the concept "hermeneutical circle" as a metaphor to illustrate this reciprocal undertaking (Koch 1995). Heidegger is commonly believed to have rejected the concept of bracketing instigated by Husserl (1969).

The intention of the study was to "return to the things themselves" (Husserl 1936, 1970) that is, events of the last year and surrounding death as lived by carers. Merleau-Ponty (1954, 1962) suggests to return to things themselves is to return to a world which precedes knowledge of which knowledge always speaks. In returning to events identified with participants knowledge gained from their experiences will help inform future knowledge and work in the topic area.

Within a phenomenological framework the researcher is required to be reflexive and needs to take into consideration and be aware the effect their personality or presence may have upon the research process or investigation (Miles & Huberman 1994). This includes being aware of how one presents oneself to participants. Fontana & Fray (1994) suggest the way in which the researcher presents themselves can influence success or failure of the study. For the purposes of the study and in accordance with Heideggerian hermeneutical philosophy of phenomenology, bracketing was not carried out. Bracketing is an important process by which researchers can examine their own personal commitments and prejudices prior to beginning data collection. This is done in an attempt to reduce researcher bias in both data collection and analysis. The researcher came to this project with extensive knowledge and experience of working with people with dementia and their carers. It is extremely difficult to completely divorce oneself from this knowledge and experiences during the research process.

Having identified and discussed the philosophical and epistemological influences for the study the choice of methodological approach will now be addressed. As identified earlier in this chapter, phenomenology informed the study as a philosophical stance rather then a methodology. The rational for this being phenomenology as a methodology seeks to describe interpretations of lived experience rather than explain it. The researcher did not want to just provide description but wished to interpret and explain these interpretations in order to develop a theory. This theory could then be utilised in practice and inform any changes identified as being necessary.

3.4. Choice of methodological approach

As identified earlier, quantitative and qualitative research paradigms originate from different sets of assumptions about the nature of knowledge and reality. Their goal typically is to address different research aims. Quantitative research is positioned more within positivist epistemological perspective, typically aiming to test or verify hypothesis. Qualitative research is positioned more within constructivist epistemological perspective. It is an independent research method that involves studying experiences and social factors but which can also be used to underpin and shape the hypotheses of quantitative research (Denzin and Lincoln, 2000). As identified earlier, there are several qualitative methodological approaches available to researchers. For the purposes of this study, Grounded Theory (Glaser & Strauss 1967) and more specifically, Charmaz's (2000) interpretation of this and the constructivist approach was drawn upon.

As with the philosophy of phenomenology, grounded theory has the characteristics of focusing on richness of human experience, understanding participant's perspectives and allows for a degree of flexibility within data collection. It has been utilised previously in research where the focus has been on death and dying. Historically it has been used within health care but not exclusively. Grounded theory is also recognised as an appropriate method to use when there is a dearth of knowledge or theory on a topic. It is also a useful methodology to engage with when the focus of research may include such things as uncovering basic processes, exploring affects of groups, uncovering facts underlying social processes and when there is some intervention required at the end as with this study. The decision to utilise this particular qualitative methodology rather than any others identified earlier was based upon consideration of applicability and feasibility of the method and

research question in the context of phenomena under study. Methods synonymous with grounded theory methodology will not be discussed here but are presented later in the methods chapter. Briefly, these comprise data collection, theoretical sampling, coding of data (differing levels), constant comparison across transcripts, memo writing, categorising (themes) and theory development.

3.5. Historical perspectives of Grounded theory

Grounded theory seeks to construct theory about issues of importance in peoples' lives rather than those of the researcher (Strauss and Corbin, 1998, Glaser, 1978, Glaser and Strauss, 1967). This is achieved through a systematic and structured process of data collection, organisation and analysis. It is inductive in nature in so much as the researcher has no preconceived ideas or theories to prove or disprove. Issues which are of importance to participants emerge from their narratives about an area of interest that they have in common with the researcher.

The roots of grounded theory can be traced back to symbolic interactionism. Its origins lie in the work of Cooley and Mead (1863-1931). They were concerned to avoid the polarities of psychologism and sociologism. Psychologism being a view based on the assumption social behaviour is explicable in genetic terms by logical or neurological processes and sociologism being the opposed fallacy which considers personal conduct as if it were in some way programmed by societal norms (Goulding 1999). Any distinction between individual and social groups is mistaken as our self identity is born out of our relationships with others. In other people ourselves are mirrored. Individuals engage in a world which requires reflexive interaction as averse to environmental response. Actions are purposive and people react to environmental cues, objects and others according to meanings these hold for them. Meanings

evolve from social interaction which is symbolic due to interpretations attached to various forms of communication such as language, gestures, and significance of objects (Goulding 1999). These meanings are modified, regrouped or suspended in light of changing situations (Schwandt 1994). From this viewpoint the researcher hopes to construct what interactants view as their social reality and how objects and experiences contribute to construction of this reality (Goulding 1999). Methodologically the researcher is required to enter the worlds of those under study in order to observe their environment, interactions and interpretations. The researcher engaged in symbolic interaction interprets actions, transcends rich description then develops a theory which incorporates concepts of self, language, social setting and social object (Schwandt 1994). This developed theory is then presented in a form that creates an eidetic picture.

Using these principles as a basic foundation, Glaser and Strauss (1967) created a more defined and systematic procedure for collecting and analysing qualitative data, grounded theory. This reflected the source of the developed theory which is ultimately grounded in behaviour, words and actions of those under study. The method was devised whilst they were researching experiences of chronically ill patients. It offered a means of systematically collecting data which could be interpreted and developed through a process of offering clear, precise guidelines for verification and validation of findings. They felt such a procedure was necessary in the climate at the time which largely viewed qualitative research as subjective, unsystematic, unscientific and unworthy of serious recognition. For them a method which would track, check and validate theory from a qualitative perspective was timely and necessary.

Grounded theory, in contrast to theory obtained by logico-deductive methods, is theory grounded in data systematically obtained through social research. Its development was an attempt to avoid highly abstract sociology and part of an important growth in the 1960s and 1970s. The main impetus behind the movement was to bridge the gap between theoretically uninformed empirical research and empirically uninformed theory, by grounding theory in data (Goulding 1999).

As a formal methodology grounded theory was first presented by Glaser and Strauss in 1967. The emphasis behind grounded theory became one of "new" theory generation. In keeping with its principles, theory evolves during the research process and is a product of continuous interplay between data collection and analysis. Unlike many other methods, grounded theory does not involve waiting until all data is collected before analysis begins. The search for meaning through interrogation of data commences in early stages of data collection and informs future sampling.

3.6. Evolution of Grounded Theory Methodology

Glaser and Strauss (1967) in their first work on grounded theory outlined a number of core concepts which distinguished grounded theory from other qualitative methodologies. These included "theoretical sampling" and "constant comparison" methods. Their earlier work found receptive audiences and became a major force igniting the "qualitative revolution" that gained momentum throughout the latter part of the twentieth century (Charmaz 2006).

Subsequent solo publications, however, by Glaser and by Strauss, as well as publications by Strauss, in collaboration with Corbin, have taken grounded theory in somewhat divergent directions.

Glaser remained consistent for years with his earlier exegesis of the method and thus defined grounded theory as a method of discovery, treated categories as emergent from data, relied on direct and often narrow empiricism and analysed basic social process (Charmaz 2006). Strauss (1987) moved the method toward verification and co-authored works with Corbin (1990, 1998) furthered this direction. Strauss and Corbin's version of grounded theory favours new technical procedures rather than emphasising comparative methods that distinguished earlier grounded theory strategies. Glaser (1992) contends Strauss and Corbin's procedures force data and analysis into pre-conceived categories and thus conflict with fundamental principles of grounded theory.

On the face of this it could be argued grounded theory has split into two camps, each subtly distinguished by its own ideographic procedures (Goulding 1999). One could argue Strauss has modified his description of grounded theory from its original concept of emergence to a densely codified operation. To Glaser, the Straussarian school represents an erosion of grounded theory (Stern 1994) possibly responsible for the impression grounded theory uses qualitative research to quantify findings. Grounded theory has an in built mandate to strive towards verification through the process of category saturation, which necessitates staying in the field until no further evidence emerges. Verification is done through the course of the project rather than assuming it is only possible through follow up quantitative data. The developed theory should be true to data and should be parsimonious. This is a point of departure for Glaser who argues theory should only explain the phenomena under study and Strauss, who insists on excessive use of coding matrices to conceptualise beyond the immediate field of study (Goulding 1999).

Glaser and Strauss (1967) invited readers of their original work to use grounded theory strategies flexibly in their own way. Charmaz (2006) accepts this invitation and offers a different more flexible interpretation of grounded theory strategies. She returns to the past emphasis of examining the process, making the study action central and creating abstract interpretive understandings of data. She provides a "way" of doing grounded theory considering theoretical and methodological developments over the past four decades. Charmaz (2006) does not view grounded theory methods as a set of prescriptions or packages, more as a set of principles and practices to guide the researcher through a process. Flexible guidelines not methodological rules or recipes are requirements. Given the diversity and debate within the methodological discipline of grounded theory it was decided to draw on the approach outlined by Charmaz (2003) for this study having developed awareness and insights into Glaser & Strauss's earlier model and their emerging independent models.

Charmaz (2003) describes a constructivist approach that assumes our worlds and experiences are constructed and interpreted by all around us. Grounded theory came under attack from both postmodernists and poststructuralists despite obvious and subtle positivistic premises assumed by its major proponents and within the logic of the method itself. Despite their somewhat differing positions on later development of grounded theory Charmaz (2003) suggests both Glaser and Strauss's positions remained embedded within positivism. Glaser's (1978, 1992) often coming close to traditional positivism with its assumptions of an objective, external reality, a neutral observer who discovers data, reductionist inquiry of manageable research issues and objectivist rendering of data (Charmaz 2003). Strauss and Corbin's (1990, 1998) position assumes an objective external reality, moves towards unbiased data

collection, proposes a set of technical procedures and supports verification. A position moving into post positivism as they also propose giving a voice to participants, representing them as accurately as possible, acknowledging and discovering how participants view of reality may be in conflict with their own and some recognition of art alongside science in analytical process and product.

In considering the above Charmaz took the points further and came up with her vision of the future for qualitative research: constructivist grounded theory.

Constructivist grounded theory can be said to be celebrating firsthand knowledge of empirical worlds, taking the middle ground between postmodernism and positivism and offering accessible methods for moving qualitative research into the future. Constructivism assumes the relativism of multiple social realities, acknowledges mutual creation of knowledge by researched and researcher and moves towards interpretive understanding of participants' meanings (Schwandt 1994).

Grounded theory has varying philosophical approaches. Despite this there are commonalities across all grounded theory methodologies. Whichever interpretation of methodology used, it is an iterative process with data collection and analysis occurring simultaneously. The simultaneous nature of data collection and analysis results in researchers' analysis shaping future data collection.

3.7. Constructivist Grounded Theory

A constructivist approach places priority on the phenomena of study and lies within the interpretive tradition. It sees both data and analysis as created from shared experiences and relationships between participants and other sources of data. It is the study of *how* and sometimes *why* participants construct meanings in any given

situation. This is achieved by getting as close to the inside of experience as possible whilst at the same time realising experience of participants cannot be replicated. This approach is more than looking at how individuals view their situations, it not only theorises interpretive work participants do but is an acknowledgement the resulting theory is in actual fact an interpretation. Theory depends upon the researchers' view, it does not and cannot stand outside of it (Charmaz 2006). Different researchers may have similar ideas, how they interpret them theoretically may differ. Constructing constructivism involves seeking meanings of both participants and researchers. In seeking participants' meanings one needs to go beneath the surface meanings or presumed meanings. Values and beliefs must be sought as well as acts and facts. Beliefs and ideologies must be discovered as well as situations and their structure. It is only through studying and exploring tacit meanings we can clarify rather than challenge participants views on reality.

A constructivist approach necessitates a relationship with participants in which they can tell their stories in their terms. It involves listening with openness to feelings and experience. Researchers need to be aware of this and avoid framing questions in a way that mutes feelings and raw experience from being expressed by participants.

The constructivist approach means learning how, when and to what extent studied experience is embedded in larger and often hidden positions, networks, situations and relationships. As a result differences and distinctions between people become visible along with hierarchies of power, communication and opportunities that maintain and indeed perpetuate such things. A constructivist approach necessitates alertness to such conditions under which these differences and distinctions arise and are maintained. Rich data is required to anchor experience and entails having sufficient knowledge so as to see differences and distinctions. In extremely small

grounded theory studies there is a risk of becoming disconnected from social contexts and situations. The potential power of analysis can be diminished by treating the experience as separate, fragmented and atomistic. This study involves a larger sample (n=41) than usually found in a qualitative piece of work and hopes to avoid this.

A reflexive stance will be taken, as is common with the constructivist approach. There is acknowledgement there will be similarities within the sample but there will also be distinct differences amongst them. As identified earlier, both researcher and participants interpret meanings and actions and a reflexive nature will facilitate an understanding of how theories begin to evolve. Both data and analysis are social constructs that reflect what their production entailed, analysis is contextually situated in time, culture, place and situation (Charmaz 2006). The constructivist approach requires the researcher's awareness of any presuppositions and how they may affect the research process. Pre-conceived ideas can be imported into the work if the researcher remains unaware of their starting assumptions as discussed earlier. The researcher was aware of these and how they may impact upon the work and their interpretations of situations, context and culture as well as interpretations of participants. It is intended to keep these pre-conceived ideas in the background to allow theories to emerge from the data. Problems encountered throughout the work associated with this are discussed in a later chapter.

Grounded theory methodologies do not come without criticisms (Seale 1999). Much of the criticism comes from the stance grounded theory in its traditional sense is objectivist in nature. With the accusation coding and categorising of data fractures and decontextualises it preventing full portrayal of an individual's experience. These criticisms are rooted in assumptions of an objectivist methodology. There is also a

danger of placing too much emphasis on identifying codes as the exclusive feature of the process. This is without theoretical coding taking place and being the means by which an explanation of how codes relate to each other being given (Goulding 1999). Constant comparison should remain an integral feature and action of the process, without this, emerging themes cannot be sorted on basis of similarities and difference. Theoretical sampling informed by data collection and data should direct the researcher to individuals, situations, contexts and locations. Goulding (1999) warns against theory being developed and presented until all core concepts and categories are saturated. A situation Charmaz (2006) identifies as potentially difficult to achieve with the constructivist approach considering individuals perception of reality and uniqueness of this. Limited ideas about the form of inquiry grounded theory takes also lead to criticism. Treating grounded theory as only a variable analysis, for example, can lead to a reductionist frame and encourage favouring those variables within easy grasp. When this occurs a superficial study may result that skims the border of a category without explicating it (Charmaz 2006).

Charmaz (2000) believes much of the criticisms applied to grounded theory are indeed answered by the constructivist movement. She purports greater emphasis is placed upon meaning and less upon belief there is one external reality and the method being prescriptive.

The constructivist approach has also received criticism. Glaser (2002) refuted the idea of a constructivist approach, suggesting it is no better than a form of descriptive qualitative data analysis merely disguised as "constructivist grounded theory", a criticism opposed by Bryant (2003). They suggest the constructivist approach is a valid form of grounded theory that challenges areas an objectivist approach does

not, for example, how formation of patterns in data take place and explanations for this.

"*So who's got the real grounded theory?"* (Charmaz 2003 p256)

Glaser (1998) contends he has the pure vision of grounded theory. That can be said to be correct if one agrees early formulations of the methodology should set the standard (Charmaz 2003). Different proponents assume grounded theory essentials *ought* to include different things. These "*oughts"* shape their notions of real grounded theory for them. Authors may write mechanistic prescriptions for beginners to get them started and compose more measured pieces for peers, new developments influencing them. A more simplified, flexible constructivist version of the methodology can supply effective tools to be adopted by researchers from diverse perspectives using a variety of data and sources.

Several authors (Glaser 1998, Freshwater 2000, Heath and Cowley 2003) suggest novice researchers find out about the process of researching through learning in the process of carrying out research and we stop talking about grounded theory and just get on with doing it. Anxiety about "doing it right" should be set aside. In adhering to principles of constant comparison, theoretical sampling and emergence, an approach that will best help achieve balance between interpretation and data that produces a grounded theory will be discovered.

Glaser (1999) commented if initial attempts at grounded theory prove at first less than successful they should not be discredited. He highlights grounded theory is a methodological approach which requires time and often a number of research studies to learn, perfect and appreciate fully. Provided the researcher is continuing to

develop their skills at employing grounded theory Glaser states any errors in their application of grounded theory should be seen as developmental.

It was with this in mind and for the purposes of this doctorate, a learning experience was embarked upon utilising the constructivist approach to grounded theory.

3.8. Ethical considerations

Ethics are concerned with values, what is right and what is wrong with any given situation or actions (Leino-Kilpi & Tuomaala 1989). The right and wrong elements of ethics can be discussed in terms of Beneficence and Non-malificence. Beneficience is the obligation to provide benefits and balance those against risks. Non-malificence is the obligation to avoid causation of harm (Beauchamp & Childress 2001).

Kumar (2005) highlights different codes of ethics professions and organsisations may be guided by. These have evolved over time to accommodate changing ethos, values, needs and expectations of those who may hold a stake in the profession.

Those employed/engaged in health research have the Research Governance Framework (2005) to guide best practice. This governs the way all types of health and social research is carried out and provides a structured framework for researchers to conduct their work. This framework also applies to students who are required to undertake a piece of research in order to acquire an academic qualification. It is this framework that has guided the ethical considerations for this study outlined below. Approval from the University Ethics Committee (UREC) to conduct the study was obtained.

3.8.(i). Sample

Bereaved informal carers were necessary to undertake this study. Appeals for volunteers to take part were made via posters displayed in community venues i.e libraries, community centres, University intranet, Alzheimer's Society, Age Concern (now Age UK) and local press releases. Potential participants were encouraged to approach the student/researcher. Due to the sensitive nature of the topic under study and potential for emotional or psychological distress, those recently bereaved were not excluded from participation but in collaboration with them, the researcher and supervisors, a decision was made as to how best to include them possibly necessitating a delay.

3.8.(ii). Informed Consent

Written informed consent was obtained from all participants by the researcher. This was mostly done on a face to face basis at time of interview. On initial contact about participation either during telephone conversations or email contact, all aspects of the study were discussed for example exactly what participation would involve including audio recording of the narrative interview and anonymised use of data. A participation information sheet and copy of consent form was given to each participant. For those who choose to write their narrative the above process was followed as closely as possible, however the consent form was signed by the researcher retrospectively upon receipt of it via Royal Mail.

3.8.(iii). Confidentiality

In an attempt to maintain confidentiality and anonymity all participants were assigned a number. All possible identifiable information was removed from transcripts.

Participants were discussed with the supervisory team using a number only. University Research Ethics Committee approval was obtained to maintain contact details of those recently bereaved to enable the researcher to return to the potential participant at a later date. Digital interview recordings and transcripts were kept on a password protected computer. Hard copies of transcripts for the purpose of the initial coding process were kept in a locked cabinet to which only the researcher had access to.

3.8.(vi). Psychological, emotional issues/risks

It was acknowledged some participants may have had negative experiences to share which may have been a source of anxiety or distress. As a result there was a moderate risk of emotional or psychological distress occurring. Potential participants were asked to recall events during the last year of life and surrounding the death of someone with dementia. This was a person they had provided care for on an informal basis. The majority of the sample were spouses or siblings and had emotional attachments to the person with dementia. Participants were asked to narrate their experiences and how they have been affected by these.They may have had negative and positive experiences to share and some may be painful to recall and a source of distress.

Considering the concept of non-malificence above (Beauchamp & Childress 2001) and desire to cause no harm, a distress protocol was devised to manage this (Appendix 1). A list of suport organisations was to be made available to participants upon request, this did not occurr. The researcher is also a Registered Mental Health Nurse and has extensive experience of working with people with dementia and their carers in a variety of care environments at different points in the disease trajectory,

including end of life. She has experience via her clinical and research roles, of working with people in times of distress and managing this.

Whilst the study asked participants to recall experiences that may have been painful, there is evidence in the literature to suggest the use of narratives may have a therapeutic impact on individuals. Having the opportunity to tell their "story" sometimes enables a person to feel more comfortable and at ease with the event (Kumar 2005). This is supported by Hudson (2003) in their work with family caregivers of palliative care cancer patients. They suggest, despite concerns regarding the ethical merit of involving this group in research as participants it is safe to do so and they can actually derive benefits.

3.8.(v). Risks (researcher)

Due to the sensitive nature of the topic under study, last year of life for people with dementia, it is possible the researcher may become distressed as a result of carrying out in-depth interviews with participants and the type of information divulged. To minimise any distress the researcher was encouraged to discuss, in confidence, any issues or concerns that may have arisen. This was defined and initiated by the researcher as and when required. It was mostly with a member of the supervisory team. There was also the opportunity to engage in a newly formed support group set up within the researchers' institute for researchers and students working with emotionally challenging data.

Project interviews took place at a time and location convenient to those wishing to participate. This necessitated visiting partcipants within their own homes. The University lone worker guidelines for researchers was adhered to on these occasions. A University contact person was identified prior to each visit and

information pertaining to the whereabouts of the researcher given to this person. Contact was made with this person at the beginning and end of each visit to ensure researchers' safety.

3.8.(iv). Use of Data

Data obtained was used to contribute to the production of this thesis in order to gain an academic qualification. Participants were informed they could see the completed work if desired and they would receive an executive summary of results upon completion of the project. A note was made of those expressing this wish. Elements of data were, and continue to be used in anonymised form at conference presentations and on submission for publication. This was outlined in the participant information sheet and University Research Ethics Committee application.

3.9. Evaluative Framework

Although qualitative methods of inquiry are increasingly accepted as relevant to achieving goals in nursing and medical research they continue to be criticised for failing to pass tests of methodological rigour (Sandalowski 1986). Criticisms of qualitative work continue to focus on the issue of scientific adequacy and credibility of work grounded in accounts of subjective experiences. It is difficult to apply criteria for evaluation of quantitative methods in terms of validity, reliability and generalisability to qualitative studies. These criteria will inevitably favour the research tradition that generated them (Sandalowski 1986) and are associated with realist and positivist positions which assume existence of a single truth (Ballinger 2004, Mays & Pope 2000).

Seale (2002) highlight difficulties faced with establishing and finding quality in research suggesting it is elusive and hard to specify but often we feel we know it

when we see it. In this respect they state research is rather like an art than a science. Corbin and Strauss (2008) agree with this position, quality in qualitative research is something we recognise when we see it, however, explaining it or how to achieve it is much more difficult.

An important question to ask in relation to rigour is whether an appropriate method of enquiry has been adopted by the researcher to meet objectives of the study. One of the objectives of this study is to gain an understanding and interpretation of the "lived experience" of the last year of life and events surrounding the death of the person with dementia and experiences of carers from their perspective. The philosophical and theoretical underpinnings of the study have been outlined and discussed in detail and not "hidden" from the reader. The methodology is informed by the philosophy of phenomenology which has provided an appropriate framework to achieve the objectives of this study.

Having considered and reflected upon the literature (Glaser 1978, Miles & Hubermann 1994, Barbour 2001, Guba & Lincoln 1994, Charmaz 2006) and different frameworks and suggestions for attempting to establish rigour in qualitative studies, it is proposed to utilise the framework of Guba & Lincoln (1994) for the purpose of this study. They identify four factors relating to the test of rigour in conventional scientific research and "naturalistic inquiry". These will be outlined below. I have also included the "auditability" aspect of Miles & Huberman's (1994) framework for establishing rigour in qualitative studies. This refers to the underlying issue as to whether the process of the study has been consistent over time.

3.9.(i). Credibility

Guba & Lincoln (1994) suggest credibility is concerned with what they refer to as "truth value". In qualitative research truth is described as a much more elusive goal. The "truth value" of qualitative inquiry generally resides in discovery of human phenomena or experience as they are lived or perceived by others/participants, rather than a priori conception of those experiences. Significantly they suggest truth is subject oriented rather than researcher defined. They suggest credibility rather than internal validity in the quantitative sense be the criterion on which truth value of qualitative research is evaluated.

3.9.(ii). Applicability/Fittingness

In quantitative research certain conventions of sampling are observed to ensure representativeness or generalisability (Guba & Lincoln 1994). This is not applicable to qualitative work. Sampling in quantitative work is typically statistical as it is intended to reflect the distribution of certain variables in the population from which the sample was drawn. In contrast, sample sizes in qualitative work are typically small although sample sizes are increasing with time, but still do not involve large numbers seen in quantitative studies.

In addition sampling is theoretical as with grounded theory, rather than statistical. Samples in qualitative work are not representative in the quantitative sense. Anyone's experience, if well described represents a view from the life world (Husserl 1970) and is considered appropriate subject matter for qualitative work (Sandalowski 1986).

3.9.(iii). Consistency

Consistency rather than reliability and ability to report this in terms of measurements is the term used by Guba & Lincoln (1994). Qualitative research emphasises the uniqueness of human situations and importance of experiences that are not necessarily accessible to validation through senses. Variations in experience rather than identical repetition are the objectives.

3.9.(v). Neutrality

Guba & Linclon (1994) suggest this refers to freedom from bias in the process and end product. In quantitative research this is achieved by seeking and attempting to maintain a distance between researcher and participants. In contrast qualitative work emphasises the meaning of the findings. This is achieved by researcher, participant and data being closer than found in quantitative studies. Qualitative research values subjectivity rather than the objectivity found in quantitative work.

3.9.(vi). Auditability

Miles and Huberman (1994) refer to this as the underlying issue of whether the process of the study has been consistent over time. They suggest the question to be answered is "have things been done with reasonable care?"

Auditability is achieved when the researcher leaves a decision trail concerning the study from beginning to end. Any reader other than the researcher should be able to follow the progress of events in the study and follow their logic.

3.10. Summary

The philosophical and methodological underpinnings of the study and rational for selecting these have been described in the text above. It has been outlined how the approach is suited to eliciting information about personal experience and how this also supports interpretation of this by the researcher. Ethical considerations of conducting this kind of work with what can be viewed a vulnerable group, discussing potentially distressing events, have also been addressed. The evaluative framework for qualitative research upon which the work may be judged has also been identified and discussed. Further details pertaining to the application of this and a critique of the study utilising this framework are included in the discussion chapter later in this thesis.

Having described the approach taken by this study, ethical considerations and proposed framework for evaluating rigour, the following chapter will go on to describe methods employed to conduct the study and collect data.

Chapter 4: Methods

4.1. Overview of methods and design

The preceding chapter described the research approach, framework for establishing rigour and relevant ethical considerations. The following chapter aims to provide a more detailed description of methods used in conducting the study including data management and analysis. Methods used to conduct the literature search have been described in chapter two. The main methods used to conduct the research will be described in detail here and includes, methods of sampling, data collection, management of data and finally, methods used for analysis. The use of in depth, narrative interviews and their relevance to the study are justified. This chapter also considers the epistemological position and ethical considerations described in the preceding chapter.

4.2. The research population

As noted in the preceding chapter, the purpose of qualitative research is not to establish a random or representative sample drawn from a population but to identify specific groups that either characterise or live in circumstances relevant to the phenomenon under study (Strang 2000). It can be argued all qualitative research begins with purposeful sampling and then, as is the case with grounded theory, it develops into theoretical sampling (Coyne 1997). Theoretical sampling is applied in grounded theory to ensure sampling is adequate. This suggests the researcher has no initial limits on number of participants or interviews required and this is determined by researcher returning to the field until nothing new is said about concepts or categories being explored. Initially purposive sampling was adopted and participants selected in accordance with needs of the study. As data collection progressed theoretical sampling was used in accordance with the methodology in an

attempt to explore and pursue issues that may have been new, similar or different within the sample.

The aim of the study was to explore experiences of being an informal carer caring for someone with dementia in their last year of life and surrounding death. Therefore the following inclusion and exclusion criteria were established:

Inclusion criteria:

- All participants must have been an unpaid carer of someone with dementia in their last year of life and at time of death
- Male or female
- Aged 18 years or over
- Reside in the UK
- Good command of English language
- Relationship to person with dementia and socio-economic backgrounds not restricted
- Death must have occurred within last five year period
- Death can have occurred in any care environment (family home, care home, hospital)

Exclusion criteria:

- Paid/ formal carers
- Under 18 years of age
- None UK residents
- Poor command of English language
- Death occurred outside of last five year period

People from black and ethnic minority groups did not volunteer to participate. Every attempt would have been made to include them if they had, although project funds to engage interpreters, had they been required, were limited.

In an attempt to protect those participants who may have been particularly vulnerable, those who had been bereaved within the last six months were not automatically excluded. Implications of participation were discussed at length with them and supervisors before a decision was made on how to proceed. This situation occurred on two occasions, one person was included, the second person was spoken to again by the researcher after a period of a further three months had passed, they declined to participate at that time and were not contacted again.

In order to acknowledge and reflect diversity of informal/unpaid carer's that may be within this group, the part local communities may play in this and who may adopt this role, relationship of the carer to person with dementia was not restricted.

Years post death was restricted to five as it was felt any longer period than this would affect recall and memory of period of time under study. It was hoped issues with care for this group outside this time point may have been addressed resulting in establishing what needed to be changed, if anything, becoming problematic.

In total there were 60 responses to the appeal for study volunteers. Of these, 16 were excluded for a variety of reasons including: person with dementia still being alive, paid carers from nursing and residential environments being excluded and death of the person with dementia occurring outside specified time period in inclusion criteria.

4.3. Recruitment of participants:

In order to capture as wide a population as possible and in accordance with the methodology, recruitment occurred in three phases and was informed by interviews, constant comparison of transcripts and ongoing analysis. Initial phase of recruitment involved posting an appeal on the University of Liverpool intranet. Following on from this, posters (Appendix 2) were displayed at various other public locations including the University campus, public libraries, community centres, galleries, shops and post offices. Information leaflets were also distributed at relevant professional events and conferences. During initial phase of recruitment between February-September 2009, 27 responses were received out of those 17 volunteers were recruited.

As data collection and analysis progressed recruitment became more focused on certain groups and locations, i.e. male carers, semi rural and rural areas. This involved appealing for volunteers in a much wider area of the UK, North East of England, Wales and Scotland. To facilitate this process, organisations such as the Alzheimer's Society, Age Concern (now Age UK) and Alzheimer's Scotland were contacted and invited to publicise the appeal through newsletters and carers groups held within local branches. Difficulty was experienced in attempting to recruit volunteers via the Alzheimer's Society in the south of England. A request for support with recruitment via telephone and email was made. All study documentation, including the protocol was sent to the head office of the Alzheimer's Society, at their request, on two separate occasions, however no response was received. Brief telephone conversations revealed they were anxious involvement in the study of their carers may result in increased distress their volunteers would need to manage, as a result they were unwilling to support recruitment.

A press release was also made in Wales which resulted in a further two responses, none of which were recruited due to the person with dementia still being alive. There was also an element of "snowball" sampling that occurred which was unexpected. Potential participants heard about the project from other sources and volunteered to participate. Between October 2009 and August 2010 a further 33 responses were received, total sample at the end of this period was 40. Recruitment was discontinued at this point as the interviews did not reveal any new information and data saturation had occurred.

Those interested in participating in the study contacted the researcher and further information in the form of a covering letter (Appendix 3) an information sheet (Appendix 4) or booklet, explaining the study in more detail and what it involved, was sent to them by their preferred method, either e-mail or Royal Mail. This information sheet included details about informed consent, data protection, risk, confidentiality and included all the researcher's contact details.

It was negotiated on first contact with potential participants the researcher would speak to them again either via e-mail or telephone in a week to discuss the study further, answer any questions they may have and make an appointment for the interview to take place at a convenient time and location of their choice with those who were willing to take part. Names, telephone contact and e-mail details were obtained and recorded to facilitate this process and kept securely, as agreed in the University Research Ethics Committee application. Every potential participant who was sent information via Royal Mail was spoken to by the researcher. Some of these contacted the researcher themselves on receipt of information. Those participants who were sent details via e-mail and who didn't respond were contacted again by the researcher on one more occasion. If there was no response following this, it was

accepted those people did not wish to participate in the study, in total there were three.

It can be argued there are limitations to such methods of recruitment in which participants are self selected. Grinyer (2006) suggests respondents to such appeals are in danger of over representation of particular socio-economic backgrounds. Despite this, it would seem that judging by content and form of narratives obtained and from backgrounds of those included, the sample is extremely diverse (table 5 p.122).

4.4. Data collection methods

The following section will describe data collection methods and procedures used in the study. It is important to note for purposes of clarity and organisation data collection and analysis are presented separately. In the methodology that has informed the study these are not separate processes. In grounded theory these processes occur simultaneously, whilst data was collected, analysis of each transcript was also undertaken. This analysis then informed future data collection in a "cycling back and forth" and constant comparison type process.

Participants were given the choice to have an in depth narrative interview (face to face) with the researcher or provide a written narrative.

4.4.(i). In depth narrative interview, (face to face)

One of the main and primary sources of material for the qualitative researcher is the interview. This can take several forms from being structured, semi-structured or unstructured as was the method used in this study. The interview process was informed by narrative interviewing (Wengraf 2001). Unlike the traditional structured interview that has a detailed series of questions to be answered, the unstructured

narrative interview is designed to provide an opportunity for the participant to give a detailed account of a particular experience, event or point in time (Murray 2003). There are a variety of ways of designing the narrative interview (Wengraf 2001). In this study a single question was used to elicit the narrative and is characterised by minimalist intervention from the researcher.

4.4.(ii). Written narratives

Written narratives are also in keeping with qualitative research methods. Participants were given the choice to write their stories in their own time and in the absence of the researcher. One of the main benefits of this method is it enables participants to remain in control of the process. If recruited into the study, contributions can be made at a time of their choosing, be at their own pace and according to their feelings on any given day (Grinyer 2006). Grinyer (2006) suggests there may be circumstances where participants may value the written narrative compared with a face to face interview as it allows the option and flexibility of how and when to reflect on their experiences. The study was asking people to recall personal experiences of caring for someone with dementia and events surrounding the death of that person. This was likely to be an emotive and painful recollection. Bingley (2008) intimate, some potential participants may welcome the opportunity to select the moment, length of time taken over the task and not to have to pre-empt in advance of the researcher's visit that they will be able engage with this person and their story at a particular moment in time for a certain period of time.

One participant chose to write their narrative. Lack of contextual data, absence of non-verbal and visual cues, diminished rapport and inability of the researcher to probe and interpret certain responses compromised analysis of this story and is discussed in a later chapter.

4.4.(iii). Field notes

In qualitative research field notes are considered an important element of data collection. They enhance data and therefore support and enrich analysis (Bluff 2005). Field notes were made at the end of each interview as suggested by Charmaz (1995) in her description of grounded theory. Bluff (2005) also highlights the importance of field notes as an aid to memory regarding events and settings for the researcher. Considering this, the researcher wrote field notes as soon as practically and conveniently possible, usually within an hour post-interview. These included observations and thoughts about how the interview had gone, reflections on relationships with participants and person with dementia and others involved in their care, information about setting and context of interview, how interview did or did not relate to the last one and what information was new or similar. Notes also included conversations of relevance between researcher and participant prior to and following the interview. They were an important aspect of the going analysis process and contributed to initial thoughts and interpretive hunches, possible alternative interpretations and thinking on potential emerging themes and theories. They were also a useful resource and source of information that contributed to and informed future interviews.

4.5. Data collection procedure

This began with expressions of interest from individual potential participants. Aims of the study were initially explained to people via a telephone conversation email. Once eligibility to participate in the study had been established, participant information sheets (Appendix 4) or booklets were sent to interested people via email or Royal Mail. Potential participants were contacted approximately one week later to discuss the study in more detail, answer any questions reading the information had

generated about the study, to outline consent process, confirm consent and permission to record interview and discuss convenient time and location for the interview to take place. Some participants contacted the researcher independently upon receipt of information. This initial introduction to the study and the researcher was designed to increase participants' sense of competence regarding involvement in the research, establish a rapport and assure them their contribution was valuable. Participants recruited via the University intranet were interviewed on campus in a private room located within the researcher's Department. Most interviews took place within participants own homes. University policy for field researchers working alone was followed on these occasions in an attempt to reduce risks to researcher and ensure their safety.

Participants can become distracted by several things when interviewed in their own homes as identified by Bowling (2000). Distractions such as interruptions from other family members, unexpected visitors to the home and telephone calls occurred. On these occasions this was managed in a sensitive manner, interview was interrupted if necessary and participant wished to do so, this was then recorded in the transcript. As soon as was convenient the interview was re-commenced.

Two participants elected not to be interviewed within their own home. Instead one was interviewed in a private room at the main office of the organisation they were recruited from, the other was interviewed in a local hospice familiar to participant and researcher. Offering to hold interviews at a time and place convenient to participants also helps to ensure equity within power relationships (Mills et al 2006). The researcher has minimal if no control over distractions and interruptions within participants own homes unlike interviews that may take place on neutral territory.

On meeting participants the information sheet or booklet was re-visited and any further questions answered. Consent process was discussed and included confirmation again about recording the interview. Once consent forms (Appendix 5) had been signed prior to the interview commencing, several short answer questions were asked in order to elicit demographic information. The reason for adopting this strategy was to orientate the researcher to the unique situation and context of each participant and to give interviewees the opportunity to acclimatise to the focus of the research and idea of being recorded. On occasions participants moved directly into the narrative about their experiences. When this occurred a flexible approach was adopted and demographic questions asked when a timely opportunity arose. Some narratives contained this information which resulted in it not being necessary to do so. All participants retained a copy of the information sheet/booklet and signed consent form for their records.

Demographic questions asked included and sought the following information:
Name of carer, address, contact details, geographical location, location/environment in which death occurred, date of death, age of person with dementia on death, gender of carer, date of diagnosis of dementia, length of time caring, length of time since death, relationship to person with dementia, concomitant health conditions of person with dementia (Appendix 6). Demographic details were also supplemented by eliciting information in the interview that pertained to spouse, siblings and other ongoing relationships.

The aim of the interview was to elicit narratives which focused on a particular point in time, experiences within this time frame and an event, death. To use a pre-structured interview design would have only allowed participants to select isolated parts from their own story (Riches & Dawson 1996). This in effect means they are filling in or

completing pre-existing narratives of the researcher. Whilst there were specific things the researcher was interested to hear about and a list of these made (Appendix 7) to aid memory, this list was not used as a topic guide for interviews. An open ended and informal approach was adopted which enabled the participant to control and set the agenda. Riches & Dawson (1996) suggest encouraging participants to set their own agenda emphasises the value of their perspective and is considered empowering.

In order to elicit narratives each participant was invited to tell their story and highlight any issues important to them, this involved minimal interruption from the researcher. Schulz (2003) asserts the decision about where to begin the narrative is frequently indicative of enduring personal concerns. The narrative was elicited by asking the simple question:

"Can you tell me about the last year of (name of person with dementia) life? I'd like to hear about the issues that you feel were important to you both during this time and surrounding (name of person with dementia) his/her death".

Participants were encouraged to find their own starting point within that time frame. Interestingly stories usually started many years before the last year of life and death an issue discussed in a later chapter.

One individual had difficulty deciding where to commence their story and asked for prompts from the researcher. This came in the form of a conversation about the person with dementia and their care which lead to probing for more personal details using such questions as:

"can you tell me a little more about that, why do you think that occurred? or how did that make you feel?"

The person who chose to write about their experiences was advised to do this in their own time. Participant information sheet and informed consent was discussed with them via email. Demographic questions and introductory question designed to elicit the narrative were provided in written format and sent via email. A stamped addressed envelope was sent at their request, for return of signed hard copies of consent form and narrative. This was then transferred into a Word document by the researcher and saved securely with existing data.

Caring for a person living and dying with dementia can be a major source of anxiety, stress, despair, grief, frustration and exhaustion for the person with dementia and their carer and can be a very emotive issue to discuss (McCurry 2006). Bereavement in general has been identified as being a particularly sensitive issue due to its emotionally charged nature and manner in which interviewing may threaten the bereaved individual. The researcher is a registered mental health practitioner (RMN) with a wealth of clinical experience in working with this group in a therapeutic manner. She also has an understanding of difficulties that may have arisen for carers who had opportunity to discuss their experiences with a person independent of their circumstances. The researcher was aware distress may occur at any time during the process. As a result and for the purpose of informing the ethics committee this had been considered, a distress protocol (Appendix 1) was devised to support management of this. Distress when it occurred, was managed in a sensitive and positive manner by the researcher. Breaks were offered, tissues and drinks were made available and opportunity to cease the interview and re-commence at another time or cease completely, was discussed. Due to the background and knowledge of the researcher, they would have been able to identify any ongoing problems that may have arisen. In collaboration with the participant, having gained their consent,

onward referral would have been made if necessary, however this situation did not arise.

On completion of the interview, participants were thanked for their interest in the study, for giving freely of their time, for sharing personal information and their participation in the study. Their permission was also sought to verify the transcript at a later date once the interview had been transcribed. Two participants didn't feel this was necessary and were happy for the transcript not to be verified and information to be used. All participants were informed they would receive an executive summary of results at the end of the study.

4.6. Data analysis

All face to face interviews were recorded using a digital recorder (Olympus, model DS-40) and transcribed as soon after the interview as practically possible and according to the following protocol:

- Arial font point 12, normal
- Each line numbered in ascending order
- Interviewer identified with initials
- Participant identified with their own initials
- Names of areas (locations), care establishments i.e. care homes and hospitals were omitted and replaced with letters
- Paralinguistics such as "tearful" placed in brackets and in bold italics
- Extralinguistics such as "telephone/doorbell rings" placed in brackets and in bold italics
- Nonlexical expressions such as "uh huh" and " erm" remained in the transcripts
- Local dialect, slang and accents were included in the transcripts
- Hesitations and pauses were marked with (.) or (…) depending upon the length, longer pauses were identified by (PAUSE) in bold text

- Emphasised words were in bold italics
- Unrecognisable parts of the conversations were marked with (????)
- Double quotation marks used for reported conversations

In order to maintain anonymity participants were assigned a study number and only their initials were used. This was negotiated and agreed with participants at commencement of the interview. Initially, the opportunity to use pseudonyms was explained and offered for the reasons outlined above, however this was declined. Rather than delegating the task of transcription to someone else all interviews were transcribed by the researcher. This enabled as many features of speech as possible to be captured and allowed the researcher to remain close to the data supporting interpretive and analytical processes.

Once transcribed narratives were returned to participants, where they had consented to do so, for verification. This process of checking accuracy of transcripts with participants enables them to identify any inaccuracies within transcripts prior to more detailed analysis being undertaken. Transcripts were sent to participants who were asked to comment on them within a two week period. No response by them within or after this time frame being assumed they agreed the transcript was a true reflection of the conversation that had occurred on the day and they were happy for information shared to be used. Three participants contacted the researcher. This was to give further information having the opportunity to read the transcript had triggered. In addition, it provided an initial validity check by allowing possible areas of misinterpretation to be identified. This process also demonstrates credibility and transparency of the study, enhances rigour and integrity of findings. It is also an indication of value placed by the researcher upon participants (Valentine 2008).

Analysis of study data was based as closely as possible on the method described by Charmaz (2006) and was as follows. Immediately after the interview, when possible, field notes were constructed as described earlier. Following this and using the protocol above, the interview was transcribed. Once transcribed, each transcript was read and re-read and interview recordings were listened to on several occasions to establish a flavour of the data. After this initial stage of familiarising oneself with the data coding phase of analysis began. A line by line analysis of transcripts was conducted initially which involved writing notes on printed transcripts. This is also useful for audit purposes and demonstrating transparency. This line by line analysis involves examining each line of data and defining actions and events one sees occurring in it or as represented by it (Charmaz 2006). It is an open ended approach to coding which facilitates analysis based on data rather than on pre-conceived agendas or personal interests and opinions. It is a fundamental step in giving the researcher ideas on what kind of data to collect next and in identifying leads to be pursued.

Line by line coding leads onto the second step of coding which Charmaz (2006) describes as "focused coding". This involves taking earlier codes that continually re-appear in initial coding and using those codes to sift through large amounts of data, it is more directed than initial coding phase. In both coding strategies researcher returns to the data in order to confirm concepts or examine an event from an earlier interview with a new eye based on coding of a more recent transcript.

The next phase of analysis consisted of categorising data. By categorising the data certain codes are selected as having overriding significance in explicating events or processes in the data. A category may include common themes and patterns in several codes. By making a code into a category it is treated more conceptually and

analytically than descriptively (Charmaz 1995). In order to develop categories via focused coding comparisons between data, incidents, contexts and concepts must be made. Charmaz (1995 :42) recommends the following:

1) Comparing different people (beliefs, situations, actions, accounts and experiences)

2) Comparing data from the same individuals with themselves at different points in time

3) Comparing categories in the data with other categories

These comparisons were taken into consideration in the study whilst undertaking the analysis.

Further details and examples of analytical procedures followed and how themes began to emerge from within the data, can be found on the pages overleaf.

Table 3: (a)

Examples of initial coding from text and memos:

Participant:	Initial coding:	Text:	Memos:
Subject 24 KW	Vulnerability of carer emotionally, vulnerability of person with dementia, protective nature, protection at all costs, unable to communicate, after all she's/we've gone through, capacity issues, control, feeling out of control, not wanting to complain but feeling had to, coping with the changes, uncertainty, advocates, ???negative care	"I'm not a complaining person normally but I felt I had to protect my wife as much as possible and I felt I was there for her as she wasn't able to do it for herself by this stage because she'd gone through the illness and to the stage where she wasn't really aware of who I was or anything like that but erm the first thing that happened, they said don't come and see her for three weeks"…….,	Vulnerability of all involved apparent on emotional and practical levels. Person with dementia unable to speak for themselves so carer has to do this on her behalf, feels he has to be her voice in the absence of her own. Think about capacity issues and best interests here, across scripts, carers have to be advocates for person with dementia, emergence of carers feeling they have expert knowledge. Protect her from what??? them and us culture apparent here

Table 3: (b)

Examples of initial coding from text and memos:

Participant	Initial coding	Text:	Memos:
Subject 36 EB	Control, collaboration, attempts to include as well as being/feeling excluded, anger towards formal carers, vulnerability of person with dementia	"and then like when they wanted to turn her and change her position, they were very good a that and she had mouth care and they asked if I wanted to do it and things like that, she really didn't need a lot of care towards the end, mum she was just never, she was just so undemanding, she was amazing, didn't really need very much so when we were asked to leave the room, we both went out the room, he used to get very angry about that "why you putting me out?" and things like that and so forth"……..,	Person with dementia so dependent upon others now for all activities of daily living interpreted by daughter as undemanding, is this measured by communication and requesting things verbally? Appeared to demand high levels of input from formal carers, could be interpreted as being demanding by them?? Demanding upon resources?? Feeling excluded from care, explanations for this action from formal carers could have reduced anger felt at exclusion, similar to other scripts, subj 14

The two examples below demonstrate how text in the "initial" coding phase above was taken and coded in a "focused" manner.

Table 4: (a)

Examples of focused coding from text

Participant:	Focused coding:	Text:
Subject 24 KW	Protection and advocating on behalf of person with dementia Capacity issues Exclusion, out of control	"I'm not a complaining person normally but I felt I had to protect my wife as much as possible and I felt I was there for her as she wasn't able to do it for herself by this stage because she'd gone through the illness and to the stage where she wasn't really aware of who I was or anything like that but erm the first thing that happened, they said don't come and see her for three weeks"

Table 4: (b)

Examples of focused coding from text

Participant:	Focused coding:	Text:
Subject 36 EB	Positive care, attempts at collaboration Undemanding care and interpretations of this Exclusion from care	"and then like when they wanted to turn her and change her position, they were very good a that and she had mouth care and they asked if I wanted to do it and things like that, she really didn't need a lot of care towards the end, mum she was just never, she was just so undemanding, she was amazing, didn't really need very much so when we were asked to leave the room, we both went out the room, he used to get very angry about that "why you putting me out?" and things like that and so forth"……..,

A total of 190 initial codes were developed in the first instance. In the process of coding there were occasions when sections of text would be appropriate for more than one code. Coding at this stage remained predominantly descriptive the process of developing categories from these codes eventually made this more manageable.

Evidence of emergence of categories and themes from coding strategies and some of the researchers thinking integral to this are provided overleaf.

CATEGORIES

(devised from initial and focused coding/memos in transcripts need to consider potential emerging themes/theories)

KNOWLEDGE: knowledge of formal and informal carers. Issues around poor, limited knowledge for both, informal carers asking for information

INTUITION: knowing when someone is going to die instinctively. **(*Is this intuition or experiential knowledge? Is this the carer as expert re: pwd?*)**

STIMULATION/OCCUPATION: (*last yr, prior to death still important for carers that pwd included)* keeping pwd occupied based on information, life history

LIFE HISTORY: Knowledge of pwd, knowing where they have come from, supporting care, supporting carers (*links to knowledge, stimulation/occupation)*

+ve, -ve care: *(links to knowledge, stimulation, life history)* differing acceptance, understanding of what constitutes positive and negative aspects of care

KINDNESS: Care issues for carer and pwd. Kindness of strangers (*links to +ve care),* kindness of family members

SPIRITUALITY: Links across transcripts but very different meanings for individuals, carers and pwd

DECEIT: Last year, formal caring environments usually, lie telling

GUILT: Dying alone, promises made to self and pwd(*links to deceit lie telling),*

MOVING ON: Life after death, coping strategies, support from peers

PRACTICALITIES: Practical issues on death, information, finding out, coping

RELIEF/RELEASE: Meanings for pwd and carer, different, *(links to burden and release from this for carers)*, relates to perceived "suffering" for pwd

BEING: Time to "be" with pwd, limited facilities for this towards eol, also important to carers when dementia advanced

1ˢᵗ and 2ⁿᵈ DEATH: Tales of distressing disintegration of personalities (pwd) and loss of pwd then ultimate death of physical body. 1ˢᵗ death=social death, 2ⁿᵈ death=physical and final death **(*does this link with information, communication, knowledge)***

LOVE: Expressions of love for pwd from carers despite changing personalities (links to communication, knowledge)

TRUST: Carers experiencing difficulties with trusting the professionals, reluctant to leave pwd in hospital environments particularly for fear of no support with feeding,

meds etc. Concerns about level of knowledge in caring for pwd, (**does this link with knowledge, communication, information, +ve care, life history)**

CULTURAL ISSUES: language barriers affecting care and carers expectations of care **(is this culture or linguistics??)**

TRAUMA: has become more common as data collection continues, trauma at eol and marked changes in pwd as 2ND death approaches, links to weight loss mainly and ill preparation for death (**does this link to communication, knowledge, information)**

DEATH TALK: language used by professionals to carers appears to be avoidance of the reality, carers desire openness and honesty (*links to communication*)

RELIGION: range of faiths now included, affects on care, carers, eol and death, faith based care homes

COMMUNICATION: all aspects from all quarters and people involved, encompasses many of the above, good and bad examples in the data, open, honest communication and inclusion is desired

EXPERTS: carers feel they are the experts and ones who know pwd best, desire to have this acknowledged and not overruled by professional carers, partnerships in care desired (*links to communication, knowledge, trust, information, life history, +ve and -ve care)*

ENDURING SELF: carers ability to recognise person within their dementia, signs observed for to let carers know "they are still there", maintenance of personhood (links to love, 1st and 2nd death, communication, experts, faith, intuition or experience, knowledge), however some carers feel person "within" lost to disease and cannot find/observe any sense of "self" in pwd, quite sad, there must always be a slight something?? Is it just about connecting to that, discovering the person "within" the illness

Figure 1:

Emerging themes

Themes emerging from continued comparison of transcripts and development of categories.

Below demonstrates which categories have been placed within which themes.

COMMUNICATION (all types)			
Experts Knowledge, information, love, trust, intuition, experiential knowledge, expectations of care, guilt, life history, enduring self	**Unpredictability Uncertainty** Knowledge, information, 1st and 2nd death (social/physical), death talk, deceit, eol symptoms, transitions, relief, release	**Hard job of Caring** Knowledge, information, stress, sacrifice, deceit, guilt, practicalities, trust, trauma, knowledge occupation/stimulation, uncertainty, unpredictability, moving on, finances	**Kindness and Humanity** Knowledge, information, +ve and –ve care, kindness of care, faith based care homes, stimulation, occupation, being, spirituality, religion

Titles of themes developed as writing up of data commenced

It is important to note Charmaz (1995, 2006) adopts a more flexible approach to analysis than prescriptive and technical methods described by Strauss and Corbin (1990). They describe a phase of coding they refer to as "axial coding" that is used to relate categories to sub-categories (Charmaz 2006: 60). Charmaz (2006: 62) believes relying on axial coding limits what and how researchers learn about studied worlds and may restrict codes constructed. She develops subcategories within categories thus demonstrating how the researcher makes sense of data. In the study, categories and subcategories were developed using the "memo" system described by Charmaz (2006). She described this as the intermediate step between coding and first draft of completed analysis. Memos for each theme were developed in this way for the study. These memos included quotes from transcripts and demonstrate where the researcher's ideas came from and ground analysis completely. Memos changed and were developed with repeated visits to the field, (further interviews) ideas, hunches and theories were checked by returning to data and aided development of analysis. Memos were influenced by comparisons of data (in accordance with the constant comparison methods of grounded theory). They were instrumental in shaping analysis and influenced data collection via the introduction of new topics which aided clarification of ideas used to develop theories.

The researcher was responsible for the primary analysis of data. Transcripts were seen and read by the primary supervisor (Professor Mari Lloyd-Williams). A selection of transcripts and extracts from others were also seen and read by secondary supervisor (Professor Ken Wilson) along with an external advisor (Siobhan Horton, Clinical Director, St. Luke's Hospice, project funders). This was done for credibility purposes in accordance with the evaluative framework utilised for this study.

Developing codes, categories, memos and emerging themes were discussed and compared with this group of people at regular meetings.

As data analysis progressed following constant comparison of transcripts, categories were developed and theories began to emerge from within these and memos. During this phase the literature was re-visited on several occasions. This was in an attempt to support development of analysis and emergent theories. This was also a useful exercise for identifying challenges to theories as they emerged, again this was discussed with the group of people identified above.

4.7. Ensuring rigour

The framework for evaluation and ensuring rigour of the study has been outlined and described in the preceding chapter. A discussion as to whether or not this was successful in the current study is provided in discussion chapter.

4.8. Ethical approval

The study did not involve recruiting participants from the NHS, it was therefore not necessary to apply for ethical approval from the National Research Ethics Service. An application to proceed with the study was submitted to the University of Liverpool Research Ethics Sub Committee located within the researcher's Department in December 2008. This committee judged the application against explicit criteria to ensure beneficence, avoid malificence, establish procedures for informed consent, ensure equal opportunity and affirm technical competence of the researcher and any other personnel involved. Approval was granted from UREC in January 2009 (Appendix 8). Initial data collection commenced in February 2009 and continued until August 2010**.** There were three subsequent submissions to UREC for substantial amendments to be considered. These were related to increases in sample size to

ensure data saturation and notify them of changes to study documentation following a move in location of the researcher. All of these substantial amendments were approved by the committee. Annual and end of study reports were also submitted to UREC in accordance with theirs and research governance requirements.

4.9. Summary

This chapter has provided a detailed description and justification for data collection methods, data management and data analysis processes use to conduct the study. Data collection methods included face to face interviews with the researcher, written narrative, and field notes. The framework for evaluation and ensuring rigour was identified and discussed in the methodology chapter and will be referred to again in later chapters. This chapter concluded with the provision of information regarding ethical approval for the study.

The following chapter will present results from the study. This will commence with information pertaining to participant's backgrounds and demographics of study sample. This will help to contextualise the study and results for the reader. Individual themes derived inductively from data will then be presented and discussed.

Chapter 5: Results

5.1. Overview of Results

The study's results will be presented in this chapter. Information pertaining to demographics of the whole sample and backgrounds of participants will be presented in the first instance. Following this, and divided into sub sections of the chapter, themes derived from narratives will be presented and discussed individually. Exploration revealed whilst narratives were unique, the researcher was able to organise these around the following five common themes:

1) Carers as experts

2) The hard work/job of caring

3) Living and dying with uncertainty

4) Kindness Humanity and Compassion

5) Communicating in a world of chaos and uncertainty

Extracts from narratives have been used in each sub section of the chapter (themes) as exemplifiers which typify similar issues or where they diverge around certain cultural or social circumstances and situations. If one participant is referred to more than others this indicates researcher felt these particular narratives were more "quotable" or succinct than others. Where a quote has been used in more than one theme the researcher felt this was an example of how the themes linked together, this will be more apparent in the communication theme.

5.2. Demographics of Study Population

A total of 41 (n=9 males and n=31 females) participants were recruited into the study between February 2009 and August 2010. Ages ranged from 18-86, there was no representation from black and ethnic minorities. Socio economic background was

varied (table 5.p.121) relationships ranged from siblings and spouse to friends/neighbours. Participants were from both Christian and non-Christian backgrounds including Roman Catholic, Protestant, Methodist, Baptist and Muslim.

A total of 22 participants were recruited from North West of England, four from North East of England, six from Scotland and nine from Wales. These were recruited from a wide range of areas including suburban, urban, rural and semi rural. Length of time from diagnosis to death was varied (table 5 p.122) as was the number of years spent caring (table 5 p.122). There was one unexpected death that occurred suddenly within a day care setting and four of the sample also had a diagnosis of cancer. Three of these people with a dual diagnosis experienced specialist palliative care services in the hospital environment and community with one attending hospice day care. Types of dementia experienced, where known, was mainly of the Alzheimer's and vascular type. Average age of person with dementia on death was 80.5 years, deaths in the hospital environment n=22, in a care home environment n=14 and deaths facilitated at home out of the sample n=4. All but one participant experienced formal support and care from the voluntary sector, social services and the NHS. This would be from individual agencies or a combination of several in varying amounts. The participant who did not engage with any formal support services made this decision based on negative observations and reports of others in a similar position to herself.

5.3. Whole Sample Demographics

Table 5

Study ID	Relationship to person with dementia	Age on Death	Time from Diagnosis to Death	Time since Death (at interview)	Time spent Caring	Place of Death	Occupation of Carer
HR 01	Husband		10 yrs	11 months	8 yrs	Nursing Home	Retired preacher
JK 02	Daughter	81 yrs	4 yrs	1 year 11months	1 yr (last yr)	Family home	Nurse
HL 03	Daughter		5 yrs	9 years	5-6yrs	Nursing home	Physiotherapist
DQ 04	Daughter	*	*	*	7 yrs	*	Lecturer
LP 05	Granddaughter	81 yrs	4 yrs	11months	6 yrs	District General Hospital	Student
PJ 06	Daughter	84 yrs	5 yrs	5 years	6 yrs	DGH	Trainer
JK 07	Granddaughter	87 yrs	2 yrs	9 months	3 yrs	DGH	Student
GA 08	Granddaughter	75 yrs	8 yrs	3 years	7 yrs	Day Care	Student
MP 09	Daughter	80 yrs	1 yr	1 year 8 months	2 yrs	DGH	Hairdresser
CB 10	Daughter	87 yrs	2 yrs	2 years	5 yrs	Discharge ward DGH	Retired
NB 11	Daughter	81 yrs	2 yrs	4years	2 yrs	DGH	Civil Servant
DP 12	Husband	83 yrs	10 yrs	1 year 5 months	8 yrs	Nursing Home	Retired
KH 13	Husband	85 yrs	8 yrs	4.5 years	10 yrs	Family home	Retired
PJ 14	Wife	75 yrs	7 yrs	3 years	10 yrs	DGH	Retired
MH 15	Son	86 yrs	2 yrs	2 years	2 yrs	DGH	Varied, NHS, paid carer
MK 16	Wife	72 yrs	7 yrs	3 years	7 yrs	Nursing Home	Retired
CM 17	Son	82 yrs	4 yrs	1 year	1.5 yrs	Nursing Home	Corporate Insurance Broker
BEP 18	Wife	80 yrs	3 yrs	3 years	5 yrs	DGH	Retired
PT 19	Wife	80 yrs	8 yrs	1 year 2 months	6 yrs	Nursing Home	Retired paid carer

Study ID	Relationship to Person with Dementia	Age on Death	Time from Diagnosis to Death	Time since Death (at interview)	Time spent Caring	Place of Death	Occupation of Carer
TD 20	Daughter	71 yrs	1 yr	8 months	1.5 yrs	Acute Medical Ward DGH	Book keeper Own business
JJ 21	Daughter	84 yrs	4 months	2years 9 months	5 yrs	Acute Medical Ward DGH	Admin worker for police
J Mc 22	Husband	78 yrs	20 yrs	3 months	20 yrs	Mental Health Organic Illness Assessment Ward	Retired GP
FJ 23	Wife	86 yrs	3 yrs	1 year 9 months	3 yrs	DGH (? ward type)	Retired
KW 24	Husband	80 yrs	4 yrs	1 year 8 months	8 yrs	Nursing home Elderly Mentally Infirm Unit	Retired teacher
JB 25	Granddaughter		4 yrs	6 months	3 yrs	Nursing Home EMI Unit	Occupational Therapy Student
BS 26	Daughter	86 yrs	4 yrs	8 months	6 yrs	Specialist EMI Residential Care Home	Practice Development Manager Alzheimer's Scotland
AH 27	Wife	75 yrs	14 yrs	6 months	13 yrs	EMI Nursing Home	Retired nurse, publican
AC 28	Wife	80 yrs	2 yrs	1year 8 months	10 yrs	Acute Medical Ward DGH Lived in residential EMI prior to death	Retired nurse
GJ 29	Wife	84 yrs	2 yrs	2years months	2 yrs	Small Cottage Hospital whilst on respite	Retired
MJ 30	Wife	79 yrs	9 yrs	11 months	5 yrs	Acute Medical Ward DGH	Retired
DT 31	Husband	82 yrs	3 yrs	9 months	6 months	DGH (? re-hab ward)	Retired Artist, Property Manager
MD 32	Wife	69 yrs	2 yrs	1 year 10 months	4 yrs	Family home	Retired teacher
MB 33	Wife	73 yrs	3.5 yrs	8 months	4 yrs	DGH (? acute medical ward)	Retired Bookkeeper, shop assistant
JA 34	Daughter	77 yrs	4 yrs	1 year 8 months	10 yrs	DGH Acute Medical Ward	Paid carer
PD 35	Husband	73 yrs	8 yrs	3 years 3 months	10 yrs	Family home	Retired designer

Study ID	Relationship to Person with Dementia	Age on Death	Time from Diagnosis to Death	Time since Death (at interview)	Time spent Caring	Place of Death	Occupation of Carer
EB 36	Daughter	83 yrs	5 yrs	11 months	7 yrs	EMI residential care home	Retired nurse
JH 37	Wife	70 yrs	13 yrs	1 year 2 months	9 yrs	Mental Health Ward (cottage hospital)	Retired
BC 38	Friend/ neighbour	85 yrs	1 yr	2 years 1 month	2 yrs	EMI Unit within DGH	Retired
BJ 39	Daughter	93 yrs	8 yrs	1 year 4 months	5 yrs	Nursing home owned by Baptist church	Writer
AB 40	Daughter	96 yrs	5 yrs	1 year 4 month	5 yrs	Nursing home EMI floor on respite	Housewife/carer for both parents (father had A/D) Retired
ML 41	Son	71 yrs	12 yrs	11 months	10 years 2 full time	EMI Unit, satellite dementia unit of DGH	Paid carer/support worker in learning disabilities Gave up paid employment to be full time carer

A total of 60 responses to appeals for volunteers were received

41 of these were recruited

16 were excluded (reasons for this have been outlined in an earlier chapter)

3 did not respond to the Patient Information Sheet when sent or follow up after this

* DQ participant number 4: person with dementia remains alive, end of life issues being addressed by family was the reason for inclusion. However, this transcript was not included in the analysis of the data or in the introduction to participants below.

Participants 1, 3 and 25: missing data on age of person with dementia on death was due to this not being obtained at interview or volunteered in participant 25's written narrative. Requests for this information post interview yielded no responses.

There were 28 people with moderate and twelve with advanced dementia upon death. A number of co-morbidities were present including: pneumonia, urinary tract infections, fractured neck of femur (hip), de-hydration, chest infections, pressure sores, chronic heart disease, diabetes, arthritis, hypertension, angina, spondolitis, stroke, Parkinson's disease and four with different types of cancer.

5.4. Introduction to participants

Information on participants provided below was elicited from narratives and questions relating to demographics at beginning of interviews. All participants were assigned a subject number and only their initials were used, as discussed and agreed with them at point of consent. There is a summary of each individual participant and their circumstances. Purpose of this background information is to enable the reader to familiarise themselves with participants, set the scene and contextualise the study.

All participants were offered to be interviewed at a location and time convenient to themselves, 29 were interviewed within their own homes, seven were interviewed in a private room on the University of Liverpool campus, two chose to be interviewed at their work locations and one person was interviewed at a hospice local to them. Most interviews were conducted individually however, there were two where daughters of the person with dementia were also present. One of these chose to be interviewed rather than her mother, who sat mostly quietly just confirming or disputing some information offered. The other daughter sat quietly whilst her mother was interviewed

her mother had requested her presence for support. When interviewing participants within their own homes, each individual was asked where would be the best place for the researcher to sit before commencing the interview. Drinking water and tissues were made available to those being interviewed outside of their own homes. Further details of procedures followed at each interview can be found in the methods chapter.

Subject 01 HR:

HR was the husband of person with dementia, a retired preacher, they lived with dementia approximately 10 years after diagnosis. He cared for his wife for six years within their home before she was admitted to 24 hour residential care following a fall resulting in a fractured neck of femur. He was interviewed 11 months after his wife's death. Family members found visiting distressing towards the end of his wife's life with some, especially grandchildren choosing not to visit. She died in the care home with HR present. He believed his wife was dying for three days before her eventual death. Family and a wide circle of friends built up through their faith supported him in bereavement.

HR died himself from cancer approximately six months following study interview.

Subject 02 JK:

JK was the daughter of person with dementia. Her father's care was mainly provided by her elderly mother within their family home (farm). Her brother also lived there and supported care along with formal/paid carers. They lived with dementia for four years following diagnosis, she spent approximately one year caring for him. She was interviewed one year and eleven months after he died. JK was married with a husband and adult children, she retired from work as a district nurse early in order to

increase her support and maintain her father at home which is where the family decided he needed to be. Six weeks prior to his death the person with dementia was still being included in farm life by his family who took him onto the land in a tractor. Death occurred within the family home, supported by the palliative care team and surrounded by family members.

Subject 03 HL:

HL was the daughter of person with dementia she had one brother. His relationship with his father was not particularly good so he did not support care. Her father's care was mainly provided by her elderly, physically frail mother within the family home. She described her father as a very intelligent man, he was a doctor himself with a very full life. They lived with dementia for approximately five years following diagnosis, she spent approximately six years caring for him as problems were noted prior to diagnosis. HL was married with a young family during this period and also worked full time as a physiotherapist. He was admitted into a residential care home initially following a sudden deterioration in his wife's health necessitating surgery. He was transferred from here to a nursing home having developed a pressure sore residential care couldn't manage. He died two and half months after transfer in this nursing home alone in the early hours of the morning with no family members present.

Subject 05 LP:

LP was the granddaughter of the person with dementia. She was a full time undergraduate student at the time of caring. Her grandfather lived with his elderly wife and was the father of LP's father. All family members supported where they could. They lived with dementia for approximately five years following diagnosis but problems noted beforehand necessitating help. LP was interviewed one year after

her grandfather's death. He died in an acute ward of a district general hospital having spent a period of time in a mental health ward for assessment of behavioural problems and becoming de-hydrated. He was surrounded by his family at the time of his death.

Subject 06 PJ:

PJ was the daughter of the person with dementia. She had returned from New Zealand to care for her elderly father. Upon her father's death she transferred to caring for her mother who had by this time developed dementia. Issues and conflicts within relationship with mother made choice to care and caring difficult, however some healing occurred during the years spent caring for her mother. They lived with dementia for approximately seven years following diagnosis. PJ was employed full time as a trainer and also experienced her own health issues whilst caring (ovarian cancer). She cared for approximately six years then her mother was admitted to 24 hour residential care. She was interviewed five years after her mothers' death. Her mother died on an acute medical ward in a district general hospital having been admitted there from the care home. PJ was not present at the time of her mother's death. She was undergoing chemotherapy for ovarian cancer at the time, her mother had a hospital acquired infection and medical staff advised PJ against visiting due to the risk to her own health.

Subject 07 JK:

JK was the granddaughter of the person with dementia. Her grandfather lived alone and was the father of JK's father who lived abroad. JK was closest family member in terms of location, all others scattered across UK and internationally. She was a full time post graduate student at time of caring. They lived with dementia for two years following diagnosis but problems were noted for years beforehand. She was

interviewed nine months after his death. Her grandfather also had a diagnosis of stomach cancer and they experienced specialist palliative care services within the hospital environment. He lived in a residential care home prior to death and was admitted to hospital from here with problems related to nutrition. He died in an acute ward of a district general hospital.

Subject 08 GA:

GA was the step granddaughter of the person with dementia. Her grandfather lived with his elderly frail wife, other family members also supported care. GA was a full time undergraduate student. They lived with dementia for approximately eight years following diagnosis, GA was a carer for seven of these. She was interviewed three years after her grandfather's death. He died suddenly in a day hospital environment having had a cardiac arrest.

Subject 09 MP:

MP was the daughter of the person with dementia. She was married with small children and also worked full time as a hairdresser whilst caring. Her father lived within his own home with his elderly frail wife. They lived with dementia for approximately one year following diagnosis but many problems were noted for years prior to this. MP cared for approximately two years. She was interviewed one year and eight months after her father died. Her father had spent some time in a mental health ward of a district general hospital for assessment of behavioural problems prior to admission to a specialist nursing home for people with dementia. From this care home he was admitted to an acute medical ward of a district general hospital with a chest infection. He died on this acute medical ward, in the open ward with no family members present.

Subject 10 CB:

CB was the daughter of the person with dementia. Her father was married for a second time, brother and step sister were also involved in care. The second wife of her father, step mother, also developed dementia as a consequence they eventually moved into residential care together. They lived with dementia for approximately two years following diagnosis of her father but problems noted for years before this. CB worked part time initially, then retired early in order to fulfil a caring role. She cared for approximately five years including time he spent in a care home. She was interviewed two years after her father died. He died in a district general hospital having been admitted there from the care home with a urine infection. He died following a cardiac arrest in the hospital whilst in a discharge decant ward awaiting transfer back to the care home.

Subject 11 NB:

NB was the daughter of the person with dementia. She was a single parent and employed full time as civil servant whilst caring. A large family (9 siblings) who all supported care in different ways. Her father lived with his elderly frail wife who experienced physical and psychological issues herself. Nursing home care was tried on one occasion and failed so her father returned home to the care of his wife and family. They lived with dementia approximately 10 years following diagnosis. NB's father also had a diagnosis of liver cancer, no specialist palliative care services engaged. She was a carer for two years prior to his death. She was interviewed four years after her father died. He died in an acute medical ward in a district general hospital with several family members present.

Subject 12 GP:

GP was the husband of the person with dementia. They lived for approximately 10 years with dementia, He cared for around three of these within their family home. Their adult children and grandchildren also supported them. GP was interviewed one year and five months after his wife's death. She was admitted to a hospital based mental health unit for assessment due to behavioural problems at home and limited acceptance of home care. Seven months were spent on this unit. She moved from this unit into a 24 hour specialist nursing care home where she eventually died with GP present.

Subject 13 KH:

KH was the elderly husband of the person with dementia. His wife had been married previously and had one adult son. They were estranged for a long time but back in contact at the time of her poor health and death. They lived with dementia for eight years following diagnosis but KH was a carer for approximately 10 years having noted problems before formal diagnosis. KH was interviewed four years and seven months after his wife's' death. She died within their home with KH present and the support of primary care and specialist community based palliative care services.

Subject 14 PJ:

PJ was the wife of the person with dementia. Their son and daughter in law lived close by and also supported care. They lived with dementia for approximately seven years following diagnosis but PJ was a carer for 10 years as problems noted beforehand. Her husband was prone to urinary tract infections which had a marked effect upon both his mental and physical health at the time. PJ cared for her husband at home until this became too stressful mainly due to poor mobility. He was admitted

to a residential care home. PJ was interviewed three years after her husbands' death. He died in an acute ward of a district general hospital having been admitted there from his care home for problems related to nutrition and hydration.

Subject 15 MH:

MH was the son of the person with dementia. He was one of two children, his brother lived in Canada. He was a bachelor and had lived with his mother for many years. He worked full time whilst caring, services were engaged to support his mother and he arranged most of this independently. They lived with dementia for approximately two years following diagnosis, problems were noted beforehand however. His mother had breast cancer and had undergone a mastectomy in 1985. She also had lung cancer and was the only participant in the study to experience and attend their local hospice for day care. He was interviewed two years after his mother's death. She died in an acute ward of a district general hospital having been admitted with breathing difficulties. Transfer to their local hospice as she neared the end of her life had been offered and discussed, however the carer declined as he felt hospital was the best environment for her. She died on this ward with her son present.

Subject 16 MK:

MK was the wife of the person with dementia, they had three children. Her husband was one of five siblings, with his four brothers still alive. They lived for approximately seven years with dementia following diagnosis, MK was a carer for three of these. She described her husband as a very active man, he had worked in the pits and enjoyed helping others. He suffered from spondolitis and also had a myocardial infarction and angina following this. MK also experienced some health issues, she had arthritis and had undergone a triple heart bypass some time ago. MK was

interviewed three years following her husbands' death, he died in a nursing home with his family present.

Subject 17 CM:

CM was the son of the person with dementia. He has a sister and there was some ongoing family conflict regarding his mother's care and her location. CM was married with two adult children, his wife also supported care. His mother lived in the south of England originally in sheltered accommodation. She moved up north to be nearer her son. She moved into specialist nursing care as her needs changed. They lived for approximately four years with dementia, he was a carer for about 18 months of these. He was interviewed one year following his mother's death, she died in the nursing home.

Subject 18 BEP:

BP was the elderly frail wife of the person with dementia. She experienced health problems herself with arthritis. They had one son and two grandchildren. They lived with dementia for approximately three years following diagnosis, problems noted prior to this however, she was a carer for five years. Her husband had a permanent indwelling catheter as a result of an enlarged prostate. Surgery for this was discussed but it was felt the risk of permanent incontinence following this on top of all their other difficulties, was deemed too great to go ahead. She was interviewed three years after the death of her husband. He died in an acute ward of a district general hospital having been admitted following a collapse at the family home. BP was on the ward at the time but not present as he died when the nurses were attending to him.

Subject 19 PT:

PT was the wife of the person with dementia. It was the second marriage for them both, they had eight children between them. There were some conflicts within the family over caring responsibilities and roles. They lived with dementia for approximately eight years following diagnosis, PT was a carer for six of these. Her husband also had angina, type 2 diabetes and suffered with arthritis. She was interviewed one year and two months after her husbands' death. He died in a nursing care home, end of life care was delivered by care home staff and primary care, morphine was administered via a syringe driver, she was present at his death.

Subject 20 TD:

TD was the daughter of the person with dementia, she also had a sister who helped support her father. Her father lived with their elderly mother in their own home. TD was married with two young children and also worked in full time paid employment whilst caring. They lived with dementia for approximately one year following diagnosis, however, TD was a carer for 18 months as problems were noted prior to this. Her father had health problems over a number of years related to his circulatory system necessitating several hospital admissions. He had experienced several strokes, had surgery on his carotid artery and underwent a coronary artery bypass in the last months of his life. She was interviewed eight months after her father's death. He was transferred to a respiratory medicine ward in the district general hospital following by pass surgery. He died on this ward having contracted MRSA and pneumonia. TD and other family members were present at the time of his death.

Subject 21 JJ:

JJ was the daughter of the person with dementia, she was an only child, married with one son and in full time employment whilst caring. Her husband and son also supported care. Her father lived with his elderly frail wife in their own home which was in close proximity to JJ. Her father was of Polish decent and had lived and worked in the UK for many years. They lived with dementia for approximately one year following diagnosis however, JJ had noticed problems many years before this and was a carer for five years. He was eventually admitted into a specialist nursing care home when his behaviours became too difficult and unpredictable for the family to manage. She was interviewed almost three years after her father's death. He died on an acute medical ward of a district general hospital having been admitted following a fall in the care home, sustaining a fractured neck of femur. He was also dehydrated and had a chest infection at that time and admission to hospital was being considered by the formal carers. As her father approached the end of his life, palliative care was discussed with them, in terms of "nothing more could be done". Morphine was administered for pain relief at family's request. He died on this medical ward in the early hours of the morning with no family present.

Subject 22 JM:

JM was the husband of the person with dementia. They had three children and four grandchildren who also supported care and maintained contact. JM was a retired General Practitioner. His wife was diagnosed with dementia at an early age (58 years) problems were noted prior to this, they lived with dementia for 20 years following diagnosis. During this time JM was a carer within their family home for his wife for six years. The next 14 years of life with dementia, his wife spent as an inpatient in a continuing NHS care bed in the mental health unit of a local district

general hospital. JM was interviewed three months after his wife's death, he was very keen to be involved in the project and share his experiences. His wife died as an inpatient in a mental health unit having been promised a bed for life many years previously. JM and his family were present at the time she died.

Subject 23 FJ:

FJ was the elderly frail wife of the person with dementia, they had been married for 60 years. She described her husband as being a physically fit an active man, he served in the RAF and was a retired policeman. FJ had suffered a stroke and was disabled herself as a result and had paid carers supporting her as well as her husband. They lived with dementia for approximately four years following diagnosis, problems were noted prior to this, FJ was a carer for three of these years. She was interviewed one year and eight months after her husband's death. He was admitted to a district general hospital with confusion and transferred to a local cottage hospital where he died suddenly whilst awaiting nursing home placement.

Subject 24 KW:

KW was the husband of the person with dementia, they had three children and several grandchildren. They lived with dementia for approximately five years following diagnosis however, KW noted problems for several years prior to this. He was interviewed one year and eight months after his wife died. She died in a specialist dementia unit attached to a nursing home, KW was not present when she died.

Subject 25 JB:

JB was the granddaughter of the person with dementia. She was a full time undergraduate student at time of caring, her parents also supported care. Her

grandfather lived with his elderly frail wife. They lived with dementia for approximately four years following diagnosis. JB was involved in caring for this period of time. This was a written narrative provided approximately six months after her grandfather had died. He was eventually admitted into a care home eight weeks before he died as the family could no longer cope or manage his behaviour. Three weeks before he died he was hospitalised with a chest infection. He was discharged back to the care home after nine days and died 18 days later.

Subject 26 BS:

BS was the daughter of the person with dementia. She was in paid full time employment at the time of caring working for a charitable organisation specialising in dementia. Her mother was a widow and lived alone initially, other family members supported the care within her own home. They lived with dementia for approximately four years following diagnosis however problems were noted prior to this, BS was a carer for six years. Her mother was admitted into residential care initially, then transferred to a specialist home registered to care for people with dementia. This was due to challenging behaviours and was owned and run by a Christian organisation. BS was interviewed eight months after her mother's death. Palliative and end of life care was provided within the care home supported by the General Practitioner and district nurses. Morphine for pain relief was administered via a syringe driver. Her mother died in this care home with her family around her.

Subject 27 AH:

AH was the elderly, frail wife of the person with dementia. They had seven children, four still living, several grandchildren and great grandchildren all of whom were involved and supported care. The person with dementia was described as being physically fit and active, he had been employed as an electrician had also been a

publican. They lived with dementia for approximately 14 years, AH had been a carer for 13 of these. Her husband was admitted into 24 hour care due to her failing health. They experienced two different care homes that were specialist and registered to provide care to people with dementia. NHS continuing health care funding was awarded three months prior to his death after what she described as a long battle. She was interviewed six months after her husband's death. The community palliative care team were involved in the last 48 hours of his life, a syringe driver was insitu to manage pain. AH described conflicts with medical and care staff over pain relief. She requested to take her husband home to die as his death approached and was told it was too late. He died in this specialist nursing care home with his family around him.

Subject 28 AC:

AC was the wife of the person with dementia. Both had been married previously with children from these different relationships which were a source of conflict within the caring role. AC was younger than her husband and had been a paid carer actually managing a local nursing care home. She described her husband as an active, interesting man. He was a businessman, enjoyed car racing and actively participated in this sport and was also a keen sailor. He was well known and respected in their semi rural community. They lived with dementia for approximately two years following diagnosis however, problems were noted several years prior to this and AC was a carer for 10 years. She was interviewed two years and eight months after her husband's death. He was admitted into specialist residential care due to her being unable to manage some of his behaviours. He died in an acute ward of a district general hospital having been admitted there from this care home with concerns for his physical health, AC was not present at his death.

Subject 29 GJ:

GJ was the wife of the person with dementia. Her husband had been married for three times and had children from other relationships but contact with these was limited. GJ was younger than her husband and they had no children together. Her husband had other physical health problems including, swallowing difficulties, problems with enlarged prostate, Parkinson's disease and a history of stroke. GJ had problems with her own health which affected her mobility creating some issues with her caring role. They lived in a semi rural area which she did not feel affected access to paid support and care other than when problems occurred outside of the usual working hours i.e. M-F and 9-5 and the air ambulance was required on these occasions. They lived with dementia for approximately two years following diagnosis, she was a carer for all of this time. She was interviewed three years and 10 months after her husband's death. He died in the local cottage hospital close to their home following a fall whilst there on respite, GJ was present when he died.

Subject 30 MJ:

MJ was the wife of the person with dementia. They had been married for 50 years and had two children and one grandchild. They live in a semi rural area and were supported with paid carers. She described her husband as an active man he had been employed as an electrician and a milkman and was very handy around the house with DIY. They lived with dementia for approximately four years following diagnosis however, she noted problems prior to this and was a carer for five years. She was interviewed 11 months after her husband's death. He was admitted to a district general hospital in a nearby town for a medication review, discharged home with pneumonia and admitted straight back to hospital. He was transferred from there to a rehabilitation unit for physiotherapy then transferred from there to a care

home. He died in an acute ward of a district general hospital having being admitted from the care home with dehydration and kidney failure, his wife and family were with him when he died.

Subject 31 DT:

DT was the husband of the person with dementia and the oldest person in the sample at 86years. They had been married for 60 years, had one daughter and three grandchildren who lived close by. They lived in a rural area that was quite isolated however access to paid care and support did not seem to be a problem for them. His wife had survived breast cancer, having a double mastectomy some years earlier. They lived with dementia for approximately three years following diagnosis. DT did not recognise the symptoms of dementia or understand the difficulties his wife was experiencing and attempted to continue as they always had done with minimal support. He was a carer for around six months before she died. He was interviewed nine months after her death. She was admitted to the district general hospital some miles away having had a fall in their family home sustaining a head injury. From there she was transferred to a rehabilitation unit for physiotherapy again some miles away from the family, and generally deteriorated, taking less and less diet and fluids, developing a urinary tract and chest infection until she eventually died on her own with no family present in the early hours of one morning.

Subject 32 MD:

MD was the wife of the person with dementia, they had four children and five grandchildren who were spread around the area in which they lived which was semi-rural. Her husband originated from Turkey, his family were still alive there, they were frequent visitors to Turkey and had a home there. They lived with dementia for approximately three years following diagnosis however MD had noted problems prior

to this and was a carer for four years. Her husband was also diagnosed with a brain tumour some years after his dementia diagnosis. She was interviewed almost two years after his death. He died within their family home, specialist palliative care services supported and facilitated this, MD and her children were with him at the time he died.

Subject 33 MB:

MB was the elderly wife of the person with dementia, they were married for 40 years. They had two children, a son and a daughter and one grandchild who lived reasonably close by, all supported care. They lived with dementia approximately four years following diagnosis however problems were noted prior to this. MB was a carer for her husband for four and a half years. He had three admissions into hospital in the last year of his life. She was interviewed eight months after his death. He died in a district general hospital in a side room on an acute ward having been admitted with pneumonia with his family present. This participant was put on the Liverpool Care Pathway by ward staff.

Subject 34 JA:

JA was the daughter of the person with dementia. She was married with two children and worked in paid employment for a voluntary agency whilst caring. Her mother lived alone but in close proximity to JA. Neighbours local to her mother also supplemented care. They lived with dementia for five years following diagnosis however, JA feels she spent 10 years caring for her mother as problems were noted many years before this. Her mother also suffered from emphysema which impacted on her mental and physical health. She was interviewed one year and eight months after the death of her mother. Her mother died in an acute ward of a district general

hospital having been admitted from home, JA was not present at the time her mother died.

Subject 35 PD:

PD was the elderly husband of the person with dementia. They had no children, PD cared for his wife within their home which he had had built and specially adapted to meet her needs as her dementia progressed. They lived with dementia for 11 years following diagnosis and he was a carer for 10 of these. PD would take his wife on trips back to her homeland, Ireland as often as he physically could. He continued to take her for beauty treatments at a local salon and attempted to maintain her social interactions as long as possible. He was interviewed three years and three months after her death. She was very advanced in her illness she suddenly deteriorated and died peacefully within their home one New Year's day with family present. Primary care out of hours GP had visited and decided not to admit to hospital.

Subject 36 EB:

EB was the daughter of the person with dementia. She was single and had one brother who was not really involved in the care of his mother. EB had been a qualified nurse and also worked in education, she gave up paid employment to fulfil her caring role, caring for both parents at one time. The person with dementia lived with her elderly frail husband independently in their family home initially and then they both moved into residential care together. They lived with dementia for approximately five years following diagnosis. EB was a carer for about seven years as problems were noted for her mother prior to diagnosis. EB's mother shared the same bed and room as her husband in their care home until death. EB was interviewed one year and 11 months after her mother died. She died in the care

home with her husband and EB present. End of life care was delivered by care home staff and primary care.

Subject 37 JH:

JH was the elderly wife of the person with dementia, they lived in a semi rural area. They had two children who lived reasonably close who also supported care. JH had her own health problems. She required two hip replacements at the time of caring these were postponed. They lived with dementia approximately 10 years following diagnosis. Her husband also had a diagnosis of Parkinson's disease. He had a permanent indwelling catheter to manage continence issues and this was the source of many problems, necessitating support from primary care and frequent hospital admissions. One hospital admission involved seven transitions within the one admission. JH cared for approximately nine years within the family home. Aids and adaptations were required to meet both of their needs but the cost implications affected provision of these. She was interviewed one year and two months after her husbands' death. He died in a local cottage hospital on a mental health ward they used for respite purposes having being transferred there from a larger district general hospital in a nearby town, JH was present at the time of her husband's death.

Subject 38 BC:

BC was a long standing friend (20 years) and neighbour of the person with dementia. She lived very close to the person with dementia, the same lane, in a hamlet, in a semi rural area. The person with dementia was a widow and lived alone. She had no children however, her deceased husband had been married previously and had children who were not involved in care at all. There were some complicated caring issues relating to self neglect, acceptance of home based care and the use of the

Mental Health Act (DoH 2005). Conflicts with other neighbours over the caring role who should assume this responsibility highlighted the vulnerability of people with dementia in this situation on many levels. They lived with dementia for approximately one year following diagnosis. However, many problems noted for a long time previously prior to this being given. BC spent approximately two years as a carer following the death of the husband of the person with dementia. She was interviewed two years after the death of her friend. Her friend died in a mental health unit attached to a district general hospital with no-one around her apart from clinical staff.

Subject 39 BJ:

BJ was the daughter of the person with dementia, she also had a brother residing close by who supported care. Her father moved in to BJ's family home, in a semi rural area, to live with them when problems were first identified. BJ was married with adult children but these were of a younger age when her father lived with them. They lived for approximately eight years with dementia, BJ caring for approximately five of these. She gave up paid work to care for her father as his dementia progressed. She was interviewed one year and four months after he died. Her father was admitted into 24 hour nursing care, after a hospital admission for a cerebral vascular accident. This was a faith based care home, Baptist, who had carers that spoke his first language (Welsh), he died in this care home with family present.

Subject 40 AB:

AB was the elderly daughter of the person with dementia who was 96 years old on her death. AB was one of three siblings, her brother lived close by and offered support regularly sleeping overnight, their sister lived in Australia. AB was married with no children, her mother lived alone but on the same lane as AB. They lived with dementia for approximately five years AB cared for her mother all of this time. AB

had supported her grandmother for a number of years previous to this who also had Alzheimer's disease. She was interviewed a year after her mothers' death. Her mother died in a nursing care home whilst on an emergency respite, AB was not present.

Subject 41ML:

ML was the son of the person with dementia. They lived with dementia for 15 years following diagnosis of early onset type, 10 of those ML spent caring. A younger, single carer who gave up employment as a paid carer in a learning disability service to care for his mother full time for two years within their family home prior to admission to 24 hour nursing and then hospital based care. This was the only person in the sample to have an artificial feeding tube (PEG) insitu. He was interviewed 11 months after his mother died. She died in a community hospital environment with specialist mental health provision. Palliative care was delivered by hospital based nursing staff experienced in dementia care, ML was present at the time of her death.

5.5. Individual Themes

Individual themes derived inductively from within data will now be presented and discussed. There are five in total, informal carers as experts; kindness, humanity and compassion in care; living and dying with uncertainty and unpredictability; the hard work of caring and communicating in a world of chaos. The latter is the underpinning theme that focuses on all aspects of communication and as such will be the last theme to be presented and discussed. Extracts from individual transcripts will be used to demonstrate interpretations and meanings throughout the themes.

5.5.1 Theme 1: Informal Carers as Experts

> *"a person who has extensive skill or knowledge in a particular field"*
> (English Dictionary and Thesaurus 2000).

The above dictionary definition enlightens us as to what constitutes an expert. Experts can be found across the life spectrum and in many different disciplines. The term and concept will be discussed in this theme relating to informal and formal carers and care experienced in the last year of life and around time of death for a person with dementia. There will be a specific focus on healthcare and nursing.

As indicated in the above definition, to qualify as an expert one has to get to know pretty much everything about a subject, an issue or a person. Development of competent skills and extended knowledge about a given subject, place, issue or person is crucial to being assigned this title. However, not everyone is comfortable with this title and some may advise against its use or being referred to as an expert. One such person is Winslow (2007), he is troubled by the title "expert" and suggests it is an unfavourable label that may not be so desirable after all. He purports when one acquires this title, in whatever way, problems commence. It exposes the person (the expert) to critique, criticism and conflict from all manner of directions, an issue that occurred within the study addressed later in the chapter. In his opinion an expert is not necessarily a writer of books or articles but someone who can be asked any question about something in their domain, field or industry and be able to talk at length about this and answer the questions asked in laymen's terms and without using buzz words or technical jargon, depending upon who they are talking to. An expert who is a layperson should be able to explain issues using very basic analogies, a scientist or studier in a field however, should be able to take that

conversation to another level and discuss it at the highest levels of human thought using their own terminology or industry terms (Winslow 2007).

Whilst the above dictionary definition and Winslow's (2007) interpretation of what constitutes an expert may initially appear quite straightforward and simple, this is not necessarily so or case in health care. The concept 'expert' became common in nursing literature with the advent of Benner's (1984) work nearly three decades ago. Benner's (1984) analysis of observations in nursing practice demonstrated what expert nurses do in specific situations and how beginners and expert nurses do things differently. Within this and in both practice and education becoming expert is viewed as the pinnacle of attainment. Whilst the term has a common meaning, it is apparent when used in nursing it refers to a multitude of attributes and lacks clear definition. Jasper (1994) attempted to devise an operational definition for the concept of 'expert' in nursing. She suggests defining attributes are a possession of a specialized body of knowledge and skill, extensive experience in a field of practice, highly developed levels of pattern recognition, and acknowledgement of all these by others. Lack of acknowledgement by professionals of the suggestions above was a source of conflict, anger and distress for participants in the study as will be demonstrated later.

One could argue there was a combination of experts in the study. Those who were professionals (formal carers) and paid for providing a service in which they were viewed as experts by lay people (informal carers/participants) and lay people who considered themselves as experts above professionals when it came to care of the person with dementia. There were elements of conflict and criticism amongst these

147

groups Winslow (2007) identified. This was mainly attributable to lack of acknowledgement and value placed upon carers expert knowledge and skill relating to care of the person with dementia by professionals.

One participant who may be considered a lay person, according to Winslow's (2007) interpretation of an expert, felt decidedly uncomfortable with what he thought a consultant in gerontology was attempting to tell him, his wife was nearing the end of her life and any attempts to sustain this would be futile. This carer considered himself the expert in relation to his wife who had advanced dementia and experienced some conflict which he verbalised as the quote below demonstrates:

"I'd seen the consultant on Monday morning, he said, "things have changed" I said "yes they have" "it's not looking good" I says "but she's come round", "yes"… I had a feeling he was trying to say well you know this is the end but I'd seen her, it wasn't the end, he walked in… walked in with his entourage… introduced himself… I hadn't seen him before he walked round the bed… said "now then Mrs. H", J never said a word, she was sat up, propped up, he turned to me and said "you see, almost comatose" **(PAUSE.)** *he said "can we have a word outside?" ….word comatose stuck…. she greeted me when I walked in I'd had a smile from her, I'm thinking well no way am I gonna say well fair enough you can, I said "well, once the speech and language therapist have been in we can start feeding her, she can be taken off the drips" "I can get them in any time" I said "well you know I've been spoon feeding her for long enough now I don't know what's required but we'll just have to see how it goes" I was thinking I don't like, I don't like his approach to this. I went back in the room I went to sit down and said "how are we love?"* **(gestured a smile as response)** *that said it all…………"* (Subject 13)

This participant took his wife home from hospital after this event. He cared for her within their own home with support from Primary Care services until her death occurred some months later. He was also offered the option of feeding his wife via a naso gastric tube in order to support her nutritional status in consultation with his stepson (P), declined this on the basis that in the absence of her being able to

communicate her wishes independently, it wasn't in her best interests and as the person who knew her best, he felt she would be traumatised by the event.

"P, I've got to be honest with you, I can't put her through that it would be so unfair" *he said "well, I've got to agree with you" I said "it's gonna be hard but, I can't do it" it's got to be in the best interests of J to put her through that wouldn't have been in her best interests, you know to put her through the trauma… she couldn't swallow so we'll have to push and push **(gestured pushing something down J's throat)** I know they would be gentle but the trauma that would create… possibility of that coming out…. I said "P, I can't do it" I went back and passed the message on…………."* (Subject 13)

The above quotes alert us to two issues. Who is the actual expert in relation to people with dementia and at what point in the disease trajectory? Also the issue of proxy's as decision makers for people with dementia. Carers may be experts in relation to day to day events, personalities, behaviours and what the person with dementia needs regarding activities of daily living. However, when more specific knowledge and experience of health and end of life care are required, we appear to have a paradoxical situation on our hands which leads us to question who the expert actually is on these occasions. Is it so difficult to assume we have, or may have, several experts in these circumstances who need to work together acknowledging and valuing individual skills, knowledge and role each person has to play in supporting one another at potentially difficult times?

The quote below is another example of conflict between formal and informal carer as experts. Recognition of expert on this occasion appears to be one sided with no flexibility on the part of professional expert or acknowledgement from them of the value the knowledge the carer brings to this difficult situation. Hospital protocol

stated all person's had the right to know their diagnosis regardless of any concurrent diagnosis such as dementia that may influence this. The person with dementia had also been diagnosed with cancer and it was his family's wish that he wasn't informed of this at each appointment. The informal carer had spoken to the palliative care nurse linked to the hospital and expressed this wish. This was not carried out and the cancer diagnosis discussed in the presence of the person with dementia at a consultation. This is how the carer felt on this occasion knowing she would have to manage the consequences of the professional's actions:

"it was my belief he'd not got the mental capacity to know, every time he was told it would be like telling him again…. he would have that terrible… she was really quite .. not aggressive… it was her opinion he should know that was it…. I think relatives know… well I know my husband better than anybody, we'd been married for forty five years….. it wasn't appropriate to tell him.." (Subject 32)

The issue of using proxy's as decision makers on behalf of people with dementia, has also been addressed in the literature review. With regards to this, the question that remains is, can we ever be sure decisions made are in the best interests of the person with dementia or are the same decision they would have made for themselves in different circumstances if they were capable?

Abel (1998) in a study of female carers across chronic illnesses which included dementia, identified conflict amongst the group of women who had acted as proxy decision makers on behalf of the person with dementia. Difficulties in separating out what these carers would have wanted for themselves in a situation and what the person with dementia would have chosen either in a different time or as they were now, were a source of anxiety and inner conflict. Dealing with a person who appears

different from the person they once knew and making decisions on their behalf was not an easy task for them. It was difficult to take comfort in decisions they had made for people based on what they appeared to want as they were unable to communicate their wants and needs independently. Powell (2011) discussed similar issues when faced with making a health choice on behalf of her mother who had dementia in the last year of her life. For her conflict arose between the professional and within the family. Potkins et al (2000) specifically studied carers as proxy end of life treatment decision makers for people with dementia in two different caring environments, continuing care and assessment. At that time they suggested, whilst carers play a vital role in making decisions on end of life and treatments, consideration needs to be given to previous and current views of the person with dementia. In an attempt to address and facilitate this, the Mental Capacity Act (DoH 2005) was implemented in England and Wales. Scotland has its own mental capacity legislation which has been in force since 2000.

Whilst this act was viewed as a positive move for those who lack capacity to make their own decisions and a way to make previous wishes known, implementation and uptake of this amongst people with dementia and their carers continues to be minimal and problematic. This may be attributable to several influencing factors including, financial cost, dementia remaining largely a disease of old age and continued stigma attached to both of these and death and dying in general. Another issue with regards to formalising views and wishes of people with dementia and their carers is the timing of such conversations. Potkins (2000) suggested conversations about care and treatment decisions take place earlier on in the disease trajectory or at diagnosis. This would enable evolution of a balanced view point to be elicited

based upon carers' knowledge of the person with dementia and clinical realism of the situation. It is hoped this would facilitate development of a relationship with clinical teams where open discussion of such issues feels comfortable for all. Natural progression would be to think about and develop advanced care plans and treatment directives in anticipation of deterioration and eventual death. People may not be open to discussing such emotive issues as death at an earlier time in the disease trajectory. As discussed previously, unlike some of the other terminal illnesses, it is more difficult in dementia to suggest time limits or predict how long a person may live with the disease. None of the participants in the study had considered advanced care plans or treatment directives. A number had spoken about death, disposal of body upon death and funeral arrangements. These conversations however, tended to be tongue in cheek and superficial rather than any firm requests or choices being made and documented. In these situations carers did recall these conversations and ensured what appeared to be the wishes of the person with dementia were carried out as closely as possible as the quote below demonstrates:

*I said "I'd like the priest to come see him, not to give him last rights… the fact he is a Catholic and would like a priest of his faith to come see him"… a lovely priest came out….. so I had done what I thought was the right thing to do with him because it was something we hadn't discussed, death and that sort of thing….." (*Subject 28)

"he said to me he wanted to be cremated, wanted his ashes scattering at O P now he said that years and years and years ago, that's what I did for him, he was cremated…." (Subject 28)

The quote below appears to demonstrate an occasion where "experts" in the circumstances were collaborating, acknowledging and valuing each others contribution along with their knowledge and roles in maintaining well being of the person with dementia. Over many years together the carer had acquired intimate

knowledge of her husband and symptoms he experienced when he was developing a urinary tract infection. She had specific management strategies in place to avoid/reduce the risk of these occurring. She shared this information with professionals taking care of him for periods of time in an attempt to continue to minimise the risk. It also demonstrates a decision being made by carer as expert in the best interests of the person with dementia that would probably resonate with one they would have made independently to avoid ill health had they been in a position to do so.

*"I could alleviate that by knowing symptoms, I knew what to do, he was by then going to W H for day care **(specialist day service for people with dementia)** I would contact the manager, say my suspicions of a possible UTI, they would give him liquids all through the day……"* (Subject 14)

In the following quote we become aware of inner conflict a carer has regarding a decision he made on behalf of his mother at a time when she was vulnerable and unable to communicate her choice independently of him. No conversations had taken place between them at an earlier time about consequences of her diagnosis or how this may affect her in the future.

"the consultant mum was under he discussed PEG feeding with me, I knew about PEG feeding for years before I'd seen that as being a scenario looming for years.. he was in two minds whether or not mum was suitable for that procedure….. I think part of him was concerned about quality of life mum had then and would subsequently endure if you like ….I remember him saying to me was mum was still a relatively young woman at the time, mum then would have been 66 at the time so he canvassed my view, obviously I said "yes" admittedly from a sort of selfish stand point in part I just wanted so desperately to hold onto mum, I wanted mum to go on, therefore he agreed to do it, so he did the procedure……that's how mum came to be PEG fed….I've had to live ever since you see with degree of guilt …would mum herself, had mum have been in a position to make that decision, have elected to be PEG fed…..was I just prolonging mum's condition which was going to continue to deteriorate and her poor quality of life with no prospect of getting any better…..I was

desperate to keep mum in my life I loved her so much…. didn't want to be without her…….." (Subject 41)

The quote above also demonstrates possible conflict professionals as experts may experience when faced with making decisions about treatments that will prolong life of a person with dementia whose quality of life appears to them to be poor. In the absence of any clear written wishes or instructions professional as expert has to make decisions taking several influencing factors into consideration. This may include what can be subjective wishes of a carer who is desperate to prolong a life in order to meet their own needs rather than those of the person with dementia. Emotive, difficult, moral and ethical decisions have to be addressed throughout the journey of dementia and continue up to and including end of life. There are no easy solutions to these, however, acknowledgement of relationships and knowledge informal carers may bring to these situations is necessary.

Disagreeing and being in conflict with professionals over care of a loved one who is incapable of making their own decisions and communicating choices can be a real disadvantage for carers of people with dementia (Hughes 2006). In addition to feeling uncertain, anxious and possibly guilty carers may feel unheard by those whom they view as experts and are relying upon to provide appropriate care and advice. This can occur when carers feel attention to what maybe considered a basic need becomes problematic for professionals. The sense of frustration felt by the following carer when information and knowledge of her husband and his needs had been shared with hospital carers and not acted upon, is evident in the quote below.

"they won't listen to what you say to them, I used to go in some days, there would be a drink, they'd say "he's had nothing to drink", I'd say "no, he won't if it's over there on the trolley, he can't pick it up!" you know you can't have a drink if you can't hold it

for god's sake, he's not able to hold it, I would maybe give him a drink, he'd take a bit, he did drink the whole lot eventually but you can't get through to them……..."
(Subject 37)

 All participants in the study encountered different professions, professionals and formal care at some point within the time frame being studied in relation to caring for the person with dementia. This was in a range of environments including their own family homes, care homes and local hospitals. Participants' social construction of concept of expert in relation to this group appeared to be influenced by several factors. These included, environment in which formal carers worked, nature and hierarchy of their roles within this (ie doctor, nurse, dietician, physiotherapist, carer, care home manager) and perception of specialism's by participants. Generational linked ideologies of professionals, respect for and expectations of these groups by informal carers in relation to care provided or omitted also appeared to influence this.

Carers in the study believed they were experts in relation to needs and care of the person with dementia. This view was largely borne out of being in a relationship with the person with dementia over a number of years either as a spouse or sibling. Some of carer dyads had been in spousal relationships for as long as 40, 50 and 60 years as demonstrated in one of the extracts earlier. Knowledge acquired about a person over this period of time can be vast and extremely valuable (Hughes 2006). When faced with a formal health care situation in which informal carers may encounter several different people and professionals in the supportive role, it is this knowledge that can make the difference and be crucial to the well being of carer, care recipient and overall experience of end of life care and eventual death. Hughes (2006) identified and acknowledged the broad range of professionals who may be involved in caring for someone with dementia at any given time and the level of

knowledge and expertise they bring to delivering palliative care to people with dementia and their carers.

Knowledge of dementia and living and dying with dementia has been an issue throughout the study data. This has been on different levels and involving different groups of people. Knowledge will be discussed in different contexts in individual themes. In relation to this theme, carers as experts, it will be discussed in terms of what informal carers know about the person with dementia, how they know this and how, in accordance with what they feel, this may qualify them as expert above professional/formal carers.

Knowledge, similarly to concept of expert, is difficult to define. Debates amongst philosophers and within the field of epistemology as to what constitutes knowledge and how to define it continue. Discussions on how knowledge relates to truth, justification, belief and individual interpretations of it can be found in the literature (Einstein 1966, Reaney 1988, Weinstein 1993, Gasset 2002). Knowledge can be defined as facts someone knows about a subject, something or someone. It can be argued expertise and skills required to assume this knowledge is acquired through experience of something, someone or education (Oxford Dictionary 2002).

Knowledge can be either explicit, that which is learned from a book and studying or tacit, knowledge that is personal and intuitive. Tacit knowledge and intuition can be difficult to separate and define individually. Kontos et al (2009) describes tacit knowledge as that which is unlearned, comes from within, is unspoken and is deeply rooted in an individual's action and experience. It is intuitive and subjective whereas explicit knowledge is scientific and objective.

Kontos et al's (2009) discussions around tacit knowledge are based on results of a qualitative study of formal carers of people with dementia they undertook. When analysing their data they drew upon theoretical precepts of embodied selfhood rooted in Merleau-Ponty's (1962) reconceptualisation of perception, Bourdieu's (1990) understanding of this and Bourdieu's (1990) notion of *habtius.* This was in an attempt to understand and place meanings upon carers actions and interpretations of behaviours of people with dementia and where these originate from*.*

Merleau-Ponty (1962) describes a pre-reflective state in which caring would be tacitly known to the body and thus to selfhood itself. He argues embodied consciousness is a fundamental level of existence that does not involve cognitive consciousness. Embodied consciousness is the body's pre-reflective directedness towards the lived world. He uses the body's ability to co-ordinate visual, tactile and motor elements as an example of the pre-reflective state and unlearned and suggests tacit knowledge is a field of possible movements, a kind of inner map of movements the body "knows" how to perform without having to reflect upon them. In his reconceptualisation of perception, Merleau-Ponty (1962) suggests we share a corporeal existence with other beings which to some extent indicates we have a level of shared knowledge of sensory experience that is tacit. In contrast, Bourdieu's (1990) *habitus* interpretation of tacit knowledge is based on investigation of social genesis of competence, know how, skill and disposition. His approach to understanding the embodiment of social structures relates to the relationship between socio-cultural bodily dispositions, tacit knowing and caring practices. The concept of *habitus* is used to describe the practical logic of social and cultural customs and the regulation of human behaviour. *Habitus,* or socialised inclinations associated with membership in particular cultural

groups instills in individuals dispositions and schemes for being and perceiving. Dispositions are embodied and materialise as postures, gestures and movements. Bourdieu (1977) purports these dispositions are a product of a modus operandi of which the individual has no conscious mastery.

Knowledge is said to be tacit when it cannot be explicitly articulated (Polanyi 1996) when the body knows what to do without deliberation or forethought (Benner & Tanner 1987). In relation to formal carers, Kontos et al (2009) suggest the tacit knowledge paradigm is gaining recognition as an important source of knowledge that informs clinical decision making. It is limited however by what they describe as an exclusive focus on knowledge acquired through clinical practice and education. In doing so, Kontos et al (2009) argue the consequence of this is a neglect of primordial and socio-cultural significance of embodied selfhood, described by Bourdieu (1977), which provides foundational structure of tacit knowledge of caring and facilitates its manifestation.

Their findings suggest social and cultural habits, movements and other physical cues disclose significant information about individuality of care recipients which brings their personhood into focus for formal carers. In addition to this carers use their own bodily dispositions to make meaningful connections with people with dementia. In the course of providing care this can be applicable to formal and informal carers. Carlsson et al (2002) argue caring does not develop through theoretical learning but is assimilated as bodily knowing that becomes an extension of the learner, whoever that may be. One participant who had also had formal caring experience expressed this as follows:

"I think you've got to be a certain calibre of person to do that day in day out I really do but I couldn't fault the NC it was lovely……" (Subject 28)

"I think it's something that's within you I could tell when I had nurses coming under me on a training programme, you could tell who was going to be good nurses, they didn't necessarily have to be academic…." (Subject 28)

The participant above appears to be inferring caring or ability to care maybe something fundamental to being human that is inherent, unable to be taught or learned. An issue addressed later in this chapter and occurring in one of the other themes derived from the data.

Tacit knowledge has been identified as key to clinical assessment in several areas of practice (Christakis et al 2003, Greenhalgh 2002, RCGP 2003) and contributed to establishment of its legitimacy and creation of a new epistemic potential for understanding competence, expertise and caring in clinical practice. Consideration needs to be given as to how this may apply to informal carers and their caring roles. There is evidence in the study data suggestive of conflict in knowledge of formal and informal carers that leads us to question whose knowledge supersedes whom or in fact does it?

Issues that appeared to complicate this matter was the situation where the participant was employed, or had been employed as a formal carer in a nursing capacity and their knowledge was different to other participants. The following quote demonstrates this carer had explicit and tacit knowledge when it came to care of her father. The example below informs us this carer felt at an advantage to those who may be in a similar situation to her but with different levels of knowledge. This carer, as did others who had been in a similar position to her, felt her background and

knowledge acquired during her nursing career had helped support family through their journey with dementia up to the end. She felt saddened to know others would not experience the same.

"*I wish everybody could have what we had, I wish everybody had the knowledge perhaps that I had….*" (Subject 02)

There were other situations in which knowledge of informal carers regarding health care decisions in the last few months of life could be related to the *habitus* Bourdieu (1977) described. Decisions were made having lived with the person with dementia over a long period of time, being deeply rooted in the culture of that family and as such having intimate knowledge of that person. In clinical situations some decisions were made considering knowledge of informal carers, but this was disregarded by professionals resulting in anger and frustration as demonstrated below:

"*they said about peg feeding him through his nose, I said "no" I knew he'd be traumatised, I knew he'd pull it, he wouldn't like being held down having that done so I said "absolutely no, no way that" …. when I go back in the afternoon they'd done it, he'd bin very traumatised by that, I was furious……*" (Subject 09)

The carer above may have acquired knowledge used to inform the decision via different means as identified above. She may or may not have witnessed her father's behaviour in relation to the insertion of tubes, canulas etc to support his health which may have influenced her decision making. One could argue, use of tacit knowledge by the informal carer in this decision making process was vastly different to explicit knowledge possibly used by professionals in overriding this decision. This example may once again lead us to consider and question in this kind of health care situation, who might the expert be and whether there is only one.

Ferrell (2006) explored the impact on nurses of "medically futile care", described as life sustaining care that is unlikely to result in meaningful survival. Conflicts were most common in this work amongst physicians, patients, families and nurses. They also identified conflicts over care within families, between physicians and nurses or nurses and nurses. Most conflicts appeared within care of elderly people or those with cancer. Conflicts also arose between physicians and patient proxy when patients were unable to make their own informed choices, as has been observed in this study's data.

There are times when we know something to be true but we do not know why or how we arrived at the understanding. One form of intuition arises because we know something so well and so thoroughly we do not have to reason things out again but we immediately know it. The participant below experienced conflict with formal carers whilst his wife was in a care home. He visited on an occasion and intuitively knew something was different about his wife which care home staff appeared to have no recognition of.

"I went one day, D were int same position, I said "what's the matter with D?" they said "nothing's the matter with D", I said "there is"… I would like some medical attention here, "why D?" I said "because something's happened to D" it turned out she had had a slight stroke…. that's what was causing her to be unsettled, be uneasy, before she were settled she'd got no strength whatsoever….the doctor came and he did say that…..” (Subject 12)

"well before she was comfortable with me, then she was totally uneasy with me, so I started thinking was it something had happened with some et staff had made her uneasy but they said there were nothink whatsoever but she were highly disturbed about 4 am the previous morning, that's the only thing, the doctor said she had this stroke… I saw it straight away…. not that I'm clever…..” (Subject 12)

"I just knew there were something different, then from that day on D started to deteriorate… light in her eyes when I walked in had disappeared…. she was just laid there stagnant….. did a thousand things to try, took photographs, tried to sing everything no recognition whatsoever……" (Subject 12)

It is clear from the extracts above this carer knew his wife extremely well. His observation of what appeared to be a change in her appearance alerted him to the fact something was different and potentially wrong which he wanted investigating. Formal carers however had not observed anything that would alert them to this fact or alarm them in any way.

Another participant went to what appeared to be extreme lengths to continue to care for her husband once he was admitted into 24 hour nursing care. She had cared for her husband over many years and felt she knew his needs and how to meet those better than formal carers. In attempts to maintain his well being and mobility she felt she had no choice but to secretively take him to his room and encourage this.

"they weren't standing him up were they? that's one of the reasons I took him upstairs to stand him up so at least I could get him moving but they just didn't seem to understand that at all, I think the experts, is me, looking after him, they didn't want to listen to me, they would not listen to me so I suppose I was a nuisance….." (Subject 14)

The participant above described several battles throughout her caring career with various professionals in relation to the care of her husband. There is a sense of how this made her feel over time in the above quote. He was eventually admitted into a local District General Hospital, where he died, she attributed this mostly to poor care within the care home.

The majority of participants had no health care background but felt their knowledge of the person with dementia, mainly tacit and intuitive, up to point of death on occasions, was more valuable than had been acknowledged. Differences in recognition of symptoms experienced were apparent. On occasions informal carers appeared to intuitively know the death of the person with dementia was approaching. It was difficult to establish what this was attributable to as a very small number had experienced or witnessed the actual death of a person in order for this to inform their thought processes and feelings.

The quotes below reveal the family had an intuitive feeling the person with dementia was nearing death despite formal carers being unable to verify this for them when asked about this directly.

"ok, is he going to die? When is he going to die?" they would sort of um and ah, it's like they don't want to say it…. to us it never seemed likely he was going to leave the hospital bed, we knew that at the back of our minds" (Subject 05)

Informal carers interpretation above of reluctance to advise, was formal carers did not want to make a judgement or give a time limit to life when in reality it is not always possible to do this. With regards to dementia prognostic indicators discussed in a previous chapter may support this, however, it is notoriously difficult to predict with any degree of accuracy when death will occur in this group as the quote below demonstrates:

"he didn't seem too bad…. she'd more or less said…. they'll know because they know what they're dealing with… we'd already been told that they didn't think he was

going to make it but it might be today, might be tomorrow, might be a week, so we went up and we sat…." (Subject 37)

Knowledge informal carers possess about the person with dementia whom they may have cared for over a number of years is of value and can be crucial to informing formal care. It is not only acknowledgement or lack of this and use of it when it has been given that creates the problem for informal carers, but transferring, exchanging or sharing this knowledge can also be problematic in certain environments. All types and styles of communication are required for this to be successful.

The Alzheimer's Society (2009) launched a leaflet taking into consideration these issues in the hospital environment. It can be completed by the person with dementia or their carer. It is a simple, brief, transferrable, dynamic document that can travel with people into unfamiliar care environments. Although it was originally devised with the hospital care environment in mind it is transferable to any care environment and can even be used within the person with dementia's own home. It supports transfer and provision of expert knowledge from one group of experts to another and if used appropriately, can inform and facilitate good care.

Life history work with people with dementia and their carers as a means of enhancing care has been in the literature for a number of years (Kitwood 1997, Cayton 2004, Williams et al 2006, Baldwin et al 2007, Bruce et al 2008). Using life histories is a way of validating people's present by remembering their past and has been used in care planning and enabling formal carers to get to know the person with dementia for whom they now care better. It may also have a therapeutic purpose for those involved (Cayton 2004). Involving informal carers in telling and sharing of life histories is a way of maintaining their inclusion in care and a way of

validating their past and present relationships with the person with dementia up to death.

Life history work and exchanging and sharing of information in this way has no less importance in the last year of life and surrounding death, one could argue it is more relevant at this time, even more so on death. In the absence of any other formal instructions, life histories can be a way of establishing final wishes of the person with dementia in order for them to be considered and acted upon. The leaflet discussed above is a brief way of communicating some of this information and maintaining inclusion of any informal carers. This document and information can be built upon when opportunity arises for example when someone is transferred to 24 hour care.

As discussed in a previous chapter, a purist Grounded Theory (Glaser, Strauss 1967) approach was not adopted and literature was searched at different points throughout the study as analysis progressed. Whilst re-visiting the literature the researcher became aware of evidence suggestive people with dementia often have undetected, untreated pain resulting in prolonged discomfort and often what is viewed as a painful death for that person (Kovach et al 199, Allcock et al 2002, Buffum et al 2007, Close et al 2004, Zwakhallen et al 2008, Jordan et al 2009). Zwakhallen (2008) suggests studies on pain and pain prevalence for older people with dementia are limited compared to those studies on cognitively intact older adults and pain prevalence in this group is estimated to be between 23% and 83%. Most of this literature relates to results of research conducted in 24 hour care environments i.e. general hospital wards, nursing and residential care. There are many different types and dimensions to pain it is important to note, for purposes of this study and

theme, it will be considered and discussed in terms of physical pain for the person with dementia.

Pain can be described as an unpleasant sensory and emotional experience. Under recognition and under treatment can be found throughout the health care system and does not necessarily pertain to older people and people with dementia alone (Reynolds et al 2008). However it is more striking in nursing home environments due to high rates of dementia within that population (Reynolds et al 2008). Ordinarily it is a complex phenomenon derived from sensory stimuli or neurological injury which is modified by individual memory, expectations and emotions (American Geriatrics Society 2002). Persistent pain, a painful experience that continues for prolonged periods of time, is common in older people, mainly as a result of muscular skeletal conditions associated with aging.

Reynolds et al (2008) discovered among nursing home residents cognitive impairment is strongly associated with lower reports of pain and less treatments despite there being no differences in painful diagnosis amongst nursing home residents. Residents with no or minimal cognitive impairments were receiving regular pain relief whilst residents with more severe cognitive impairments received pain relief on an as required basis or none at all. In relation to the acute hospital environment there is also evidence to suggest differences in assessment and treatment of pain for people with dementia. Morrison and Sui (2000) conducted a study within the acute hospital environment focusing on older patients who had undergone hip replacements. Based on comparisons of requests for analgesia and those administered, they discovered people with dementia received a third the opioid medication cognitively intact patients received.

The gold standard of pain assessment and treatment is self report, this provides the most valid measurement of pain (Melzack and Katz 1994). Assessment of pain in the older population can be more complex (Closs et al 2004) and can be even more so for people with dementia depending upon their level of cognitive impairment and compromised communication skills. This necessitates an awareness of observable behaviours that may indicate the person with dementia is experiencing pain. These include the following:

- Facial expression

- Verbalisation

- Body movement

- Changes in personal interaction

- Changes in activity patterns or routines

- Changes in mental status (Herr et al 2005)

According to Nichols et al (2002) one of the most challenging issues related to pain and people with dementia is getting people to recognise this group actually experienced pain at all. This was an issue for one of the participants. She had been informed by a consultant at the hospital her husband would not experience any pain, this person had a dual diagnosis of cancer and dementia.

"I'll tell you another thing first, I was told S wouldn't have pain, he was in the most terrible pain………. one of the doctors at YG…….., so I didn't expect pain, my son in law's a dentist, he was sitting here, S was doing this **(gestures rubbing head)** *and he said "S's in pain" I had to go through NHS direct they sent this doctor out, all he could offer S was Calpol* **(PAUSE….)**……….."* (Subject 32)

Scherder et al (2003) discussed the neuropathology of dementia and its role in pain and assessment. They focused on the neuropathological affects of dementia on medial and lateral pain systems. Particular attention was paid to Alzheimer's disease, vascular dementia, fronto temporal dementia, Lewy- body disease and Creutzfeldt-Jakob disease. They concluded although subtypes of dementia show common neuropathic features (atrophy, white matter lesions) the degree by which they occur and affect pain related areas determine the pattern of changes in pain experience. More specifically, in Alzheimer's disease, even more so in fronto-temporal dementia, a decrease in motivational and affective components of pain is generally present however, vascular dementia might be characterised by an increase in affective pain experience. This kind of work has important implications for assessment and choice of treatment for pain in people with different types of dementia.

As the research and analysis progressed the researcher developed awareness from the literature of issues surrounding pain for the group under study. A conscious decision was made not to influence participants in this direction but to allow them to identify pain as a problem without any prompting if they perceived it to have been. This was in keeping with narrative style of interviewing in which the participant is encouraged to tell their story in their own words with minimal questioning and direction from the researcher, usually resulting in sharing of information of importance/relevance to them and not researcher. As recruitment progressed pain was not something that participants were identifying as a problem during interviews. This was something that raised curiosity for the researcher whilst reflecting upon interviews, during constant comparison of transcripts and development of analysis. A large percentage (55% in a hospital environment, 35% in care homes) of participants

had experienced care in the last year of life and eventual death of the person with dementia in care environments the literature on the topic of pain pertained to, general hospitals and care homes. Following discussion with the supervisory team, it was agreed a simple prompt question was to be asked in future interviews:

> *"do you think (name of the person with dementia) was ever uncomfortable or in pain as they approached the end of their lives?"*

Despite asking this question directly in order to explore this, pain and discomfort was not something so common across transcripts it developed into a category and subsequent theme as data analysis progressed. Informal carers did not identify pain and discomfort as something in their opinion had created distress for the person with dementia or them. Considering length of time of informal caring relationships in the study, one may expect the informal carer to be aware of signs and symptoms that may indicate pain and discomfort in the person with dementia. On occasions they were and this was acted upon with formal carers. Answers to the above question were mostly brief on occasions pain and discomfort were identified as a problem in some form, the following quotes are examples of these.

> *"once or twice he had tooth ache, he'd go" **(gestures facial grimacing)**, or when he drank something cold or something….he couldn't tell you… the dentist she used to come down… she was good as well……"* (Subject 37)

The above quote enlightens us to some difficulties we may encounter establishing whether someone with dementia is experiencing pain, exact location, how severe, what kind and effective ways to identify this. The important role observation of behaviours and tacit knowledge of the person in pain is apparent here.

The quotes below again demonstrate difficulties encountered in knowing whether and when someone with dementia is experiencing pain/discomfort. As identified, compromised communication skills influence ability of the person with dementia to self report requiring a level of knowledge about the person and good observational skills if pain is to be identified and managed.

"she's caught her leg you see those chairs, as they dropped her down, she's caught her thigh on the arm of the chair, it had hurt enough for her to try to tell you know when I said she was……." (Subject 40)

*"in this skirt she was so etchy, she was like this **(gestures uncomfortable and restless)** she couldn't tell me, she was shifting about, I said "what is it? is it because you're next to the television?" "oh, oh, oh" this went on a couple of days after that skirt business then I got a call one morning from K, she said "it's my job to tell you your mother's got a bruise…. we don't know how she's got this bruise…."*
(Subject 40)

The extract below demonstrates an "if in doubt treat" attitude of professionals, rather than allow someone to experience and suffer pain untreated.

"she gave him some different kind of pain killer, don't know what she gave him, a strong pain killer of some kind, if he really was in big pain they could put him morphine patches on, before he died he was on morphine patches because they didn't know whether he was in pain or he wasn't in pain …." (Subject 37)

There were also occasions where pain and discomfort was not an issue. It had been identified and assessed and any suspicion of pain was being treated accordingly as the following demonstrates:

"they gradually built those up, it's the kind thing to do, they just gave him pain relief, he just gradually got weaker and weaker but he lasted about three or four days which was longer than we thought" (Subject 03)

Morphine patches were in place for the person with dementia and any discomfort, as far as this carer could observe, was being successfully managed up to the point of a peaceful death.

5.5.1.(i) Summary

As has been demonstrated in this theme, establishing who the expert in caring for the person with dementia in the last year of life and surrounding death is, or can be, a contentious issue amongst both formal and informal carers, a source of anxiety, frustration and conflicts. One thing clearly illustrated throughout this theme is necessity and importance of positive communications between all groups in order to better understand everyone's needs at this time. This is necessary in order to meet these resulting in more positive outcomes for all.

The following subsection will present and discuss the kindness, compassion and humanity theme derived from the data. Quotes will be used to illustrate construction of meanings and interpretations.

5.5.2 Theme 2: Kindness, Humanity and Compassion

"*the carers, they were just as gentle and kind……."* (Subject 01)

When one thinks about words "kindness", "humanity" and "compassion" any number of other words spring to mind in an attempt to try to define and understand these concepts. These include words such as, caring, warm, kind hearted, selfless, good, altruistic, benevolent, neighbourly, understanding, gentle, human nature, empathy, kindness, even the words compassion and compassionate appear within this group (Oxford Dictionary 2002). Words used to define compassion and compassionate include, kind, lenient, considerate and humane. It is easy to see how all concepts and words above may relate to caring and medical professions and could be considered a fundamental aspect of it.

It is necessary at this point to identify and understand differences between kindness and compassion as these two concepts are often confused and can be interrelated and used interchangeably. It can be argued kindness and compassion are two core human values important in society. Aside from other moral values, kindness and compassion are the foundation of social and personal relationships. Although these two values may seem quite similar, kindness and compassion are two different things. Connection between these two values is more of a cause-and-effect kind of relationship because most of the time, kindness results from compassion. The eventual outcome may be the same thing that does not mean kindness and compassion are the same.

Kindness is an act or a gesture done out of goodwill towards a person another living creature. It has the same etymological origins as words such as "kin" "kindred" (family) and "kind" (type) (Rowland 2009). It always involves two parties, giver of the

act and its recipient. Examples of acts of kindness are smiling and greeting people, assisting elderly, feeding the hungry, giving shelter to homeless and not judging others.

Compassion, on the other hand, is more of a deep and personal emotion. Its origins are deeply rooted in religion and spirituality and much of the literature pertaining to compassion is in this area, particularly Christianity and Buddhism (Lampert 2006). It is defined as ability to understand the emotional state of another person i.e "putting-yourself-in-another's-shoe". Compassion is a much stronger feeling and is what pushes a person to do something to alleviate or reduce suffering of another. Having compassion often leads a person to show kindness towards others. Everyone can be generous and show kindness to others but not everyone can show compassion. A lot of people nowadays show kindness because they need to, or because it feels the natural and right thing to do. However, only few people can feel genuine compassion to others.

Having clarified differences between kindness and compassion, this theme will now discuss concepts of kindness, humanity and compassion in relation to caring for a person with dementia during their last year of life and around the time of death. This will be in a range of environments and social contexts. Informal carers' descriptions and subsequent construction and interpretations of what constituted these concepts will be presented using extracts from transcripts.

This theme commenced with an extract from a transcript that was a comment made by a participant in the study when talking about care he and his wife had received during the time frame being studied. This was time she spent in a nursing care

home. Many comments of a similar nature and words from the list above were used by participants in their descriptions and interpretations of acts of kindness, humanity and compassion throughout the study. These pertained to a range of caring contexts and environments. These words were used spontaneously by participants, they were not prompted and they were not in response to the researcher using them during interviews and conversations.

Tacit and explicit knowledge (Kontos et al 2009) also have a role to play in this theme as with other themes but in a slightly different context. With formal carers their explicit knowledge acquired via any training may compliment any tacit, experiential, intuitive knowledge required in order to display what informal carers constructed and interpreted as kind and humane caring. Personal experiences of certain circumstances and situations may have influenced their ability to display humanity and kindness towards informal carers and person with dementia. Unlike some of the other themes in which knowledge, including all types and levels, about the person is required to facilitate good care, carers at all levels, both formal and informal do not require in depth knowledge of a disease and its trajectory to incorporate acts of kindness into caring, deliver care or treat people in a humane manner. As will be demonstrated using extracts from transcripts it would appear for some people, knowledge may not have a role to play in their acts of kindness and humanity towards people in time of need.

The literature informs us many people with dementia end their lives in 24 hour care environments (DoH 2009) and this occurred with 90% of this study's sample. This will either be hospital or care home, as with the participant in the transcript extract above, and people encounter different professionals including nurses. When considering what it means to be a nurse, Chambliss (1998) suggested hospital is a

normal place in which routinisation and traumatic events appear normal to nurses employed there. They highlight what was once a frightful emergency to the novice becomes more and more accepted as routine and common place. The more experienced nurse casually handles any manner of things including naked bodies, bodily waste and routinely deals with dying patients. None of these things Chambliss (1998) argues, once the nurse has "leapt" into a routine disrupts their daily life or causes concern. He further argues this is what separates nurses from other health workers and this separation is morally relevant and a distance between what nurses and laypersons see as the "right way to behave". Patients are regularly subjected to events no one outside the hospital would willingly undergo including invasive procedures, humiliating examinations and radical surgery. These things are not only considered acceptable but in a sense good and rarely are they given a passing thought. Not only is there a shift in what is thought good and bad but some very serious matters may not be thought about much at all (Chambliss 1998). We could interpret what Chambliss (1998) is saying here as implying nurses within a hospital environment because of the nature of their work are, or maybe unable to display acts of kindness and humanity towards their patients. Quite the contrary, he states nurses are a particular kind of hospital worker with at least three difficult and occasionally contradictory missions:

- To be a caring individual
- To be a professional
- To be a relatively subordinate member of the organisation

Nurses may argue amongst themselves what these directives require or even if they should exist, particularly the subordinate one. "Care" is the key term in the nurses'

definition and crucially defines what nurses and others believe to be their task. This can be said of nursing/caring in any environment and not solely related to hospitals.

Chen (2009) purports the purpose of medicine is to prevent illness, cure disease, relieve suffering and maintain health. Duty of physicians is to rescue life, cure disease, relieve suffering and promote health. However, "birth, aging, sickness and death" are all unavoidable on the path of human life, birth and death in fact, being a "rite de passage" for all. When a person has reached the end of their life, and death is impending, the duty of medical professionals should be to provide love and humanistic care for the patient, to relieve pain and suffering and provide a peaceful and dignified demise. The caring domain of a physician is from birth to death, from "womb to tomb" (Chen 2009). This is the humanism in medicine, in contrast to the purely "scientific and heroic fighting" of saving life to the last minute. Hospice has historically been the environment in which humanistic care intended to alleviate suffering during life limiting illness and up to the end of life has been provided to those fortunate enough to be in a position to receive it.

5.5.2.(i). The Kindness, Humanity and Compassion of Strangers

There were many acts of what participants perceived as kind, humane and compassionate in the data. Some of these were from groups of people who could only be described as strangers (people they didn't really know or know at all) to carers and people with dementia but who none the less appeared willing to help in times of need.

The quote below pertains to a difficult situation carers found themselves in when attempting to maintain the smart appearance of the person with dementia. The

family, who had a good level of knowledge and a wealth of experience in caring for this person were unable to maintain this and explored the option of outside support.

"*dad took him in the barbers once, barber was really, really good with him, he sort of understood the situation, he used to like going to the barbers, he would let the barber shave him properly, he would let the barber cut his hair, wouldn't let anyone else do it……………*" (Subject 05)

The description of the barber being "really, really good" with this person enlightens us to how appreciative these carers were for the success this stranger had in completing a task that had become almost impossible for them. The barber appeared to "understand the situation" they were in without any prior knowledge or experience that we know of, with regards to people with dementia.

The following quote is another example of how important and meaningful acts of strangers are to informal carers in times of need and stress.

"*I would definitely say kindness of strangers was something that really became apparent you can be so reliant on strangers…. we had a couple of taxi drivers who gave him free lifts back when he was found wandering, that type of thing……….*" (Subject 07)

Another significant group of people who demonstrated acts of kindness, humanity and compassion were funeral directors. One may expect in their line of business personal values that underpin demonstration of awareness and understanding of the concepts would have been apparent to employers. One could argue this would have been a pre-requisite of successful employment. This was a significant finding as the researcher was unaware of the importance and extent of the role this group of people played in relation to the group under study.

"the funeral director, he was so polite, so nice they rang me everyday before K's funeral to ask if I was alright…….." (Subject 19)

*"funeral directors arrived, they looked so smart (**cried**) J, it was six o' clock in a morning, they were so nicely dressed, I thanked them for being nicely dressed because K (person with dementia) was a nicely dressed man……."* (Subject 19)

"they were a good help really the funeral directors, we knew nothing, there was no help at the hospital whatsoever…… he got taken to the C funeral service… where we saw him again…. he looked beautiful there…. I mean he looked thin but immaculate absolutely immaculate….." (Subject 09)

The death of a loved one can be a traumatic time with lots of practicalities to deal with. In the quote below the undertaker was particularly appreciated as they had donated the brain of the person with dementia to research. Specific protocol has to be followed in these circumstances. The funeral director appears to have been sensitive to this and this carers needs.

"undertaker took over, that's what I did, we went down to the undertaker, I have to say the undertaker was marvellous, really lovely, I say again I can't praise them high enough………"(Subject 22)

Kellehear (2005) purports in modern day society and western world death and loss is frequently left to psychological professions. In doing so the idea has that emerged that death is an individual and private matter continues to be supported. Alternatively, the problem of mortality is handed to hospice and palliative care. Giving them the equally false impression end of life is merely terminal care in the final months, weeks or days of life. The universality and common place ordinariness

of dying, death and loss is no longer spoken about. Except for significant disasters, recognition of an individual's death is seldom recognised as a community experience (Kellehear 2005). He considers of end of life care a public health issue, one that can be addressed via a re-engagement of the whole community in care of the elderly, vulnerable and dying. He suggests there needs to be re-acceptance death is a natural part of the life cycle and something which the whole community has a role to play and not professionals in isolation. In the quote below there is evidence Kellehear's (2005) vision for a whole community based end of life care may just be possible in some communities. This participant lived in a semi rural area where it could be argued this may be more achievable. There was also an indication some of kindness restored belief in "the sense of community" faith in humanity and human nature. The quote below demonstrates a sense of surprise but delight in people's willingness to help without being asked. Although these people were almost strangers to this person they were an integral part of their local community.

"another thing, postman here he knew S was ill, if I was in he would never put letters in the post box he would put them under the mat… just another act of kindness… my neighbours "can we do anything practical for you?" we are not really very neighbourly we're not….. they opened up their caravan so my other daughter and her children could sleep in there…. she offered me any room in her house as well, very, very kind there were lots of little things like that, they are very important aren't they?............" (Subject 32)

The carer above had a further positive and for her, surprising experience of an act of kindness from a total stranger as we note in the quote below. Although the person responsible for delivering the act of kindness was employed in a health care setting, this was not a health care worker.

"another act of kindness was when he was in hospital the secretary of the vicar in charge of the hospital, I went down enquiring about services, Muslim services, she said "I believe your husband likes nice coffee, he can have a nice cup of coffee with

me" so she brought special cups in, biscuits and special coffee for him……."
(Subject 32)

It could be argued for some, kindness and humanity are an integral part of who they are and is embodied within their very being. Rowland (2009) suggests we have good reasons for understanding kindness to be a natural disposition based mainly on origins of the word "kind" discussed earlier in this section. Schachter (2011) however, considered whether kindness is something that can be taught. This was in relation to school children and education. He concluded it was something that could be taught with lessons in kindness beginning at home within the family and then extended into formal education. It could be argued this is in conflict with Rowland's (2009) notion kindness is a natural disposition, something inherent we all possess. Phillips et al (2009) also discuss kindness in relation to childhood and its origins being within our earliest relationships. They describe it as an innate potential society tends to thwart and corrupt. They argue children, like the adults they will hopefully become, are complex creatures with an instinct for kindness and concern that is as strong as their self regarding instincts. They argue, kindness takes many forms and is partly learned from societies in which we grow up and as such can be unlearned, badly taught or even resisted. Phillips et al (2009) on discussing historical perspectives on childhood and kindness agree with the notion we begin our lives as children naturally kind and something happens to this kindness as we grow in contemporary society.

Examples of acts of kindness in transcript extracts above all come from people who were not connected to carers or people with dementia in a formal caring manner. As discussed earlier acts of kindness are usually a direct result of feeling compassion.

That is, being able to put yourself in someone else's position and as a result of being touched by their suffering, having a need to act and help ease or minimise this. When discussing relationships, kindness and honesty, Sinclair (2006) described kindness as being invisible and requiring tact and empathy which are hard qualities to muster.

5.5.2.(ii). Kindness, Humanity and Compassion in Formal Care

In response to increasing reports of neglect, disrespect and indignity in care in New Zealand, Paterson (2011) explored the issue of whether compassion could be mandated in health care. He suggests few would argue with the notion health practitioners and institutions should respond promptly and in a humane manner to distress, pain, and suffering (subject to some sort of reasonable limits). This is not the same as having the right to have suffering relieved as this is something that may be unattainable. Focus is on swiftness and humanity of response received. He considers if this is the same as requiring services be provided with "compassion" and fellow feeling for the patient and explores whether compassion can be proven, measured or legally mandated and be a legal requirement as part of care provision and delivery (Paterson 2011). He concluded there is a distinction between respect, which can be mandated, and compassion, which cannot sensibly be required, although this may be the type of care patients yearn for. Paterson (2011) further purports, compassionate behaviour is a gift from the heart of the bystander.

There are some examples in the literature from nurses and medical professionals who have shared personal experiences of being on the receiving end of health care. Scholtens (2011) was surprised when a colleague congratulated her on her kindness during a consultation. It appeared to come naturally to her, something she hadn't

realised along with the importance and significance of this until she was in a position to receive it herself.

It would appear it is the small acts of kindness that evoke biggest response and hold most significance for people in need. Dawson-Goodey (2011) in her personal narrative on being a nurse on the receiving end of care during a serious illness highlighted what was for her the importance of little things that meant a lot during this time such as a smile or a "hello" from a care worker. She described the positive feelings a smile from someone else would invoke in her at that difficult, stressful time.

Koefoed (2007) gave an excellent account of her 32 years in nursing. It is apparent from this narrative kindness, compassion and a kind, human nature was inherent in this person from the outset it didn't appear to be anything she had been taught or learned. She described her recollections of supporting colleagues, many patients and their families in different ways over her career. She describes incidences in her nursing career of facilitating carers "being" with loved ones as they approached their deaths.

There was evidence in the data of similarities with Koefoed's (2007) story. It was not a formal care worker who initiated this but the daughter of the person with dementia who had also been a trained nurse during her working life. Both her parents were cared for in a nursing care home and right up to time of her mother's death shared the same room and bed within this care home. As her mother approached her death she felt it was important for her father to observe this and "be" with his wife at the end.

"had a double bed… they had their own bed…. it was a huge room upstairs, their own bedroom so he'd sleep with her…. I sat up in the chair so when I knew the end was coming I got him, he'd fallen asleep by that time, I woke him up…." (Subject 36)

As Dawson-Goodey (2011) highlighted, it is the small things and small acts of kindness that appear to go a long way and are most meaningful to people who are in receipt of them as the quote below demonstrates:

"another little act of kindness, I bought my husband new jogging bottoms and a top …… nurse didn't put it on until just before he was going to see the oncologist ….so he wouldn't make a mess of it… I just thought… they are so busy there… little acts of kindness like that are very important aren't they?............" (Subject 32)

The following quote offers an insight into what was occurring around the time of death of the person with dementia. The carer was undergoing her own health issues at the time of her mother's deterioration resulting in restrictions on her visiting her mother during a hospital admission. This carer was experiencing many negative feelings as a result including guilt and was anxious to know her mother was being cared for and was not alone as she approached her death.

"somebody seems to be with her all the time, there was somebody with her when she died, she just drifted away, they were just so supportive I can't tell you……they rang me, told me she'd died.. how she'd died…..I could ring up at any time, they were happy to talk to me…. they were really supportive………" (Subject 06)

We can feel the sense of comfort this carer felt from the support she received from carers, mostly nursing staff, at that difficult time. Whilst this was not an ideal situation for this carer to find herself in, the response, humane, compassionate and kind from the care staff appeared to ease her suffering and distress.

The quote below is taken from another carer whose mother was residing in a nursing care home. This carer interpreted general care of all residents, and not her mother alone, as kind. She had observed what she perceived as kindness in provision of care that appeared to her to be in the face of adversity. The all too familiar issues of having to cope with poor staffing levels in a care environment that was very demanding on a physical care need basis.   Despite this the carer noted a determination from formal care staff to provide kind and humane care to their residents.

"they were very kind to them… patient… like most places they could have done with more staff…it was pretty grim sometimes…. lack of staff…it wasn't that they didn't want to try and care............" (Subject 37)

There was an occasion in the data where despite recognition and acknowledgement of a kind approach, distress felt by informal carer was not eased. In fact this appeared to be heightened and one can hear this in the quote below.

*"those girls were absolutely marvellous all of them, they were all kind in their own way, they haven't got the time, to them he was just another wash, he wasn't dad, he wasn't Mr. P, (**tearful**), that's the thing I found hardest I think….…."* (Subject 02)

We are enlightened here to the possible impersonal, undignified nature of some care delivery despite all good intentions. Intimate care being provided to her father by total strangers and entrusting him to someone else was a source of distress for this carer. Care provided by local authorities and private agencies in the community can appear this way to informal carers. Formal carers are working to tight schedules with increasing workloads and minimal financial rewards for their efforts. All too often this can have a "conveyor belt" cold and harsh appearance.

There has been an increase in media attention over the past few years in the care of the elderly both in hospital and nursing and residential care environments. Reporting of dehumanising, unkind behaviour towards patients and residents appears to have become common place, James (2010), Paterson (2011), Kitwood (1973). Philips et al (2009) asked the question "why does kindness matter to us?" They suggest one of the most distinctive things about kindness, unlike an abstract moral ideal such as justice, is in the end we know exactly what it is in most everyday situations. We usually know what the kind thing to do is and when a kindness is done to us and when it is not. There is a profound ambivalence about kindness. It is something we love, yet fear and its absence is felt very acutely.

Focus of this theme is to relay and report on kind, humane and compassionate, positive experiences of care and consider how we may be able to build upon these in the future. However, there were some instances in the data when care was interpreted as unkind and dehumanising by carers. The quote from a transcript below is one such example. This person with dementia had a large caring family but his wife was unable to manage his behaviours due to her own failing health and he was admitted into 24 hour nursing care.

"he was really getting to be unhappy, we knew he was unhappy, a woman stood outside the door in the corridor outside his room, she couldn't see me, she didn't know I was there, she said "I'm absolutely fed up with him" at the top of her voice, so me dad would've heard it without a shadow of a doubt, "if he doesn't wanna be here, we certainly don't want him here, I don't know why they don't just come and get him and take him", (tearful)why? Why the unkindness?.......I just thought that it would be not like we cared for him, I never expected that, I never expected the disrespect,the unkindness actually……." (Subject 11)

It appears from this quote above there were several issues that would be a cause for concern in this situation. Knowledge and communications skills of those involved are questionable. The inherent kindness Rowland (2009) felt we all possess and

Schachter's (2011) notion it can be taught could both be questioned. With regards to compassion it would appear this was sadly lacking also here. Kitwood (1997) developed and championed a model of working with people with dementia which he called the "person centred care model of care". This model has become synonymous with good dementia care internationally. Within this model Kitwood (1997) described what he referred to as "malignant social psychology". This refers to being aware of how we communicate with and around people with dementia including types and styles of communication and words we use. If this is not taken care over it can have a marked detrimental effect on the person with dementias' well being and their informal carers if they observe this. Communications in the quote above are an excellent example of this and how not to be. One could argue it is how not to be with anybody and not just people with dementia. With regards to humanity and a humane approach it would appear this was sadly lacking in this care situation. One could argue this approach was responsible for the person with dementia's behaviour towards care staff and reported unhappiness.

The following quote is another example of what carer perceived as negative care. As her father approached his death, there was no privacy, he was in the open ward, which was common place amongst the data, and he died whilst awaiting transfer to a single room.

"*seemed to be no compassion on the ward it was… it was horrible the way me dad died, absolutely horrible…… well I felt it was dreadful… I just felt there was no… there was no caring if he'd have been in a side room… had a little bit of dignity where he could have been quiet.. where you'd got a lot of so poorly people… you go over what he must have gone through (crying) was he on his own? we don't know.. (PAUSE..), it was sad…. a blessing in another way (crying)…*" (Subject 09)

This experience of this carer above can be related to what, and how Chamblis (1998) described with regards to nurses in hospital environments. He argued they become so focused on routine situations like this do not strike them as being out of the ordinary or requiring anything different in terms of care and support. Minimal regard being given to the impact this kind of occurrence and experience may have on carers mental health in the long term. The memories of how people die living on in the memories of those left behind for years to come.

In his work on self compassion, Gilbert's (2005) social mentalities theory explains development of compassion through an evolutionary model. This assumes life experience shapes individual's brains in terms of a number of processing systems and biopsychological structures. In Gilbert's (2009) work on affect regulation, he suggests there are three key systems at play, one of which he called the "soothing/calming "system. This he suggests is developed in the individual via a secure attachment to a significant other (often a parent) who adopts a compassionate stance towards the individual so their distress is repeatedly soothed and calmed. As a result of this the individual internalises compassion for themselves which fosters development of self soothing behaviour, empathy, a healthy tolerance for distress and a motivation to care for themselves and others (Gilbert 2005, 2009). In stark contrast, an individual who has either not experienced compassion or experienced excessive negativity from significant caregivers when the soothing/calming system is developing in childhood and adolescence will often develop significant levels of self criticism, shame, and guilt as an adult as a direct result of these experiences. The above contributes to the argument as to whether kindness, compassion and humanity can be taught or are inherent qualities which we

all possess but to be demonstrated, require nurturing and development via positive role modelling.

The quote below demonstrates the definitions of compassion discussed earlier. The ability of carers to truly put themselves in this carer's position and behave towards the person with dementia and care for them in a manner they would wish their own or themselves to be cared for.

"care given by staff was truly excellent I can only praise them…. certain older members of staff who were absolutely great with him…. when I would thank them they would say "well, we would do this for our own mum or our own dad you know" .. also what I found was the young people who were there they too were excellent, they were very patient………." (Subject 39)

This carer appeared somewhat surprised to learn young carers were able to deliver care in as positive and compassionate manner as their older colleagues. James (2010) also highlighted the importance of kindness in formal care situations and reminded us of the old maxim "treat others as you would like to be treated" or as you would like your family member to be treated, it may be us helpless in the bed next time. Whilst the world is becoming faster and more technology introduced James (2010) also reminds us there will never be an alternative to quality basic nursing care of the whole person with a humanistic, kind and compassionate approach.

So how do we ensure a kind, humane, compassionate approach or can we? Traditional teaching methods are perhaps not the most appropriate way forward in teaching such virtues in formal carers of people with dementia. Didactic teaching of the work and models of care advocated in dementia by people such as Kitwood (1973), Nolan et al (1996) Greenwood et al (2001), Brown-Wilson (2009) may not necessarily be successful. Innovative and interactive teaching techniques such as

workshops, discussion groups, role modelling, use of films, theatre art and literature could be of great value. Listening to views and experiences of informal carers as they travel along the journey of dementia to end of life may be more powerful and influential. Exposing people in medical professions to real life situations via home visits may enhance a deeper understanding of what patients and informal carers experience (Shea et al 2010).

The recent Department of Health (2009) report on the National Health Service states in providing compassionate care:

...we respond with humanity and kindness to each person's pain, distress, anxiety or need. We search for the things we can do, however small, to give comfort and relieve suffering. We find time for those we serve and work alongside. We do not wait to be asked, because we care...

The importance of compassionate care is clearly relevant to all healthcare sectors. It can be argued, we all also have a personal responsibility to treat those outside of these domains with kindness, humanity and compassion, although not everyone will be able to do this for a variety of reasons. Educators are in a position to teach students, be they in health care or other disciplines, about the nature of suffering and value patients and their carers and families place upon empathy, kindness and compassion. Health professionals are in a good position to model compassionate care for colleagues and others.

5.5.2 (iii) Summary

This theme has presented some examples from the data that would indicate acts of kindness, humanity and compassion. It has considered these from the strangers and formal care situation perspective. Interpretation and construction of these acts as

being kind, humane and compassionate by informal carers could be attributed to their own positions in relation to these concepts and how they conduct their lives and behave towards others. By virtue of being an informal carer and allowing themselves to be in the position of caring for someone else could be viewed a measure and indication of their stance. Discussions relating to the concepts, whether it is possible to teach virtues of kindness, humanity and compassion and tential inherent nature of these have also been presented.

The following subsection will present and discuss the theme derived from the data that pertains to the hard work of caring. Quotes will again be used to demonstrate constructions of meanings and interpretations.

5.5.3 Theme 3: The hard work of caring

"then began the battle to get him out of hospital, it was a battle…..they knew I wanted to get him home as soon as possible…… it took 21 days to get him home, they told me it's within the time limit…… as I pointed out to them it might have been within the time limit but in fact S died 21 days after he came home so it may have seemed within their time limits….it wasn't within our time limits… we lost valuable time where he could have been at home didn't we…………" (Subject 32)

The above quote illustrates what appeared to be a general feeling elicited from the data during the process of analysis and constant comparison of transcripts. Powerful words used by participants to describe experiences in different contexts, i.e. "fight", "battles" and "traumatic", illustrate difficulties confronting individuals. The narratives are retrospective accounts of events that occurred up to five years previously. Choice of words and language used informs us of the long lasting effect some of these incidences and memories have on those left behind. As with other themes, different categories contributed to the hard work of caring in the last year of life. These were issues pertaining to practicalities relating to the physical nature of caring and the emotional and psychological hard work. Whilst the researcher acknowledges these are interrelated, for the purposes of this theme these will be presented and discussed individually.

The issue of knowledge and information was again present in this theme. The context however was slightly different. In this theme knowledge and information pertains to practical issues regarding provision of services, paying for services, from whom to seek help and support, how to get help and support, how to access aids and adaptations required and how to get information about end of life and death. Lack of knowledge and information to support people with dementia and their informal carers is an issue that has been identified as a priority for the future and is a key objective in the Dementia Strategy (DoH 2009). There appeared to be a general

sense of ill preparation for the relentless nature of the caring role which carers attributed to lack of knowledge and information available to them along their journey.

The following quote illustrates how lack of information early in disease trajectory affected this carer into the bereavement period and beyond.

"*really in those months, years of mum having what transpired to be early onset Alzheimer's dementia opportunities were lost to talk about mum's wishes to try and get some things in order…. it has become a problem for me since mum passed away in some practical regards trying to get her affairs in order proving more complicated than ideally it would be……..*" *(*Subject 41)

Lack of information about continuing care funds to enable the following carer to take her husband home to die with the aids and adaptations he required led to restrictions on amount of time they spent together in their family home before death. Whilst responsibility to apply for this funding was not the carers, this was an articulate and assertive carer who would have insisted on a certain application being made had she had knowledge and information required to support her.

"they are desperate to get him home" it went through as continuing care.. what I didn't know at the time was continuing care and social care the actual type of care is the same….. it's to do with who pays for it….if I'd of had this information I would have said "we should have had social care" obviously we could have paid for it in a way it's not made clear to you is it?…….." *(*Subject 32)

Participants were invited to tell their story with minimal interruption and prompts from the researcher, highlighting issues of importance to them. Schultz (2003) purports, the decision where to commence a narrative is frequently indicative of enduring personal concerns. This is based on the assumption people do not relate stories haphazardly. The researcher became aware of what appeared to be an inability or reluctance of some participants to begin their stories within the time frame proposed

at commencement of the interview. A number of participants positioned their stories temporally from when they were exploring problems they were encountering, seeking medical advice or from the time diagnosis of dementia was made. They appeared to be unable to talk about the end of their stories without portraying beginning and middle in the first instance and relaying the complete story. Frequently beginnings of stories at interview were beginnings of stories on their journey through dementia or pertaining to some other event that held significance for them. These included things that had influenced them in emotional and practical terms or what carers perceived had affected and contributed to their final outcomes.

To illustrate the above, the quotes below are from some of the carers who commenced their stories a number of years earlier than the time frame under study. The researcher interpreted this as an indication of meaning and importance of these events to them.

"my father went into a care home in November 2005 he went into the home with my step mum who also had dementia, the reason it became more important they were taken into more permanent care was my step mum had fallen.. GP had decided they wouldn't be able to stay at home even with carers going in at the time……….." (Subject 10)

*"we started off in 2005 not too bad, he'd have his moments he had to have an operation to stretch the gullet, we had a pre-op in B, the nurse said to me that he had a urine infection so go see a doctor in a few days………" (*Subject 29)

"Not too bad" was interpreted as being indicative of a time less stressful for carer and a time when there were not too many problems encountered.

"before that of course we had these problems with her not wanting to go and see her daughter, getting into a state because her younger brother was coming to see her … things like that, …" (Subject 31)

"we'd returned to the UK before Christmas, that would be 2006 wouldn't it? We remained there until May 2007 we went back to Turkey, he was still working, we always returned for the grand children's holiday… we returned to Turkey in September….. S was expecting to work at this time… he went to the office, somebody from the office rang me to say S's contract had been terminated in May, he hadn't remembered on the day he was told… he didn't tell me, so he'd gone back expecting to work....." (Subject 32)

The above are quotes from a range of carers and contexts. They enlighten us to the nature of problems carers may encounter that can last for a number of years resulting in lengthy care giving careers and increase in a range of problems for carers as individuals.

Other participants didn't seem to need to begin their story so far in the past but still appeared to find it problematic locating the exact time frame and commencing their stories at that point as quotes below demonstrate.

"she went to a home for the last 18 months of her life… there is six months before this year we're talking about….. there were certain problems I had to put up with in the home…….." (Subject 24)

"my grandfather first developed dementia… he developed dysphasia, which I think looking back was a sign of dementia…. he used to stop remembering words…….." (Subject 07)

"she'd only been diagnosed with dementia probably only a year or 18 months prior to that…… I was looking after her I lived next door…. I'd always looked after her any way…….. I knew I needed some help…. after she'd been in hospital in 2004 I knew I was not going to be able to do it on my own……" (Subject 40)

The quote below is from one of a few participants who had no difficulty locating with detail the time frame under study. This was interpreted by the researcher as being a very significant event, the death of the person with dementia as such one can understand the reasons for precise recall.

*"it was the year 2006 was the last year before she died the 2nd of January 2007 she was living at home here in G, CD, she was born in G D, CA **(Ireland)** 1933…."* (Subject 35)

Reissman (1993) likened personal narratives to weight bearing walls that depend upon certain structures to hold them together. Stories told in conversation share common parameters, although they may be put together in contrasting ways and as a result point to different interpretations. Events become meaningful because of their place within the narrative. Stories inform us not only about past actions but how individuals understand those actions and place meanings upon them. Wherever carers commenced their stories, it would appear events in all the quotes above played a significant role in how these carers perceived and interpreted their situation and circumstances. They appear to be describing what they see as key events in their journey and whole story. These could be considered as the weight bearing walls at that time and point in their story that Reissman (1993) described.

Effects of caring on carers of people with dementia has been present in the literature for a number of years and has a tendency to focus on aspects of burden, depression and interventions to support carers in reducing incidence of these, (Knight et al 1993, Cahill et al 1998, Clarke 1999, Marriott et al 2000, Charlesworth 2001, Patterson et al 2003, Svanstrom et al 2004, Carlson 2004, Fisher et al 2011).

Caregiver burden is a complex and multidimensional construct (George & Gwyther, 1986, Pearlin *et al.*, 1990, DiBartolo, 2000). Zarit and Zarit (1982) distinguished between *objective* burden, stress associated with providing physical care, and *subjective* burden, psychological consequences of caregiving. Carer burden was defined by Zarit *et al.* (1986) as the degree to which a carer's emotional or physical health, social life or financial status had suffered as a result of caring for their relative. Similarly, Bell *et al.* (2001) emphasized psychological aspects of caregiving (anxiety, worry, guilt) and consequences of providing care (fatigue, impaired social interactions, employment conflicts, financial difficulties and family conflicts). There is also evidence in the literature suggesting physical and physiological effects of caring upon elderly carers who are co-resident spouse of care recipient, increases their mortality rate and incidence of certain health conditions i.e. sleep disorders, immune deficiencies and heart disease (Schultz et al 1999, Mills et al 2009). Factors that contribute to the stressful nature of caring for an individual with dementia have also been well described in the literature (Marriott et al 2000, Ferrario 2003, Hughes et al 2006). These generally include a variety of behavioural disturbances and psychiatric symptoms, usually depression, exhibited by the person with dementia. Torti (2004) postulate men with dementia appear to generate more stress in both genders of care givers than females but it is female caregivers who are more stressed within their role.

The researcher could find no evidence in the literature that identified whether these factors or changes in them, persist in contributing to the stressful nature of caring within the time frame of this study, last year of life and events surrounding death. Grafstrom et al (1995) reported on a Swiss study of changes in burden of spouses or

adult children over a two and a half year period. They concluded, female carers reported greatest burden and highest level of burden was experienced when people had mild dementia. However, one third of people with dementia in this study sample had been transferred into 24 hour care permanently by the end of this study. This could have contributed to overall decrease in burden at follow up rather than any change in factors influencing levels of burden. No evidence in the literature could be located to suggest factors that influenced burden had been studied and reported on within a certain time frame or whether these factors changed over time and if they did, whether this resulted in a reduction of incidence of carer burden.

Factors identified by carers themselves that continued to contribute to the stressful nature of caring within the time frame of this study, how these were perceived by carers and interpreted and constructed by the researcher will now be presented and discussed.

5.5.3 (i) The practical hard work

It might be expected entry into a nursing or care home, with an anticipated reduction in 24 hour care, would result in a reduction of stress for carers (Pearson et al 2003). Quite the contrary, the decision to move someone into a care home can be fraught with difficulties and is frequently a decision taken after many years of caring and carers feeling it is the only option left open to them. Whilst events and reasons leading up to this decision are multifaceted and complex in nature, it is a major stressor and source of anxiety which can be extremely stressful for all with what seems on occasions, minimal resolution to initial problems that initiated the move. Schultz et al (1993) suggest such a transition is associated with guilt, anger, despair, resentment and general psychological distress for carers. This suggests whilst

physical stress is reduced, psychological stress increases. Societal expectations and pressures on families to continue care giving may also influence how family members perceive themselves in relation to the person requiring 24 hour care. Some family expectations are affected by the commonly held view a care home is the "ideal" form of care and relinquishing a person to 24 hour care is representative of failure (Pearson et al 2003). This sense of failure and how this carer felt about the transition into 24 hour care for her mother is demonstrated in the quote below.

*"last year of mum's life we experienced her living in two different care homes, ……
we were trying to support her as long as possible at home…knew we were pushing
boundaries in terms of taking risks….. it was important to her to be at home, she'd
been there for 50 years… first home occurred as a result of a fall……………. after an
attempt to support her at home with her injury, a fractured arm we just weren't coping
because nobody was getting any sleep………..it kind of felt like the end of the
road…. giving up you know so you felt you had let her down, you had given up on
her…… first few weeks especially early months I would say hardest time of my life…
she was just so distressed….. so desperate to be home.. every visit was just so
traumatic….."* (Subject 26)

In the quote below we can see conflict between informal and professional carers in terms of location of a placement. In order for this family to be able to visit this person with dementia they would have had to travel a considerable distance. This event had significance for this carer and impacted upon relationships with professionals thereafter.

*"he said we're going to put him in south Manchester in this locked unit he was so
hostile on that ward….they were saying to me dad all the time he'd hurt P (wife) he
became quite hostile….couldn't seem to get his tablets sorted… I said "no you're not
I know my rights…. I've got his name down on three nursing homes, he is not going
to be put in south Manchester how would we ever see him? they weren't going to do
that to me dad………"* (Subject 09)

A number of participants (90%) experienced transfer into a variety of 24 hour care environments including care homes and hospitals (care homes 35%, hospital 55%). Subsequent death of the person with dementia also occurred there. It is difficult to establish from the data which of these environments created the hardest work for carers with regards to practicalities. One could assume transfer into a care home may be less stressful as people with dementia admitted into the hospital environment may be experiencing an acute episode of ill health which would be a source of anxiety in itself for carers, however, this did not appear to be the case.

Each of these environments presented its own challenges for different individuals. These were on a physical, practical, emotional and psychological level and continued in the last year of life and up to death.

The following quotes demonstrate some of the difficulties people experienced with location of nursing home placement in relation to families and the hard work that goes into finalising exactly where this should be and for what reasons.

" my father was in a nursing home for the last five years of his life, final year was spent at BH home in B, it's a nursing and residential home run by W Baptist's… it was a home highly recommended by people in the area, only draw back was it is 10 miles away, a round journey of 20 miles to see him. He was very well cared for, during the last year he was bedridden, he hardly communicated with us, he said very little during the last year, it was hard sometimes to know what to do for the best for him, both J, my brother and I went nearly every day to see him, we missed very few days… I worked sometimes across the way to BH that would mean I went there at eight o'clock in the morning, they were always very welcoming even at that time….."
(Subject 39)

*"it met all requirements… met my sister's minimum requirements for where my mother should be having suggested she might want to be down near Pembroke (**near sister/daughter**)………*" (Subject 17)

The following carer was an elderly lady who had to take up driving again after her husband was diagnosed with dementia and his driving license revoked. She had not driven for a number of years prior to this. Travelling such a distance on a daily basis presented her with many challenges. Aside from other physical things carers need to do this is one of the hidden and not so obvious tasks that many carers have to undertake that can be hard work.

"it's about 7 miles, 7-8 miles, they said "this is quite nice mam" all modern things and things but this is the thing I didn't like, I used to go there nearly everyday…………"
(Subject 30)

The quote below alerts us to factors within the hospital environment that created stress for one participant. The transition into hospital in an emergency situation was the initial trigger to this stress and anxiety which became heightened as the period of time in this environment continued.

*"within the space of five days he'd been in a holding ward, ward 35, then down to this ward into a big room, now into a little room **(PAUSE…)** they put him in there we went his tablets was just on the side, they'd not given him his tablets, they said "well, we've given them him" I said "well, you've got to give them to him….."oh we're not allowed to do that, we can only put them there" so he didn't have them, we went on Saturday we said he had to have things for him to go to the toilet… it was horrendous… my dad didn't know what to do……* (Subject 21)

Having a sick relative in hospital under usual circumstances is a major source of stress and anxiety, for this to occur at a significant time of year, Christmas, exacerbated this for this participant and the extended family. Continued transfers and moves to different wards and rooms when admitted into hospital was a problem. This participant attributed this to a further compromise of health and nutritional status for the person with dementia. The hospital is an environment carers expect such

issues would be successfully managed. When these expectations are not met further unrest, confrontations and anger are created. Examples of this within the last year and towards end of life were common place across transcripts within the hospital environment. One person with dementia experienced seven transitions within one hospital admission.

"Christmas dinner was over we all went back, when we got back there we actually found out they wasn't feeding my dad at all, they were putting the food in front of him, it was in the bed, it was in his hair, it was on the floor, it was everywhere, they'd given him a salad and black forest gateau for Christmas dinner, it was everywhere absolutely everywhere, he'd not eaten it, he didn't know how to my mum had to feed him we had to feed him he couldn't feed himself, we used to have to help him he couldn't, he just couldn't do it, was everywhere….. they were cross at him… they came to us they said "we're moving him again" "where you moving him to this time?" "we're putting him back int big ward" "why" "there is somebody who is more in need of the small room's is going in there" I wasn't very happy……" (Subject 21)

"one day this nurse said "he won't eat this Mrs. H" I said "no, he won't", for a start, she had a soup spoon, she couldn't even get the spoon in! I said "for a start, I'll feed him, first of all you can take that spoon away you'll never feed him with that you can't get it into the pot! Take it away, by this time I was getting mad, I said "take that spoon away, bring me a teaspoon, I'll give it him" so she went away, she come back, she said "we haven't got any teaspoons" I said "for god's sake, you're not going to tell me you haven't got a teaspoon or something less than a soup spoon to give somebody" she said "we've got a medicine spoon" I said "that'll do" so I fed him with this, I said "is that his medication on that trolley?" she said "yes, somebody's going to come give him it after, that's his Parkinson' medication" the afternoon went on, somebody else came in, I said "that's his medication, he still hasn't" "somebody's going to give it" we came away at tea time, his medication was still sitting there, he wasn't going to be coming to the Monday, S said on Sunday, "I'll come in and we'll go and feed dad……." (Subject 37)

*"I pulled the clothes back, I couldn't believe it, he had the biggest, great big bed sores on his heels, I started again……….. then he went down hill from there… he'd had nothing to eat basically for a fortnight… one day they tried to put him onto solids, what did they bring him **(sighs)** cheese and something bake, it was horrible, dry, it was terrible…. they could have given him a bit of soup… then they brought him up here…. he never really picked up… they were too late bringing him… he was a*

fighter that time he went in with pneumonia he wasn't expected to come out, he did but then he did go down hill… they couldn't get him to eat… I really think he gave up……….." (Subject 37)

"sister on the ward was brilliant because I went up twice a day to feed him because of my previous experiences……..." (Subject 14)

General basic care on hospital wards was viewed as problematic as noted in quotes above. The poor standard of care patients with dementia receive within the hospital environment at different points in the disease trajectory including end of life, has again been well documented and described in the literature, Sampson et al (2006), Cowdell (2010), Heath (2010), Waugh et al (2011). Implementing improvements in this area is another key objective of the Dementia Strategy (DoH 2009).

The practical task of frequent visiting to ensure the person with dementias' nutritional and health status was not further compromised was hard work and an increasing source of anxiety and worry for carers. However, this was not confined to hospital care. Some participants experienced increased stress levels and continued the hard work of caring when the person with dementia was transferred into residential and nursing home care as the quotes below demonstrate.

"I quite often had to remind her B's medication wasn't there, I used to give him some of his medication…. it just started going downhill…. he wasn't walking I'd get a wheelchair, I'd ask them to take him out of his arm chair put him in the wheel chair, sometimes I'd do it myself, they didn't like that, then I'd take him upstairs, wash his hair give him a better shave, clean his teeth and stand him up……….. they said he couldn't have cranberry juice anymore….I said "it's alright, I'll fetch me own, then you can carry on giving it him…………" (Subject 14)

"he was neglected, not by us, by people who profess to "care" every time we went into the home he was dirty, we got into trouble for asking could he be changed, we

were mithering………   they didn't even know how to shave him, when we offered our help they looked at us as if we'd gone out through the window…. last couple of weeks before he died…..he'd been to hospital, he was impacted, we were told that impaction had gone … impaction hadn't gone, he had to go back to hospital…………you used to have to beg, plead for him to have his hair done… he had sideburns A they chopped those off, they chopped his moustache off because it was easier for them to shave him………."   (Subject 27)

"he used to get awful angry they didn't always change her.........they are only allowed four pads a day……. four is not enough, in the last six months maybe more she was wet during the day, I used to beg, do all sorts of things the type of pads she needed you can't buy them, I was at the point just before she died of physically buying them from the firm that supplied them I couldn't cope with this, she wasn't getting changed to be left like that for six hours isn't satisfactory it really isn't………. other thing was food, it was a constant thing, I explained it all to them I wrote it all out the problems with her feeding before she went in, they did mention they were going to get a dietician to assess her then they said "no, we can't do that because we're private……… … I bought it for them in the home, they didn't have it what they were doing was liquidising food it was stone cold by time the person got it on cold plates, whereas this other food it looked appetising, it smelled appetising, you could get it whilst it was still hot into her……… eventually the manager of the home said "this is wrong you shouldn't be paying for this, we will buy it" I couldn't trust them that they were buying it often enough............they (care home) did pay for it I couldn't trust them how often they were getting it was £12 a packet…….you got a few meals out of it, depended on the kitchen, if they would use it or just liquidise behind my back……"
(Subject 36)

Those carers who managed to care for the person with dementia in their last year of life within the family home also experienced difficulties. These were of a different nature and more concerned with the practicalities and logistics of organising care as the quotes below demonstrate.

*"it was hard, it was different people every time, this was the problem, they didn't know dad, they didn't know the routine, they didn't know how to treat him, he was a very private man, very shy, very modest man, every time anybody went to take his pants down he used to fight **(gestured with fists)** like billyo…. he hated that… he was like that up until he actually died….."* (Subject 02)

"first care agency we had I had a lot of trouble with them, missed calls, late calls, numerous double calls I insisted from the word go we only had female carers coming on a number of occasions male carers arrived, didn't get a foot over the doorstep……… stretch cotton pants to hold them in place I think it's 15 per year, J had been in hospital on occasions… when the 12 months was up and next lot didn't arrive, I thought she's been in hospital…. still didn't arrive so I rang em up "you've not updated us" I says "you've updated the pads, pants go with the pads yes?" "yes, but you've not updated the pants" "but we've updated pads" district nurse had done that, "they come together", "oh no," I said "tell me you're joking?" ….if you need stretch pants to hold pads in place if we're still using pads we still need"…….they provided two kylie, what good is two? I bought me own disposable, I bought me own I didn't bother…………" (Subject 13)

"doctor at northern had forgotten to sign the discharge paperwork, from I think it was from three o'clock or something, they were just gonna pick her up, then they were, then they weren't, so it dragged on I was in touch with the district nurse, the care agency, she's coming home, no she isn't, the last time I can contact the district nursing team, they finish at 4.30, I ring their central control, they then have to ring back………….." (Subject 13)

"towards the very end she didn't want to go…she got tired too tired she used to go to luncheon club, that was Wednesday, sometimes I would have to phone from work to church to make sure she was still there, not wandering off I was thinking she could get killed on a road because there is a road, a crossing she has to use that's very, very busy that's why we'd ring dial a ride, sometimes she would leave, so I'd have to ring, make sure mum's there, keep hold of her until ring and ride…. …… I tend to be a person that gets on the phone and tries to hammer out what I could do for mum…. I didn't want mum to go into a home, that was the last resort, so as long as possible I wanted mum to be independent, this is why social services came in did this that and the other to help mum, meals on wheels she had that…..I just got this care book, there's phone numbers in there anything I wanted I would perhaps thumb through find out who I thought was the relevant person to contact and get on with it, ………." (Subject 15)

The above quotes contribute to our understanding of difficulties and hard work organisation of formal care services can create and impact this can have upon informal carers. Sussman et al (2009) explored the effects community services, like

some of those mentioned in the quotes above, can have upon stress levels of spousal carers of people with dementia. This survey study included 85 spousal carers of people with dementia. The results would suggest "in home" formal community support services as they are currently configured and offered, do little to reduce stress levels and burden experienced by this group. They suggest the most effective service was provision of day services which both could benefit from as this offered carer respite and opportunities for social interaction for the person with dementia. This kind of service is not without its problems however, and can result in further anxiety and stress for informal carers as will be demonstrated later in this theme. It is important to note this comes at a time when most Western industrialized governments, fearing fiscal crisis due to aging of the population, have been limiting rather than expanding parameters of government-funded community support. As a consequence, spouses of individuals with dementia must offer physical care, negotiate challenging behaviours, provide continuous emotional support, and grieve while managing a complex resource limited system of health and support services (Sussman et al 2009). They also discovered informal carers experienced high levels of service related stress. This was a common occurrence within the study data, lack of services available, timeliness of services and personnel providing these services were all issues that increased stress levels and contributed to the hard work of caring.

5.5.3 (ii) The physical hard work

The caregiving career (Nolan et al 2003) for a person caring for someone with dementia can be long, protracted, relentless in nature with no end point identified, unlike other life limiting illnesses. In the study average length of time from dementia

diagnosis to death was 4.5 years and average length of time spent caring 5.1 years. There were two exceptions to this, both were male carers, one son and one husband. The parent of the male carer lived for twelve years following diagnosis and his care giving career lasted ten years, two of these were as a full time carer. The wife of the other male carer lived for 20 years following diagnosis he viewed his care giving career as lasting the duration of this time.

As discussed previously, even the last year, months and days can be problematic to identify in people with dementia as will be demonstrated, the hard work continues during this time. Among key characteristics of people with dementia influencing caregiver outcomes are types of personal care tasks required, hours of care each day and amount of supervision needed. In addition behavioural problems, as highlighted earlier, are more burdensome than physical difficulties (Torti et al 2004). Mace et al's (2006) description of caring for a person with dementia as the "36 hour day" is an indication of the amount of time dedicated on a daily basis by many carers to caring and how relentless this may feel. This includes many physical tasks undertaken to support someone with dementia as the disease progresses. These usually increase in nature and demands as the person becomes more impaired and dependence upon others for all aspects of daily living increases within the last year of life. Following their European study on informal carers George et al (2008) report on average an informal carer will spend a minimum of ten hours a day caring for a person with dementia. As dementia progressed and became more advanced this increased to a minimum of 14 hours.

The quotes below illustrate for us increasing dependence upon carers and the hard work and creativity required in negotiating and managing some of the issues they can be confronted with on a daily basis, on occasions several times over the course

of one day. Physical care tasks need to be undertaken at any time during the day and as we can see below extend into the night time period and can be difficult to predict.

"when I used to shower him here I used to say "let's go have a shower" he would get undressed, get in the shower, I'd say "right, top button, can you click, click, click?", he'd say "why?", I'd say "well you're having a" "I've just had one!", I'd say "oh god yes of course you have, whatever's the matter with me, come on let's get you dry", I'd say "put that, step out, put this round you, put it between your legs, sit on the toilet, put this round you, rub your hair", we'd go through all the process of him drying himself, I'd put yesterdays clothes on, we'd come down, three or four hours later I'd say "do you want a shower?" "yes, yes" he'd say "I think I will" then go and have a shower, you know it is an all day job sometimes…….." (Subject 19)

"incontinence pads, she could be changed on that, put towels or something over the seat, when we came to CD here in the bathroom what we used was an ordinary chair and towels, did the same thing here on ordinary chair… she'd have a bath three times a week….. other days just a was…… nobody came on Saturday I did it all on a Saturday before taking her to the drop in place in D" (Subject 35)

Some of the practical, physical tasks that need to be undertaken during the night time are a source of anxiety and stress and can actually lead to the carer being put at risk of injury or incident themselves. This appeared to be something that carers did not occur to carers at that time and a "just get on with it" attitude was apparent.

*"about three o'clock in the morning, I woke up, all lights were on, I (wife) wasn't in bed…. she wasn't in the house………. I thought "blimey she's gone"………. it was winter time….. it was bloody cold…. I thought "I'll have to go out and find her ….once she gets on this road (lane at back of house) she can go anywhere ....so I scrambled all, got a torch, keys were in the door, door was wide open……. she had also started to wear white ankle socks…..as I was going down the garden I saw these two white things, it was I **(tearful) (PAUSE…)**…………. fallen into the hedge, I don't know how long she'd been there, **(PAUSE.)** I got her on her feet…… I don't think she knew what was going on….. we decided we would keep this between ourselves…. not tell anybody, **(tearful)** after that I always locked doors, kept the keys, only once after that did I wake up, she was starting to get dressed, I said "what you doing I?" "I'm getting ready" "it's only about 4 o'clock" she came back to bed you see every now and again she was quite normal "* (Subject 31)

"occasionally J had a night where she'd break out into a sweat, I got everything ready I got spare duvet in back bedroom, night dress and towel so it's a case of off with night dress, wipe down with towel, on with nightdress, back into bed, spare duvet, we'll sort all that out tomorrow, the form asks you how long it takes, well I don't stand there and time it, you just do it….…." (Subject 13)

The quote from the carer below offers an insight into difficulties that can be encountered with maintaining nutritional status as dementia progresses. The language used to describe his experience of this is powerful and informs us how this task was interpreted by this person and the meaning they placed upon this important role.

"you cannot hurry feeding, it's labour intensive, time consuming, I was able to devote time to that, that's really important, in retrospect, the staff was pleased I was coming in ……. I visited E regularly, I tried to be up at lunch time and tea time, I realised unwittingly by doing that I was monitoring E's care………" (Subject 22)

The two quotes below help inform and increase our understanding of potential stress community based services identified by Sussman (2009) can invoke in carers. Constant worry about whether the carer will return home in time, will overrun their allotted care hours and what situation may greet them when they eventually return home all contribute further to the hard work of caring and related stress.

"I *had to go do my shopping, I had to get to D and what have you, by the time you get him away, you come in, get your shoes on, all locked up, get the car out, you get away you're all the time looking at the clock, "am I going to be back in time?............."* (Subject 37)

"they tagged those two hours onto the first hour of the day from 10 o'clock to 11 o'clock, somebody would stay from 11 o'clock until one o' clock….15 hours a week from social services, I tried to be back before two hours was up…. there was one older carer had been a nurse…. I arrived back one day with ten minutes left, she was screaming, incontinent!, doubly incontinent! So (laughs) I was there really to help

caring attendants to change pads, that was one of the agreements I had with social services even though I had these for 15 hours I had these five hours from Monday to Friday I was expected by agreement with social services to be the helper for the caring attendant to do the changing pads, washing and so on ……..I had to be there social services said it was a two person job to look after T the only way it could be a one person job was if I was man 2………." (Subject 35)

One participant would go to what appeared to the researcher, extreme lengths to facilitate visits to extended family and relatives in other parts of the UK and his wife's homeland, Ireland. One negative experience of respite and break down of care facilitated within their own home leading to an emergency transfer into hospital and struggle to take his wife back home prior to this, prompted the hard work described below in maintaining family contact and connections.

"final year I took my wife over with me to G in CA we started to do it this way, we went on the afternoon ferry from S to B stayed Thursday night and Friday night in G, her family home, then we came back late Saturday afternoon……. I took the wheel chair ……….. she was doubly incontinent, she had large pads on, she was alright if she was changed in the morning, then I could change pads at night time, it would be once in a blue moon if she had to be changed in between……….. I decided it would be easier for myself to do it…………..her nieces sometimes helped…. I decided it was easier to take her across there myself, I could feed her, I had to feed her and so on, ….., even on Stennaline I could feed her, I could feed her at G, CA ……….. less stressful after what happened in D with her ending up in hospital, then having the sleep over here in CD which worked ok……….. went better but it was very stressful…….. I had to come back early hours in the morning, it's not the best way, easiest way was to put her in the car, take the wheelchair with us, Stennaline provided a wheelchair…. I took the wheelchair in the car….. it was buried under everything I had to take so much……. I had to take some bedding with us she was on special mattresses….." (Subject 35)

The example from the data above is an indication of the determination of this carer to involve the person with dementia and attempts to sustain their personhood (Kitwood

1973) and involvement with family occasions despite their level of impairment and advancing illness.

People with dementia are not exempt from physical health problems advancing age may bring. These conditions may be more problematic to manage with advancing disease and as death approaches mainly as a result of communication and cognitive deficits. This will frequently require support from carers. Being aware of this and attempting to support well being for the person with dementia as their illness progressed was another element of hard work for carers.

"I was conscious of her feet, she'd damaged her feet…… I used to buy really expensive slippers, they would last two weeks and go….. I'd be hunting round for these slippers…. all that I found quite stressful…..…. I had concerns because of her diabetes people who came in and cooked her meals came when they could she could have long periods when she wasn't being fed………." (Subject 06)

"began to be an issue with his medication…..just wouldn't take them. Four weeks before he died he went from being independently mobile to transferring with two. Three weeks before he died he had a chest infection, was prescribed anti biotics straight away, he only had these 72 hours and was hospitalised 3 days later…………" (Subject 25)

"*her oxygen levels kept dropping.. she was sick again… it was awful… she was so weak due to the lack of oxygen…. she wasn't de-hydrated they didn't put her on a drip…. I went in said "how much fluid has she had?" she said "she gets a cup of tea" I said "does she drink it?" "yes she drinks it aha………."* (Subject 34)

Informal caregivers and person cared-for are usually integrally related and a deteriorating health situation for one could influence the health situation of the other. Combination of loss, prolonged distress, physical demands of care giving and biological vulnerabilities of older care givers may compromise their physiological functioning increasing their risk for health problems (Schultz et al 1999). There was

evidence in the data suggesting physical health needs of participants were frequently overlooked and sacrificed by themselves in order to sustain the caring role and responsibilities. This was attributed to anxieties about provision of care and how the person with dementia would be cared for and by whom in the absence of main informal carer.

"mum's hip gave way she really was a prisoner in the house… unless somebody took over there was nowhere else for him to go…. he could not be left on his own if she wanted to go out poor thing it was the case I would go round to replace her……… isolation… mum really could not go out….. she was getting more and more tired, she had an OA hip that was groaning, absolutely groaning, she should have had it operated on about three years before dad died she just said where will he go if I'm in hospital out of action, I just can't do it….. she just kept going…. then about 15 months before dad died (PAUSE..) her hip gave way…..it became horrendous…. she had to go into hospital as an emergency for a hip replacement… I had to try find somewhere for dad immediately….." (Subject 03)

Note the metaphor used by participant above to describe her interpretation of the caring role and its effect upon her mother. Other metaphors used by this participant included feeling like "gerbils on a treadmill", "juggling all the balls" and "spinning plates". This was a younger care with other family commitments and responsibilities. The use of metaphors, application of a word or phrase to something it does not apply to literally, (Oxford Dictionary 2002) is a powerful way of comparing and relaying the meaning of something or an event. In the context of this carer it helps inform us of how this carer perceived and interpreted their roles within the caring context, the relentless nature and the hard work involved.

"when K went into the nursing home I didn't realise I had anything wrong with me I was soldiering on I found out I've got a faulty heart valve so I have pills for that…I suppose since he died I've had a terrible year I have just picked up everything……………I feel I've never been free to enjoy my life since K died… it's not his fault…….." (Subject 19)

The quote above also contains a metaphor, "soldiering on", to describe the caring situation. This immediately conjures up for listener a picture of carrying a heavy load, the hard and relentless work involved to the exclusion of all else, including herself. For this participant this resulted in a marked effect on her physical health affecting her ability to move forward and live her life post bereavement.

The quote below demonstrates the determined and sacrificial nature for some, of the caring role.

"*I was starting to struggle… I needed two new hips…. I was hobbling about on crutches in here and sticks….. I could see I desperately needed at least one hip replacement at that time….. I did have it organised he would go to L hospital I'd take him back when I was able to cope……. it never reached that stage ………. not only was I looking after G I was getting slower and slower at doing it….I wasn't very mobile I wasn't able to do very much that last year at all…. it was difficult getting in and out of the car things like that…..*"   (Subject 37)

The following quote from a younger participant again demonstrates level of sacrifice of one's own health in order to meet their caring responsibilities.

"*I wasn't taking care of myself very well for a large part that I was taking care of mum as well what happened increasingly was I would put mum before myself…. if something was going to be done it was going to be done for mum, it wasn't going to be done for me….. I let a lot of things slide dramatically in some cases over those years I was caring for mum it was quite an issue really, there was chunks of time when I was just pretty much existing…. functioning purely just to do things for mum… the essential things at that………..*" (Subject 41)

Stimulation and occupation for the person with dementia was another issue that contributed to the hard work of caring. Participants felt the need to offer stimulation to the person with dementia throughout their illness and up to the point of approaching the end of life. For some participants this task was extremely hard work

and a source of anxiety and feelings of failure if they perceived this hadn't been achieved.

The quote below is from a participant whose mother had dementia and was in a care home in the last year of her life. Stimulation and occupation for this person and importance of this had been addressed previously and expectations raised in relation to this. There was a sense of frustration and disappointment when this had not been achieved as discussions around this had informed choice of care home. This participant was experiencing a life threatening illness herself at the time and had limited opportunities for visiting and supporting activities.

"I took all her paints, her easel and things, at one point I said "you said you were going to" they said "the volunteers don't come any more, if you want her to paint you'll have to get her doing it yourself" they didn't encourage her to do any of that……..." (Subject 06)

The quote below is an example of how one family maintained inclusion, connection and personhood (Kitwood 1973) for the person with dementia. These kind of activities continued to a point that was fairly close to the death of the person with dementia.

"whenever he was out on the tractor doing jobs he used to bundle dad on, sit him on the back, off he'd go. He never accepted he'd got Alzheimer's me brother didn't, ………he never complained, he would always sit there quite happy,……….just bunged him on, he would just sit there while he was going around doing the bailing or whatever he was doing he would just go with him………..." (Subject 02)

"about ten days before he died he was getting weaker then, they bunged him in the wheel chair, took him across to see these pigs, had him looking at these pigs… it

was things like that, sounds ridiculous really… they just did it…. we just did it whatever was going on he had to see sort of thing………..." (Subject 02)

The participant in the quotes above reported her father as having following no particular faith. She did however feel he had a sense of spirituality which for him, as a farmer, was being out on the land in the presence of animals.

Searching for the person within and making connections with enduring self of the person with dementia appeared to be important for participants. They would appear to try and locate this inner person who they felt was "still there". This was achieved via stimulation and occupation on occasions. The quote below demonstrates how one participant attempted to explain how she knew the enduring self was present.

"he didn't know I was his daughter….. he knew he knew me, he knew I was safe, knew I was caring for him nicely, he appreciated it, we never lost me dad I don't think, ever…….. it depends what you think a person is, if the person is a conversation you have with them then you loose them….. I think a person's more than that, his spirit was there, (PAUSE.) he was still here, he was still TB he was the same person not just my dad he was a whole person right til the end……….." (Subject 11)

The following quote illustrates the sense of hard work in maintaining social interaction and stimulation with very limited resources whilst attempting to continue a busy life with other commitments. The sense of abandonment, loss, guilt and isolation for this participant and family is also apparent in this quote.

"If he'd have stayed at home perhaps he wouldn't have deteriorated so quickly………if somebody had come to the house twice a week that could have done something football related or taken dad out for a walk round the garden, taken him round the block…….stimulate his medical brain…. that would have been such a help…. there was just nothing, never any offer of anything like that which is why we were relying on family friends but they just disappeared……… I think what upset

both of us but mum in particular was friends you'd had for a life time, some of these friends had been at school with dad were suddenly too busy to come round, they couldn't deal with the fact dad had dementia instead of trying to support, I think the kind thing they thought to do was withdraw, that was I think the cruellest thing about it dad needed the stimulation…. people to talk to…. it was really down to mum and myself………..." (Subject 03)

There were also positive experiences in the data of attempts at stimulation and occupation which was greatly appreciated by participants. These would not necessarily always be the usual activities the person with dementia may have engaged in previously, but attempts to facilitate this were received positively by participants.

"they had a pool table in the home P and myself used to play pool with him. They used to do lots of things with them playing cards, playing bingo, he'd say at first "I'm not doing that" I'd think I'll have a go, then I'd say "ooh dad, I'm a bit stuck on this" to get him, then he'd say "give it here, give it here" he couldn't really do it we helped him along …. we'd all encourage him to get up, they used to have singing in the afternoon, they'd have little parties for them, I'd always go and dance with him, sing, he'd sing along he'd say "ooh I'm not doing that" then all of a sudden you'd hear him, you knew he'd love it on a Sunday his mates would come and bring dominoes and say "come on B, let's have a game" he couldn't really play they encouraged him, "put that one there", he'd do it….. we did keep him moving I always walked with him…….. me dad was outside more than in the nursing home… he'd sit for hours in the garden, thinking ……….." (Subject 09)

The following quote enlightens us to continued attempts by this participant to connect, stimulate and occupy the person with dementia who was in the advanced stages of the illness. All physical care was provided by formal carers and there is a sense of a feeling of redundancy for this participant. We also acquire from this quote a sense of how some carers may still want and need to be involved in supporting people at every opportunity, however small this may be.

"very little we could do for him he was doubly incontinent…. couldn't move…. all they could do really was turn him in bed using the hoist or two or three of them moving him around….. there was nothing we could give him…. he had a television we put it onto what we thought he enjoyed for instance in the summer he always liked to watch cricket we would tend to put that on how much of it sunk in we don't know….. we also had a CD player there played him his favourite tunes…. he liked hymns, certain singers…. we tried to do this…. staff knew this…. if we weren't there they would put it on………….. he slept a lot of time during that last year…. sometimes J and I would just go along we would just sit with him take a book or something…. just bear him company…… I always thought he didn't know who we were but just probably……" (Subject 39)

5.5.3 (iii) The emotional hard work

As identified earlier, the physical and psychological effects of caring for a person with dementia on informal carers along with interventions available to minimise this is well described and documented in the literature. These effects were present within a large element of the study sample as they relayed stories pertaining to different time points in their journey. Study data provides us with an indication of how and whether this continues within the last year of life, up to time of death and what issues may be contributing factors.

The quote from the participant below was early in the story. This possibly depicted on their reflection, significance for them of the effects emotionally their care giving career had had. They had experienced a range of formal support services within their family home and the last year of his mother's life was spent in a specialist continuing care hospital environment. It would appear this participant attributed length of care giving career, ten years, to psychological difficulties he experienced.

*"we're moving into emotional realms now **(laughs)**……we moved from 2007-2008 around that sort of period I'd just completed a decade as a full time carer to my mum, that had by common consent sort of really taken it's toll on me………. my health or more so mental health has suffered all those years of being a carer …"* (Subject 41)

There is evidence in the quote below of frustrations informal carers may feel having to attend physical needs and impact this may have upon them. There is also evidence of the all consuming role of carer and loss of this with transfer into more supportive care environments. This transition, as discussed earlier, despite difficulties experienced that were the catalyst to this, is related to continued carer burden, both subjective and objective that Zarit et al (1982) described.

"We experienced a lot of stress in caring: however I feel we got a lot of services that benefitted greatly. My grandmother found it difficult as he would be incontinent, she would shout: as an instinctive thing, not malicious, would cry an awful lot. She found it difficult to have a life, my granddad's care became everything she did and spoke about. So when he went into a nursing home she was lost as her whole role had been taken away. She found it difficult to cope and adopted the "just get on with it" approach rather than actively seeking a way to cope….. " (Subject 25)

For younger carers who had other commitments and responsibilities the work of caring became harder as they strove to manage all the different tasks involved as the quote below informs us.

*"At that stage I had a young family, my daughter would probably've only been about seven, my son was five, my youngest was three **(exaggerated expression of this age, huffed)**, trying to hold down full time employment as well, it was hell basically…………."* (Subject 03)

Lies and deceit were another source of emotional stress and hard work for informal carers. Transfer into 24 hour care environments for some resulted in lie telling by participants in the hope it would avoid further distress for the person with dementia.

"all the time he wanted to come home, he couldn't be taken out for the day because you wouldn't get him back, you wouldn't, I'd sit with him in the garden, he'd say "are we going home now?" I'd say, "I can't now, I've got to go to work dad" " can't you just run me home first?" I'd say, "I can't" then he'd sulk he'd forget it after it had gone, all the time he was looking, looking for his car, looking for his dog, looking for P **(wife)** *looking for me and for J* **(grandson)** *he wasn't one of them that would sit there like a lot of them in a nursing home would sit there my dad wouldn't, my dad wanted to come home* **(crying) (PAUSE..)** *all the time, he'd get in a mood with you……….."*
(Subject 09)

Feil (2003) described "therapeutic lie telling" in her work on validation therapy. She purports the practice of therapeutic lie telling is a distortion of validation therapy. One lies in order to placate the patient, instead of exploring the depth of the person's reality and the therapeutic lie maintains a superficial a politeness. Effects of this deceit and lie telling on the following participant lasted into the bereavement period.

"I think a lot of the strain on us was the fact we just felt the burden of the lie, the deceit, we knew he was never going to come home again, we'd go have lunch with him on a Sunday, quite a few times he'd sort of get hold of me by the arm as we were going and say "don't forget me, don't give up on me, take me home" you'd just sort of say "next week, next week dad" you'd just think, it's just such an awful lie to have to give…….. but I still think at that stage it would have been nice had there been more support for us, the guilt we were going through, that's what's lasted with me………" (Subject 03)

Feil (2003) argued honesty was the best approach at all times and the use of validation techniques would avoid distress for the person with dementia. Despite the emotional pain the following participant felt at the circumstances, earlier conversations about honesty were honoured. Whilst this honesty appeared to create

emotional pain for both it seemed to facilitate thoughts and conversations between mother and daughter about loss on different levels including loss of their family home and the meaning of this for them both and wider family.

" everything was so hard to take, I think it was the pain of having to say things to her I didn't want to say but you had to I had talked to her before about us always being honest with each other, when she was talking about what might be wrong with her, we'd always said we won't have secrets we'll be honest with each other, she'd look right into your face and say "do you not think if we did this and I had that, that we'll get by?" it was just so hard to say "no, I don't think we will" I would say we were both grieving actually she would be grieving I think for her home, me too for the kind of loss, she would often say to me when I was visiting, not just about herself, how she felt there my father had died in that house, she'd say "I talk to your dad there" there's all these kind of connections, it's not just a physical house it's the whole family…" (Subject 26)

For the following participant role reversal and recognition problems encountered by a significant person in her life were a source of distress. Suddenly having to engage in activities this person once performed for her was not something she had envisaged would ever happen. This was possibly compounded by the fact she was a mother herself and engaging in such activities with her children. To have to do this with her father was completely alien to her and very distressing.

"I'd have to put him to bed, I think as a daughter, I think that's been one of the hardest things which I have got over now, it would have made me cry so much it was just so upsetting, this fantastic man who'd done so much for so many other people, just become this shell terribly frightened, he just didn't know where he was, kept asking for his own mother, I think quite a few times he thought I was his mum putting him to bed which for a daughter to think your father thinks you're his mother was very, very upsetting……..." (Subject 03)

The care giving career can be fraught with difficult situations and decisions. The carer can be thrust into the position of having to make choices about a wide variety of issues on behalf of their loved ones in their best interests. These choices can

appear at various times and may be based on conversations people may have had in the past or have to be made spontaneously and with no prior information and little warning. These can be related to general care issues including potential treatments or more serious issues pertaining to end of life and palliative care as with the quote below.

"*he said you've got two choices, you either feed him or you don't feed him either way your dad's going to die, I said "can't you tell me? I don't know what to do? he's going to starve to death or I feed him and he dies, I don't know what to do?" he just said, "it's your decision I can't help you, you've got to make the decision" so I turned to my step mum and said "what are we going to do?" she said "no, I can't deal with it, you've got to make that decision" my dad was starving, he would say to me when I walked to the bed "put the kettle on duck, are we having a brew?, I'm hungry, I want something to eat" so hearing that all the time was breaking my heart, he'd be crying because he was so hungry………………so I decided, I said to the consultant "I'm going to feed him" he said " you have to do it" I said "what do you mean"? he said "you have to feed him you've decided that's what you want to do if you do feed him you know he'll choke, you know he might not choke straight away it will go to his lungs, the minute you feed him it won't be long" I said "if I don't feed him how can he live" he was getting no drinks, the drips were being pulled out…………*" (Subject 09)

The situation above found the participant in the uncomfortable position of having to make a very difficult, emotive decision based on what appears to be little information and with little time to consider this. As discussed in a previous chapter, there is a legal framework available in the UK to address such issues at an earlier stage that will avoid such situations, however uptake of this in dementia to date is minimal. Emotional effects of management of this situation and subsequent death of the person with dementia are evident in the quote below from the same participant.

"it *really haunted me, it probably always will it was horrendous because the flesh (**emphasised**) in two weeks just dropped from his bones… I have never seen anybody look like that……. he was like a skeleton an absolute skeleton when he died, to see him dead was absolutely horrendous, they hadn't even closed his eyes, they never found his teeth, they hadn't put his teeth in it was too late when they did*

find them I think to put them in so you can imagine what he was like……………"
(Subject 09)

A large number of participants were present at the death of the person with dementia regardless of environment or circumstances in which this occurred. This was a conscious choice they had made, whilst a negative experience for some, it was largely interpreted as part of saying goodbye and the grieving/healing process.

The participant below did not have this opportunity, despite making it clear to carers in the care environment caring for her loved one. She was not present at her mother's death and subsequently needed to seek professional help with resolving emotional turmoil she felt following this.

"*I took counselling after that I was really, really bitter and angry, it does go away a wee bit but it's still always there I wasn't there………"* (Subject 34)

The literature pertains mostly to negative aspects and consequences of care giving. As has been demonstrated, informal carers are individuals and respond differently to a variety of different care giving needs. There is no substitute for asking them directly about their needs, wants and consequences of caring. Not all consequences of care giving are negative, many carers report deriving pleasure from being able to help someone they love (Fallon et al 2006). Whilst participants were not asked specifically about benefits or positive aspects of their caring roles, evidence of this did appear in the data as one can see in the quote below.

"*(tearful) it was a great privilege for me, I think this is most important carers should be allowed to take part looking after their loved ones, particularly in the last stages of life…………..*" (Subject 22)

The participant below had experienced a relationship with her mother who had dementia which had been fraught with difficulties over the years. This person suddenly found themselves catapulted into the caring role whilst fighting a life limiting illness herself. Whilst she did not state any positive feelings caring for her mother had evoked at time of caring there appears to have been some benefits pertaining to healing of past hurts and resolution of anger as the quote below demonstrates.

"she's been a bigger part of my life I think since she died than she was before I find now I tell people about things she did she was quite a funny woman, I tend to have remembered all of that… my mum would've done this or my mum did a few other things, I've got a better relationship with her now I think than when she was alive, part of the problem was when she had a drink she could become quite verbally abusive that might have been beginning of a dementia, I don't know, there was a lot of pain and hurt there…that's all sort of gone…. I can get quite upset sometimes when I think about her now whereas there was none of that feeling when she was alive………." (Subject 06)

Support from family and friends can make all the difference to quality of care at home and can help avoid hospital admission. Informal carers do not always view themselves as carers rather they see provision of care for their loved one as a normal part of family life (Fallon et al 2006). Netto et al (2009) investigated gains experienced by family members of people with dementia. This was a small qualitative study involving twelve participants based in Asia. All care givers reported having gained from care giving but were asked about this directly. Most common gain was "personal growth" which comprised being more patient/understanding, becoming stronger, more resilient, increased self awareness and knowledge as is demonstrated in the quote above. A further gain included those in relationships, care givers experienced improvements in their relationship with care recipient, with other

family members or in their ability to interact with older people in general. The third gain experienced was that which they described as being on a higher level. This encompassed gains in spirituality, deepened relations with god and a more enlightened perspective in life. Results of this work support a shift from conventional focus on burdens and negative aspects of care giving to a more holistic approach that considers how care givers can grow and emerge stronger in many ways from the care giving experience (Netto et al 2009).

Reciprocity is an issue that doesn't appear in dementia care giving literature that can influence outcomes in care giver burden. In the past reciprocity has been identified as a possible important determinant regarding informal or family care (Qureshi et al 1989). Using a sample of elderly physically dependent older people mostly sibling carers, Qureshi et al (1989) investigated affect and reciprocity as bases for family/informal care. Their findings suggested neither of these were necessary conditions for provision of practical care. This was not to discount the importance per sae, they argue reciprocity is extremely important in determining the nature of caring experience. They considered relationships prior to caring and level of help and support carers had received from the parent they were currently caring for. Interesting was recall of sibling carers in relation to level of support as adults they had received from the elderly parent. They appeared to recall more instances of receiving help in the past than the elderly disabled parent recalled offering. Majority of carers in this older study reported feeling there was nothing the elderly person currently did for them indicating current reciprocity was based on past giving of the elderly parent. Carers in this study were mixed and not solely siblings never the less it is interesting to consider the concept of reciprocity, role it may play in caring for a

person with dementia, how, or if this differs and whether it affects the experience of carer burden at any time during disease trajectory.

5.5.3. (vi) Summary

This theme has presented and discussed some of the wealth of literature pertaining to the caring role of informal cares of people with dementia and the effects of this. Quotes from transcripts have been used to demonstrate what participants and the researcher interpreted and constructed as the hard work of caring and how this may relate to last year of life and events surrounding death. Factors that may contribute to the continuing hard work of caring as during the last year of life and as death approaches have also been identified.

The following subsection will present and discuss the theme derived from the data pertaining to living and dying with dementia in the face of uncertainty. Quotes from transcripts will again be used in an attempt to illustrate how informal carers live with levels of uncertainty regarding the death of the person with dementia and how this can continue for some considerable time unlike other life limiting illnesses.

5.5.4 Theme 4: Living and dying with dementia in the face of uncertainty and unpredictability

"doctors were saying "he's very poorly", she was saying "you don't know my dad, I'll come in tomorrow, he's going to be as right as rain, he'll be off this mask" they were sort of like "right, right ok" that's what happened to us so many times, then it got to Monday morning they said "he's not going to last 24 hours" I'm in Florida………."
(Subject 20)

The above quote offers some indication of the level of uncertainty carers of people with dementia may experience. This uncertainty and unpredictability in a range of domains can persist over a number of years when living with the disease. As indicated in the quote above, carers also reported finding themselves in situations where they were advised by medical staff the person with dementia is close to death only to see them recover and continue living. Again, for some this may occur on several occasions during disease trajectory and be a source of anxiety and distress.

As with previous themes, different categories contributed to this one. These were things pertaining to the uncertainty and unpredictability of the disease in last year of life and around time of death, social and physical death of the person with dementia and symptoms observed as death approached. These will be presented and discussed individually.

Issues pertaining to knowledge and information were also present in this theme. This was again in a different context to themes presented previously. In this theme it pertains to explicit knowledge (Kontos 2009) that which may be learned in a formal way i.e from a book or training rather than tacit knowledge which comes from within and experience and is not formally acquired. Carers reported lacking knowledge and information they felt was required to prepare them for and to manage certain situations and events they were faced with. This included such issues as how to

manage some more difficult unpredictable behaviours they encountered, knowledge and information on how the disease may progress, how this may affect the person with dementia and relationships and what to expect as end of life approached. Caecexia and subsequent emaciated appearance of the person with dementia towards the end of their lives was a particular source of shock and distress for informal carers as the quotes below demonstrate.

"weight loss was dramatic, very dramatic I guess she would only be, when she died maybe about five stone or something, she was just skin and bone………………"
(Subject 26)

*"*when *he were sleep he looked normal, relaxed, it were when he woke up you could see it on his face, he went really thin……………...."* (Subject 16)

Whether and when to tell people and carers the diagnosis of dementia, how to prepare people for such changes above and when the timeliest point in disease trajectory to offer this kind of information is, has been the source of much debate in recent years and has helped inform the development of carer focused interventions Downs et al (2002), Pratt et al (2003), Pinner et al (203), Marriott et al (2004). Pinner et al (2003) identified marked inconsistencies amongst professionals and their views on benefits of disclosing diagnosis of dementia and giving information about prognosis. Reasons for withholding diagnosis and other information were based on uncertainty of diagnosis, (certainty only being achieved on death and following post mortem) in more advanced and severe situations it was viewed as futile as the person with dementia may no longer have cognitive ability to understand or make use of information and lastly there was a belief hope and motivation may be reduced. They purport this view being similar to one held in cancer care and there was no

evidence to suggest this reaction occurs once diagnosis of dementia is disclosed to the patient. It could be argued, withholding information pertaining to diagnosis, course of disease and prognosis is paternalistic in nature with little or no information about patients' wishes therefore restricting forward planning. Dementia affects people differently whilst there are common symptoms one may expect to observe and experience not everyone will follow the same course. It could be counter argued, giving information about potential symptoms one may experience that may not be present at the time, may only serve to heighten anxiety and distress for the person with dementia and their carers. Individualised information that meets individual need at certain time points in the disease trajectory may be more acceptable. The skill required by practitioners is the ability to identify when this time has arrived being led and informed by cues from carers and people with dementia.

5.5.4 (i) Living with uncertainty and unpredictability

Uncertainty is an inherent part of most illness experiences and dementia in particular is fraught with uncertainties, especially for family (Stone et al 2009). A diagnosis of dementia or mild cognitive impairment (MCI), a precursor or prodromal phase to development of dementia, can be a major source of anxiety and time of uncertainty for all concerned (Oonagh et al 2007, Mast 2009, Frank et al 2006). This uncertainty can continue for a number of years and may also affect professionals involved in care of the person with dementia.

The quote below demonstrates some issues carers faced with changing personalities and unpredictable behaviours exhibited by the person with dementia that continue during the last year. Use of metaphors "demon" and "monster" are indicative of impact these changes can have upon carers which in turn may influence

how they respond and manage these behaviours. These situations could occur spontaneously when carers were least expecting them catapulting them into heightened states of anxiety and uncertainty not knowing how to respond or manage situations.

*"to see the sort of change in him, he turned into a demon **(facial grimaces)** just had no scrap of him whatsoever…… like a regression into childhood then toddlerhood like sort of tantrums ….real C would never have acted like that in a million years he just was a monster……."* (Subject 05)

The following quote is from a carer who found her husband's unpredictable behaviour extremely difficult to manage. Due to her own deteriorating health, he was subsequently transferred into a specialist nursing home. Her management strategy on the occasion below appeared generally positive. In order to avoid any confrontations with her husband she chose to walk away from the situation. However this necessitated managing her distress alone which was much less positive.

*"he'd be in his room, you'd go in you'd say "hiya, you alright?" "NO!" (**facial expression stern**) I'd say "why?" " it's this bloody thing here!" (**gestures angry response**) he'd kick the radiator there was a lady in there called C, they used to dislike one and other intently, he'd hit C, she'd bite him, he'd kick her and so on……………he used to like Pringles he tipped them all into the sink, I said to him "what you done with those K?" "I don't like them I don't want them" I said "I'll go get a bag and put them in" when I come back he'd turned the tap on… mess all over…. he also took to weeing in the sink I said "can you take the stool out of the room then he can't reach the sink" then he used to do it in the rubbish bin, then he started throwing things, you'd say "where's this?" "I don't know"…… he'd throw it out the window he became very subdued which was complete opposite of how he'd been before…………..I remember one time A (**care staff in nursing home**) said "not in a very good mood today P" I said " where is he?" she said "he's in his room" she said "actually he's coming down the corridor now" he was glaring at me, walked up to me said "what are you doing here again, I don't want you here, why are you here?" I said "actually I'm going now K" rather than have him more upset than he needed to be I would go, walk down the street crying to me it was better for me to be upset than to leave him more upset than he needed to be……………."* (Subject 19)

We can hear the desperation in the carers voice in the quote below. This unpredictable situation occurred spontaneously quite late in the evening whilst she was on her own with no support. In the absence of any thing else to support this carer, this situation culminated in a call to emergency services and an urgent transfer to hospital for the person with dementia.

*"K had a real horrendous attack, I could not control him whatsoever (**PAUSE..)** he'd taken all his medication….. he'd had his 40mg of Temazepam as well…. he'd wanted to ring a friend so I rang him and said "K wants to talk to you" he hallucinated, he saw things…………………….. I'd had to tie all my wardrobes up with string he kept going in pulling everything out…. he'd been doing that for ages…… everything was all pulled out…. going through papers that sort of thing…. the place was horrendous at times with him… I thought "what am I going to do?................."* (Subject 28)

The carer below had experienced his wife's disorientation in time on occasions. This had once resulted in him being unable to locate her in the early hours of the morning and finding her collapsed in their garden. This information was withheld from family members and professionals for fear of her being transferred into care. This was unpredictable behaviour that could occur at any time. As noted below, his management of this introduced other risks into the equation but in the absence of knowledge and information this was the best course of action he could think of to reduce the risk of her going missing again. The quote below also demonstrates how this unpredictable behaviour can challenge views of carers with regards to the illness and normality in the absence of any knowledge and information to support them.

"I always locked doors, kept keys, she'd never go wandering again, only once after that did I wake up, she was starting to get dressed I said "what you doing I?" "I'm getting ready" "it's only about 4 o'clock" she came back to bed, every now and again she was quite normal………..." (Subject 31)

The quote below is another example of the confusion carers may feel with regards to certain behaviours exhibited by the person with dementia towards them in the absence of any knowledge or information to support their attributions.

"he was fine with other people but not fine with me, he could put on a really good show but I mean he was just, really difficult with me……..." (Subject 32)

5.5.4 (ii) Dying with uncertainty and unpredictability

Having considered and discussed above some carers faced living with uncertainty and unpredictability during the last year of life for the person with dementia, the researcher would now like to present and discuss some difficulties carers of people with dementia face pertaining to declining health and predicted/impending death.

As identified earlier, uncertainty has been described as a common experience across a number of illnesses (Mishel 1981) and includes cancer (Clayton et al 2006), heart disease (Jurgens, 2006), and chronic pain (Johnson et al 2006). Dementia is no exception to this and it could be argued it may be fraught with more uncertainty and unpredictability due to the potential length and unpredictable nature of the disease trajectory.

Stone et al (2009) conducted a qualitative study informed by grounded theory, focusing on sources of uncertainty for adult children who were carers of parents with Alzheimer's disease. This was an extension of a study by Brashers et al (2003) who explored sources of uncertainty in people experiencing HIV/AIDS. They discovered three sources of uncertainty in the HIV context, medical, personal and social. These three sources of uncertainty in this illness context included issues related to ambiguity of diagnosis, financial implications and relational problems regarding

relationships around them. Stone et al (2009) sought to explore these searching for any overlap in relation to Alzheimer's disease and to establish if they could discover any new or unique sources of uncertainty in this illness context.

Participants cited several sources of uncertainty related to their experiences with Alzheimer's disease. Similar to experiences of people coping with HIV (Brashers et al 2003) participants reported medical, personal, and social sources of uncertainty. There were differences in experiences however, due to nature of the illness and focus on the non-ill person. Medical sources of uncertainty experienced by families coping with Alzheimer's disease include unknown aetiology of illness, variable symptom patterns, complex treatment decisions, and lack of information about the prognosis. Participants also reported experiencing uncertainty related to personal concerns, including possible genetic predisposition, complex and conflicting roles in caring for an ill parent, and unclear financial responsibilities. Social sources of uncertainty experienced by families coping with Alzheimer's disease included unpredictability of social reactions and ambiguity of relational implications. Issues involving unpredictable social experiences, interactions among siblings related to responsibility of care giving, and relationship between well parent and sick parent were reported by Stone et al (2009) as being particularly salient due to these uncertainties. With regard to the current study, earlier quotes presented in previous themes and those used more recently identifying some unpredictable behaviours exhibited by the person with dementia are of a similar nature to those issues and sources of uncertainty identified by Stone et al (2009).

During analysis and constant comparison of transcripts the researcher became aware there was a level of uncertainty and unpredictability within the data surrounding declining health and predicted, impending death of the person with dementia. There appeared to be a general disbelief the person with dementia may die as carers had been informed of this on other occasions in the past and death had not occurred.

The quote below demonstrates the uncertainty and unpredictability as the physical health for a person with dementia declines. The professional in the quote below felt this person was improving, possibly based on their observations. However, the carer encountered an unexpected rapid decline within a short period of time of the professional visiting and leaving.

"though it's just the last year it's a long journey…. he got pneumonia (PAUSE…)… he wasn't very well I got out of hours in…… did what they had to do…. just thought it was an infection….. family doctor came in….. thought he was getting a lot better…. said "you're over the worst….. I think it was just an infection….. I'll come back and see you tomorrow"…. that night after having being here one day saying "I'll come back tomorrow" through the night his breathing was terrible…. I was up most the night with him… giving him honey and stuff to try make it better…………" (Subject 37)

The carer in the quote below had experienced several transitions into hospital for her husband. The eventual transfer into care home appeared to bring relief for this carer who felt her husband was neglected within the hospital environment. The quote below is from the time he was transferred. This informs us how she viewed his apparent change on transfer from hospital to the care home. False hope is apparent early in the quote as she observed what appeared to be an improvement in his presentation.

"I'm not saying he'd gone any better he didn't…. the change in him he were drinking, he'd have a drink, he'd have something to eat ……………...when he got across there he seemed to come round he were fully dressed... sat int lounge we allt others… I were trying to talk to him he didn't talk a lot it were nice to see him, as it went on he'd been in a week, he were just laid in bed like we his eyes shut ...."
(Subject 16)

The following carer also appeared to experience false hope as a result of hospital staff presenting his wife differently to him than on previous occasions. Based on his observations of his wife during this visit he left at the end of visiting hours never to see his wife alive again, she died in the early hours of the following morning. This carer actually said "goodbye" to his wife on this occasion and questioned why he did so. One wonders if this carers' tacit knowledge of his wife, despite feeling she had improved, meant he intuitively knew she was going to die.

"Friday night she was sat up in bed…………first time for two or three days she was sat up in bed with a pink cardigan on…. was unusual….she could sit and watch what was going on, watch us talking to nurses… from all accounts she'd got an idea we were talking about her some things she said… why I should've said goodbye instead of "see you tomorrow" I don't know………..." (Subject 31)

Two quotes below are from carers who had lived for a number of years with the uncertainty and unpredictability dementia brings. They continued living with not knowing when the eventual physical death may occur despite this appearing close on several occasions.

"*he was a fighter that time he went in with pneumonia he wasn't expected to come out he did……………"* (Subject 37)

"*dad hadn't been well for quite a while, there were many nights when I'd left him, wondered would he be here in the morning……. "* (Subject 38)

The carer below had a long care giving career. He had cared for his mother full time over a period of ten years prior to her being transferred into 24 hour care.

"big thing for me to go in a matter of seconds from viewing mum as a lady who was seriously ill who might deteriorate and die on the other hand could rally get better and had a long history of having done so time and again…. to go from one a situation where you're trying to be cautious and optimistic to having pretty much all your hope taken away was difficult..…mum might defy their prediction again……….so I went home on Friday night half expecting the phone… my view was always there was never going to be a bedside vigil until I was told mum was dying or was likely to die, so I wasn't going to do that that night, I'd been in this situation with mum before, a lot of times over the years………" (Subject 41)

As demonstrated above, carers of people with dementia can find themselves in the predicament of facing death only to see the person with dementias' health appear to improve. They can defy death and live for what, in some situations, as in the immediate quote above, can be for many years longer than expected.

There appears to be a wealth of literature on uncertainty and experiences of living with different illnesses and uncertainty, (Mishel 1988, 1990, Johnsons et al 2006, Jurgens 2006, Goldsmith 2001, Stone et al 2009). However, there appears to be a dearth of literature pertaining to dying with uncertainty that is, coming face to face with death on numerous occasions. Nothing specific to this issue and dementia was identified. Coyle (2006) undertook a small scale qualitative study with seven people diagnosed with terminal cancer focusing on living in the face of death. All participants retained capacity and ability to communicate their feelings unlike people with dementia. Carers views were not sought or included in this study by Coyle (2006).

The End of Life Care Strategy (DoH 2008) considers different disease trajectories and suggests the elderly frail (including those with dementia) can continue along the

illness trajectory at a slower rate of decline than those with other life limiting illness such as cancer. In these situations prognostication and identifying the signs and symptoms physical death may be approaching is uncertain and can be difficult to predict with any degree of accuracy.

5.5.4 (iii) The social, physical death and sense of relief and release.

Along with uncertainty and unpredictability, Alzheimer's disease and other dementias also bring with them multiple losses for the person with dementia, their spouse and family, and professional caregivers. Doka (2010) purports grief is the constant, yet hidden, companion of Alzheimer's disease and other, related dementias. Grief can arise when someone in the early stages of the disease fearfully acknowledges the symptoms and anticipates the losses the disease entails. The person with dementia will experience major losses of memory, role and autonomy, and some would argue, ultimately, loss of identity and selfhood. Their spouse and other family members may lose the person they knew and loved, as well as their hopes and expectations for the future, their home, social networks and other important sources of identity and support as the disease progresses (Doka 2010).

Family members experience grief as they watch the slow deterioration of the memory and even the being of the person whom they love. Grief will increase as family members observe, from that decline, a stranger emerge – a stranger who often needs constant, unceasing, relentless care. Grief will be experienced even after death –complicated by feelings that arose in the course of care giving. This may include such issues as the caregiver's own losses and discomfort, possible guilt

about transfer into 24 hour care, and perhaps even troubling feelings of relief and freedom at the death (Doka 2010).

Carers bereavement may start long before the person with dementia dies as what has become known as the "social death" (Sweeting et al 1997) of the person with dementia begins to occur. There is evidence of sadness the carer below felt at what they viewed as a significant change in their parent. This illuminates us to the kind of changes and losses that may occur resulting in feelings of sadness and loss for carers when social death begins to take place before the actual physical death occurs.

"mum just stopped eating completely it had gone from food just being a bit of an issue…. it was a real shame… this might sound silly that it got to me so much my mum loved her food… I just thought one of the saddest things that could have happened to her was eating would have been a problem food was such a joy to her it must have been something to do with her taste for things changing for her… she began to find things she'd loved before unpleasant… more and more restricted in things she would tolerate in her mouth…………" (Subject 26)

In the quote below the carer talks about what would appear to be total loss of the person with dementia. She seems to compare this to what she appears to know about the context of other life limiting illnesses. Language used by this carer is extremely powerful in informing us how carers of people with dementia may interpret and perceive differences across disease areas, changes observed and effect this may have upon people.

"I think it's as bad if not worse because you actually loose the person, you know if you've got cancer, you hopefully have that person, their personality all the way up to the end with dementia you see somebody dying the person you see is somebody you love but they are not that same person……………" (Subject 03)

236

Presence of dementia on a large scale in contemporary society, dire process which it often entails raises intense questions about what it means to be a person (Kitwood et al 1992). The encounter with dementia is deeply paradoxical. On one hand, people involved in care giving often have a strong intuitive sense an individual who is severely impaired is still recognisable as a person: on the other hand progress of a dementing illness, especially if it involves a long stay in residential or nursing care, seems to be taking personhood away. Kitwood et al (1992 p.274) saw the contradictory impressions above as an invitation to enquire closely into the nature of personhood asking:

"*what is that state which we might properly call being a person?*"

Focusing on the concept of personhood, and drawing on an observation gradually being recognised as crucially significant: that a dementing illness, although often does involve disintegration of the person, need not necessarily do so; and a dementia sufferer can be in a state of at least relative well-being, Kitwood et al (1992) developed an alternative view and theory of personhood considering more positive aspects and attributes of the disease process and social death. Kitwood et al (1992) believed despite severe cognitive impairments the person within could almost always be located in some way if cared for in the correct manner.

This appears to be reflected in the quote below. Although professional carers felt this was maybe a life not worth living and care was futile, this informal carer obviously felt very differently and could still identify with the person with dementia, journey they had been on together, all the person with dementia had been and what this person continued to mean to this carer.

"staff were really good at BB… they'd come in to give mum some meds or something or take the feed out or whatever they'd say words to the effect "it's no life is it?" to me it was my mum… yes mum had changed dramatically from the mum who kind of raised me, the mum I knew of course she had, it's not I couldn't see she was profoundly disabled, profoundly compromised all these things… to me it was just my mum…. there was no difference to me in essence it was still my mum…………."
(Subject 41)

Many cultures now distinguish between biological and social death, the latter usually occurring some time before the former (Sweeting et al 1997). Patients in a comatose terminally ill phase or vegetative state may be referred to as having experienced social death as it is felt they are no longer able to engage in society and relationships (Sweeting 1997). The term 'social death' began to appear in the medical-thanatological literature in the 1960s. Glaser and Strauss (1966) for example, noted the receipt of "non-person" treatment by "hopelessly comatose" patients. Their examples include hospital personnel talking freely about issues which would matter to the sentient patient, regarding the patient as socially dead though his body remains biologically alive. Sudnow (1967), Kastenbaum (1969, 1977) held similar views on social death. In medical terms, similarly they define it as that point when socially relevant attributes of a patient begin to permanently cease to be operative as conditions for treating him and when he is essentially regarded as "already dead". Kalish (1966, 1968) went on further to subdivide concept of social death into that of "self" and "other perceived". Self perceived social death occurring as the individual accepts the notion "they are as good as dead". Other perceived is that time when people who knew an individual as alive now think of them as being for all practical purposes as dead or non-existent.

Mulkay (1993) suggests, although social death is linked to biological death, they are not identical as a result of demographic changes together with medical advances

linkage between the two has now been redrawn in Westem societies. Although it is possible for a person to sustain a personal relationship with an individual whom they know to be dead, the converse, that is social death preceding biological death, may be increasingly common. Sweeting et al (1992) identified three major, although overlapping, groups of people possessing characteristics which may lead them to become socially dead in contemporary society; those in the final stages of a lengthy terminal illness; the very old and those suffering from loss of their essential personhood.

Harris (1985) argues personhood makes human life more valuable than that of animals, fish or plants and those suffering from loss of personhood qualify for being treated as socially dead. Over the last few decades advancements in medical science and technology have forced us to question what human life means. Bound up with need to make right to life, or quality of life decisions the threshold for personhood appears to have risen. While loss of personhood will increase the likelihood of social death, the two are not one and the same. Continued involvement of relatives with a patient in a vegetative state who shows no awareness of their presence would be an example of social life in the face of loss of personhood.

The three major groups identified by Sweeting et al (1997) lengthy fatal illness, very old and loss of personhood coalesces in the case of dementia. Firstly, the lengthy but irreversible and relentless course of dementia might be assumed to encourage resolution of emotional reactions in those around sufferer. Secondly, dementia becomes increasingly likely with increasing age. Finally, people with dementia may be held up as examples of individuals for whom life may not be worthwhile anymore - it appears by attaining a certain level of dementia an individual might cease to

possess those characteristics which allow us to regard them as a person. Aronson et al Lipkowitz (1981), for example, describe those around the dementia sufferer as witnessing "slow extinction of the personality" while Alzheimer's disease and other dementias are referred to by Kastenbaum (1988) as causing "death-in-life".

In the quote below we can see this carer never felt she had lost sight of her father during his illness. She appeared to have ability to search for and discover enduring self within dementia and very eloquently described Kitwood et al's (1992) notion of what maketh the person. Caring for this carer was viewed in a positive manner despite its stressful nature. Reciprocity also appeared to be important to her, supporting care for her father also gave her opportunity to re-connect with both parents which was important for her and an opportunity she welcomed.

"people talk about dementia as you loose the person before they die, I never ever felt that with me dad ever, he was me dad…………….. that was it, he couldn't eat anymore, didn't remember me name but knew he knew me, he didn't know who I was, he didn't know I was his daughter but he knew he knew me, he knew I was safe, knew I was caring for him nicely, he appreciated it, we never lost me dad I don't think, ever……………….. you know it depends what you think a person is, if the person is a conversation you have with them then you loose them but I think a person's more than that his spirit was there, (PAUSE..)…………………. he was still here, he was still TB he was the same person not just my dad he was a whole person right til the end I've got to give something back I guess, I don't know if the rest of the family feel like that but it mattered to me ………………...something meaningful, caring for somebody is meaningful it wasn't just, send him on a holiday for their 50th wedding anniversary, or buy them a nice meal, it wasn't that, it was something that took something of yourself I actually appreciate that time……………… I got to know both of them as people………………" (Subject 11)

Over time society's attitudes to death and dying has changed dramatically. A large number of people will now die in hospitals and other types of care environments, this

was not always the case (Sweeting et al 1997). Knutson (1970) described modern day availability of such facilities for dealing with sick people as a defence which is used to protect society at large from death, comparing it with earlier periods in which death tended to be "a family affair". A further change in the experience of dying in modern societies is the increasing length of time over which death may occur, as can be the case with dementia. One implication of such a situation is those around the patient may experience "anticipatory grief" as they adjust to potential loss or endure physical separations from patient prior to actual death (Sweeting et al 1990, Holley et al 2009). Anticipatory grief has been defined by Rando (1986) as " the phenomenon encompassing the processes of mourning, coping, interaction, planning, and psychosocial reorganization that are stimulated and begun in part in response to awareness of impending loss of a loved one (death) and in recognition of associated losses in past, present, and future ". Anticipatory grief is a complex concept that encompasses grief in anticipation of future loss of a loved one, in addition to previously experienced and current losses as a result of terminal illness (Holley et al 2009).

Receiving a diagnosis of terminal disease triggers a variety of important reactions in the dying person and his or her family. The period of time between receiving a terminal diagnosis and death is often a time filled with sorrow, anxiety, uncertainty, and fear. Prolonged anticipatory grief may in some cases lead to an emotional and/or physical withdrawal from the patient. For example, while the patient is still alive, relatives may start to normalise their lives without them, just as if they had died. In the most extreme cases it is possible to all intent and purposes the patient

would become dead in the eyes of their relatives. This resonates with Kastenbaum's (1988) view on dementia causing "death in life" discussed earlier.

There is evidence in the quote below the situation described above may have started to occur for this carer and attempts to sustain life were viewed as futile by them considering what they perceived as poor quality of life for their loved one.

"doctor W eventually came there were him and this nurse talking… one of them had said, they could put a drip in…. all it would do would be feeding him well feeding him or keeping him going it were just prolonging the inevitable, I knew what they were meaning……………. I were sat at side ot bed there were our L and P there and she says, "well there's not much else only a" they gave a name for it to have tube in what I mean I said "I don't want him to have one of them" she says "we're not going to, we're just thinking" I says "no, it'll not make him better" says "what life had he got laid there?........................" (Subject 16)

The carer below appeared to have acquired some knowledge about dementia and searched for confirmation of their worst fears. This carer below lived with dementia for 15 years. The grief and worry over past and future losses they were going to incur, described by Rando (1986) and Holley et al (2009), commenced at the outset of their journey.

"one of the worst things about living with a loved one or having a loved one who's got dementia is fear of ultimate loss because you know it's coming, I can remember within weeks of mum getting an accurate diagnosis of Alzheimer's dementia I remember going over to M on my own to talk to M…. main thing I wanted to ask M was "is this condition mum now has, is this a terminal illness?" M's response to that was "yes"………..." (Subject 41)

Not all instances of loss, grief and social death elicited from the data were apparent and verbalised in a direct way. Indirectly they were present in elements of stories

that were conveyed in relation to changes observed in the person with dementia over time and how carers felt about and interpreted these.

The quotes below from two carers offer insight into some other changes carers may witness with regards to social death of the person with dementia.

"I would take my mum shopping on a Monday on a Thursday or a Sunday we'd maybe go out for coffee or whatever these things she just sort of didn't want to do any more she just wanted to sit in the chair, just become an existence really………...." (Subject 34)

There is evidence in the quote above this carer appeared to believe the person with dementia had some degree of control over disintegration of their personality. This was not common place across the data and in this case could be attributed to lack of explicit knowledge about dementia, its progression and affects of the disease.

In the quote below we can hear the sense of loss and sadness for this carer who has witnessed deterioration and social death of the person with dementia over a number of years.

"when I look back at those annual photographs that's when I look and can see the deterioration… the look getting more and more blank… he was quite a social person really, he loved to see people, talk to them… that had stopped……….." (Subject 38)

The carer below describes some of the grieving that occurred for her and the person with dementia themselves regarding the social death that transpires.

"when I lost my dad it felt like every day was a struggle, every birthday, Christmas, everything was just so painful whereas I didn't feel that this time, I don't know if that's about loosing your second parent or if it's about the nature of the, long, long process in dementia I suspect it might be more to do with the illness, you grieve for a certain loss you're kind of grieving, for example mum's loss of independence, I can

243

remember crying with her when she would get upset about it "I used to do everything for myself look at me now?" those kind of conversations, then the lack of recognition, then the physical changes it seems like there's always another notch, another bit of grieving to do, then you kind of stabilise for a bit, then it's the next bit that comes along so it does kind of feel like you're grieving in stages for lots of different things (laughs)……." (Subject 26)

The carer above is trying to interpret and make sense of the different type of grieving she experienced for the person with dementia, her mother. This was completely different to that she experienced with the loss of her father and aligns to anticipatory grief (Rando 1986) described earlier.

The advent of physical death of the person with dementia appeared to be welcomed by a number of participants. A number of them described a sense of relief when the physical death of the person with dementia finally occurred. They also described this in terms of a sense of release for the person with dementia. Carers interpreted eventual physical death as a release from suffering they perceived the person with dementia to have endured over a number of years.

For the carer below it appears she felt the person with dementia had been released from further disintegration of personhood and suffering. Release from the uncertainty and unpredictability of not knowing what was going to occur next within the illness and release from what appeared to be a long lingering uncertain future for all.

"it was a release when he died…………….it isn't a relief, it's a release, there's a big difference between relief and release………….. it's a release for him, I think same as mum, she couldn't have carried on much longer she was physically exhausted, we did it, we kept him at home, that was what he wanted, he died in his own home, he was as comfortable as he could have been he didn't suffer the last three days…………." (Subject 02)

In the following quote the carer experienced emotional turmoil regarding her father's death. This pertained to a number of issues including, the uncertainty of not knowing how her father felt as his health deteriorated and death approached, not being present herself as his death approached. Being unable to establish if any formal carers were present at his death in her absence was also a source of turmoil lasting into the bereavement period. Different language was used by this carer. Despite turmoil and anguish over unanswered questions from professionals, death was viewed positively and as some kind of "blessing". Release from what she perceived as her fathers' "struggle" with dementia.

*"you go over what he must have gone through (**crying**) was he on his own? we don't know, **PAUSE** it was sad…. a blessing in another way (**crying**) his struggle was over (**crying**) for him …….."* (Subject 09)

The researcher has interpreted the choice of language used in the quote below as implying a sense of relief unspoken by this carer. Again, we detect in this quote the level of uncertainty and unpredictability this carer felt faced with. Not knowing how much longer this situation could potentially continue for and the eventual outcome was a source of anxiety for her. In this situation, death when it occurred was perceived as "kind" and the right thing to happen.

"I just think to myself if nature is kind that was the kindest thing that could have happened to him when doctor C said to me "A, he could go on for five years like this" I thought to myself "I don't know how I'm going to handle that" going to the nursing home, visiting him, seeing him like that ………."   (Subject 28)

The carer below identifies and describes her losses in terms of social and physical death. The sense of release from the hard work of caring, witnessing disintegration of a loved one and meaning of that is eloquently portrayed.

"I think because you're going through so many experiences… certainly moving to the care home felt like she had died…. I grieved… I honestly cried harder… grieved harder then cried more then than I did when she actually died it felt tougher I know that sounds odd………. it was much tougher…. the eventual death was a bit of a release…. not that we weren't upset I think there comes a point where if you care about somebody…. you see them in enough distress and pain all you want really is for it to stop…feels like it supersedes what you might feel about loosing them….. how it feels to you their interests begin to take over……end few months especially were so very hard I really just wanted it to end for her…..I didn't want to see her in that state and distressed anymore….. so that kind of made it easier I suppose to deal with………………..." (Subject 26)

In the quote below the carer appears to be inferring a sense of relief at physical death of the person with dementia. The researcher however, had difficulty interpreting who this sense of relief was for on this occasion. One could argue it was for the carer herself considering non-verbal communication apparent in the extract of this transcript (tearfulness). However, the carer's statement about knowing "he was alright then" infers a sense of relief for the person with dementia in some way.

*"she stood like that…. she put her hand back on his neck…. I'm sat here holding his hand (**tearful**) she says (**PAUSE..**), "he's gone" (**tearful**) (**PAUSE.**) he went peaceful………..in one way I know this might sound awful to people….. it were a relief…… I new he were alright then…………"* (Subject 16)

For the carer below, who had been living for a month in the face of uncertainty and unpredictability towards the end of life, thought of the final loss and physical death brought a great sense of relief. Living with anticipation of impending death appeared

to increase their burden. The use of metaphor is an indication of how relieved this carer felt at the physical death of the person with dementia.

"I just sort of collapsed…. I realised it had happened but in a way it was relief………because we'd been like built up to it for like a month or something…. it wasn't a shock at all it was just like a weight off my shoulders………" (Subject 05)

There were some participants however, who did not view physical death of the person with dementia in terms of relief. Quite the contrary, some felt a sense of anger towards those who expressed this to them directly as the person deteriorated, death approached and then occurred as we can hear in the quote below.

"I get quite tetchy when people say that to me… "what a relief"…..it isn't a relief, it's a release for him, I think same as mum…… she couldn't have carried on much longer she was physically exhausted…………..." (Subject 02)

The following carer appears to have reached a point of accepting the inevitable physical death and is unhappy with the notion people think he and his wife are now in some way "better off" and free from burden.

*"I do occasionally meet people as one kind person said to me "J your troubles are over" **(tearful)** you see this is how they think……………. I met a carer who lost her husband last year she said "she's better off" **(PAUSE …)** I thought it's hard….I don't know how well prepared but I certainly was, certainly not ready for the situation but knew it had to happen……………"* (Subject 22)

Older people are more likely to be living alone or within an institution. As a result some would argue, their death may be likely to cause less disruption (Sweeting et al 1997). Kalish (1969) described the death of elderly people in our society as the least

disturbing, because they are not especially valued. Little progress has been made in recent years to enhance the value of older people in our societies. Older people are still most likely to be perceived as having had a full past, as contributing little to the present, and as having minimal future worth. Sweeting et al (1997) discussed the issue of people with dementia being held up in society as a group whose life may not be worthwhile any longer. The quote above and the one below appear to unfortunately uphold this view.

"*the sooner in a sense mum was put out of her misery the better was what he was kind of looking for he referred to pneumonia as "the old person's friend" almost in a manner of speaking saying well bring it on it's to your mum's benefit to get that, to be out of all this suffering of dementia, of course that's a point of view many people would share not just a professional like himself a lot of other people would share that…. I can empathise… I remember saying to him and K the other sister, "whatever happens, whatever you do when mum passes away I do not want to hear someone say it's a blessing" or "it's a good thing, do not say that to me I do not want to hear it................. …..I remember someone saying that, that's how I felt at the time it wasn't a blessing for me..................... I didn't see it as a blessing for me, for mum yes but not for me suddenly the person who by a huge length was the most important person in my life, not just at that particular time but in my whole lifetime, that will be the case even if I'm lucky enough to be a hundred, was gone……………..*" (Subject 41)

The anticipated death of the person with dementia for the carer above was likely to leave a huge void in this carers life and referring to this as a blessing was unacceptable for them.

5.5.4 (iv) Dying with dementia: identifying "the signs"

Although every one dies not everyone is exposed to the dying process, even as adults (Gabriel 2011). Current tendency is quest for eternal life in a death defying culture with a large proportion of older people dying behind closed doors more often than not in institutions rather than their homes. With advancements in science and

technology over the centuries the picture of death and dying has changed. Prior to the early twentieth century dying was most often an acute event with sudden onset and duration. Because death happened over a relatively short period of time and lack of medical technology and interventions to address main causes of death the focus of medicine at that time was primarily on comfort. Dying often occurred in the home environment with family members being primary care givers (Gabriel 2011).

The main reasons for increased life expectancy and decline in death rate stem from medical advancements including technologies and anti-biotics which have allowed health care providers to treat what were once fatal conditions. With advancement of medical technology the focus of medicine has shifted to curing illness, where it can, and helping people live as long as possible with chronic illnesses. As a result of successes of medical technology in treating acute episodes of illness that once led to death people are now dying with chronic illnesses over longer periods of time. This can be over the course of years as can be the case with dementia.

Currently, extended and nuclear families are less likely to live in the same street let alone town or city as a person experiencing life limiting illness who maybe approaching death . As a result care of actively dying has shifted to relative strangers and is more likely to occur in institutions such as acute hospitals, specialist nursing homes or residential care rather than in the family home (Gabriel 2011). As identified in an earlier chapter, this was the experience of the current study with the majority of people with dementia dying in a variety of 24 hour care environments.

The End of Life Strategy (DoH 2008) identified three types of disease trajectory. Some people with long term conditions remain in reasonably good health until shortly before their death, with a steep decline in the last few weeks or months of life. Others will experience a more gradual decline, interspersed with episodes of acute ill health from which they may or may not recover. A third group are very frail for months or years before death, with a steady progressive decline (DoH 2008). Dementia follows the "frailty" trajectory, with people suffering severe disability throughout the last year of life with a substantial decline in function (increased dependency) in the last months of life. Concurrent illnesses may accelerate decline but generally patients suffer a steady "prolonged dwindling". However, in patients who reach the advanced stages of dementia, their severe disability persists over the last year of life. Not all people will reach the terminal phase with complete activity of daily living impairment and bedridden status (Van der Steen 2010).

Prognostication across the range of terminal illnesses, including dementia, is not without its difficulties (Lamont et al 1999, Murray et al 2008, van der Steen 2010). Realistic prognoses are essential to allow patients and their carers to prepare realistic expectations for the short- to medium-term course of the disease. However, it could be argued prognostic uncertainties seen in all serious illness are amplified in patients suffering from dementia.

Dying with dementia is increasingly common, it will become even more so with the rise in the ageing population as increasing age brings with it an increased risk of developing dementia. Although prognostication in dementia is difficult, it is an incurable life limiting illness for which palliative care for the person and family is often

appropriate (van der Steen 2010). The dying phase in dementia can be more problematic to identify compared to that of advanced cancer. McCarthy et al (1997) in a retrospective study of a comparison of symptoms in the last year of life for people with dementia and people with cancer identified similar symptoms in both groups. Most frequently reported symptoms for dementia patients in the last year of life were mental confusion, urinary incontinence, pain, low mood, constipation and loss of appetite. Similar frequencies in symptoms were reported for cancer patients, but dementia patients experienced them for longer periods of time. There were different levels of dependence upon others and use of services. People with dementia required more assistance from others and accessed community based services, including primary care less than those with a cancer diagnosis.

Participants in the study described a range of symptoms they had observed over the last twelve months of life, some of those being similar to those highlighted by McCathy et al (1997) above. Poor appetites and weight loss appeared to be sources of distress especially in those who had previously enjoyed food. In the quote below we note a range of symptoms that could be an indication this person with dementia was in their last year of life and experiencing the "prolonged dwindling" identified earlier.

"last twelve months obviously were the worst…he wouldn't eat very much which mum found very distressing…. wasn't really able to wash himself or dress himself , he got very mithered and very anxious………." (Subject 02)

In the absence of any other information and observation of the person with dementia in the quote above, the researcher has interpreted "mithered and very anxious" as agitation. This is something Pautex (2007), van der Steen et al (2009) reports as

being a symptom less frequently assessed in the last phase of life in dementia but may be as common as pain and dyspnoea.

Slow insidious progression of symptoms that could indicate the last year of life are evident in the quote below. For this carer, observing changes in functional ability, eating, reduced nutritional intake and an increasing dependence upon them was a source of concern. Persistent inability to eat when fed may be another indicator of the terminal phase of the disease.

"she had difficulty in that last year feeding herself so we had a big performance, putting food in front of her, watching what she did, you know like you do with a child, I'd get up, I'd hand feed her a bit .... "*I noticed she was slowing down, it was becoming such an effort.................. that was a typical day in the last year of course it got worse because she got weaker………"*   (Subject 40)

On reflection the following carer felt he should have realised his wife was approaching the end of her life. An increasing dependence upon others was apparent alongside issues regarding nutritional status and dietary intake.

"her intake of food was getting less and less all the time, I used to go there everyday…………….. she'd be fast asleep, they said they had great difficulty getting her up, doing this and that……...at the time we should have realised she was on a one way ticket but you don't………..……….."(Subject 31)

Nutritional status, eating and drinking continues to be a concern for participants in the quotes below. This is similar to those experiencing cancer and the same problems with nutrition and weight loss. It would appear carers become focused on feeling they have to "do something" and strive to ensure similar amounts of food and liquids are accepted as previously.

"she just actually stopped eating completely she would drink a little from these you know nutritional drinks she was having that was pretty much it......so the weight loss was dramatic............" (Subject 26)

Difficulty with swallowing is another symptom experienced towards end of life in dementia that can be overlooked. Problems with swallowing are evident in the quote below. This carer continued in their attempts to feed their loved one probably unaware of potential problems this may create.

"during the last few weeks of his life he wasn't able to swallow at all I used to try give him some yoghurt he couldn't take it.... he lost a considerable lot of weight,........ the last day of his life I remember going to see him in the afternoon he was very agitated....... they said they were going to give him an injection..... they explained to me what the injection was.............." (Subject 23)

"I'd say last six or eight weeks of his life he ate about two days worth of food... lost the basic desire for food and water....we were really shocked by that... speaking to staff on the general ward they were like it's a very common thing in late stages of Alzheimer's ....we had no idea about that it's something we'd never heard of before...in a way we thought it would've been nice to be prepared for that it was something we'd never heard of at all, once we got used to that idea.. " (Subject 05)

In the quote above we note an absence of knowledge about symptoms and meaning of such when they are present. In the absence of this knowledge carers are left attempting to manage situations and make their own attributions that may not always be correct. Once knowledge had been shared with carers by professionals we note anxieties about the situation appear to be reduced.

As discussed earlier, not everyone will follow the same course when experiencing dementia, something that adds to the uncertainty and unpredictability aspect of the disease. Whilst there are common symptoms throughout the trajectory not every one

will experience these or in the same manner. Not all participants reported issues with reduced appetites and dietary and fluid intake in the last year of life and as death approached.

"night before he really took ill he'd had a damn good dinner, I can't remember what it was it was like goulash or something like that with veg and everything…suddenly like the following day he couldn't eat… that's when the pneumonia set in up to then he'd eaten really well……………...." (Subject 33)

The following quotes chart the course of decline for the person with dementia. We can note many symptoms that would indicate this person was in their last year of life and death was approaching although the eventual death occurred quite sudden and unexpectedly for the carer. This particular person did not have reduced appetite nor did this carer experience problems maintaining nutritional status prior to his wife's death, this was a symptom that occurred suddenly and out of the blue which was a source of surprise for the carer.

"it was very sudden having had a good week..Sunday night couldn't eat her meal then Monday having this breathing problem with her chest I wouldn't have thought it was life threatening…. in the recovery position she sort of eased off........ she wasn't mobile, she was sat in the chair in the lounge or lay down…. she was doubly incontinent had large pads on.. she was alright if she was changed in the morning…………she wasn't any good on one mattress..had to be two mattresses her bottom skin was breaking down…………she wasn't well day before she died… the first of January….. she didn't eat her meal on new years eve which was unusual… usually she tucked into that but she didn't…………but she was having breathing difficulties on the morning of the first of January… when the care attendant came in we had difficulty sort of walking her to the bathroom… getting her washed… incontinence was worse than usual.. more liquidy…. she was having difficulties breathing…….got her back to bed.. her breathing eased… there was no longer that deep breathing associated with the throat …. made sure she was comfortable… she died the following morning on the second of January………... she had passed that phase, it was obvious really she probably didn't have long to go……." (Subject 35)

The above enlightens us to what can be the uncertain and unpredictable nature of death for people with dementia. This person appeared to have been in the "prolonged lingering" terminal phase even prior to the time frame of the study. Despite this, death occurred with minimal prior warning unlike other participants who had been told the person was dying to see them live or linger for long periods of time.

Some participants' loved ones had reached the terminal phase of the disease process and were totally dependent upon others for all activities of daily living. The carer below was describing how she established her father's needs. Communication skills were severely impaired and compromised at this time and observation was the manner in which his needs were identified.

"He was very well cared for, during the last year he was bedridden........... guess work….. much I think as you do with a baby you know when you have a young baby you anticipate their needs…. I mean clearly he was kept clean by staff they did that three or four times a day......... obviously by the last year they were liquidising everything for him……………..." (Subject 38)

The following carer had a long care giving career spanning 20 years in total with a number of the latter years being spent in a hospital environment. The subsequent death of his wife occurred here. This person had been in the terminal phase of her illness over a long period of time and was well supported by qualified personnel. One could argue this extended her life for a longer period in the terminal phase. Availability of knowledgeable and experienced professional carers who had acquired in depth knowledge of this person's needs as a result of providing care over long periods of time may have been an asset in these circumstances. This situation had

also facilitated development of relationships with the person with dementia's family which developed into partnership and collaboration in care.

"E's physical condition meant she was extremely disabled by this time E had gone into the foetal position, total contracture of her upper and lower limbs. E was incapable of speaking for some time she required total nursing care this she got to the highest degree, we can list the main points of her care as nutrition, E was always well fed and for a long, long time people'd realised E could not feed herself she had assisted feeding……………" (Subject 22)

The quote below describes the last four weeks of the person with dementia's life and events leading up to their death. This extract was taken from the only written narrative received in the study. Events of the last four weeks of life are charted well and offer insights into sources of distress and anxiety for this carer. Caecexia was again an issue, as we have witnessed with several other participants. Apparent changes in presentation, the person's appetite and how this was perceived as positive by professional carers indicates lack of knowledge on their part.

"Four weeks before he died he went from being independently mobile to transferring with two. Three weeks before he died he had a chest infection, was prescribed anti biotics straight away 72 hours was hospitalised three days later. He spent a week in hospital, two days more to introduce warfarin. It was a horrible experience, so thin and vulnerable, it was like he was always thinking, pre-occupied in thought which was painful for us to see…………….. day before he died, we visited him, the home were so pleased because he'd eaten a full English breakfast, a full dinner and afternoon snack…. he hadn't eaten anything for around two and a half weeks. He read a pamphlet to us perfectly clear, seemed content and showed a flicker of humour which he hadn't done for 18 months. He died alone next morning peacefully in his sleep…………." (Subject 25)

Unexpected changes above may have contributed to feelings of uncertainty for this carer and although unspoken/unwritten, one wonders if sudden changes prior to

death may have added to this and even resulted in feelings of hope for the future. Sudden ending to life and potential effects of this were not addressed in the written narrative.

In the quote below there is evidence of a more natural and expected end to life. The death appeared to approach in a manner one may expect to witness that is actually more certain and predictable.

"she was bedridden wasn't really conscious .... she hardly ever woke up in the last two or three days I think she went to this stage in the last three days of her life where she was bedridden, not conscious...... sleeping all the time...." (Subject 24)

Communication is the underpinning theme within the study's data and will be the last theme to be presented in this chapter. However, the researcher feels it is important to mention communication briefly in the context of uncertainty and unpredictability and how it influences and may contribute to this. Stone et al (2010) identified links with communication and uncertainty and Mishel (1981) in his work on uncertainty in illness postulated that stress and uncertainty are inextricably linked. How deteriorating health and potential consequences of this was communicated to carers was another source of uncertainty and unpredictability for carers.

"sister on the ward and a doctor came to tell me they were stopping the drip so he was just on oxygen because they said it's not doing him any good... they don't actually say the word "die" they just say "it won't be very long" when I said "how long?" they just sort of said "well an hour.... eight hours it certainly will be today........." (Subject 14)

The information portrayed by professionals to the carer above increases the sense of uncertainty. No accurate time span can be given and in the absence of this, the carer is left wondering when death may occur.

The two quotes below are examples from the data of the kind of language professionals use to communicate the message death maybe close.

"I remember Tuesday after I'd seen mum the, the nurse took me to one side, she said "she's very, very ill" well I knew that…………." (Subject 15)

There is a sense of frustration for this carer above who appeared to desire more accurate information regards prognosis and when death may occur. There is also evidence of frustration at her being told something she felt she already knew.

The following quote emphasises language used by professionals to communicate to carer the person with dementia is dying. This carer enquired about any notable changes in their loved one as they could not observe any. Inability to identify any changes could have been the result of denial by this carer and issues with accepting the inevitable, which they had been dreading, may be close. Absence of clear information from professionals regarding symptoms and changes that informed what they were communicating to this carer increased uncertainty and disbelief. One could argue tacit knowledge of professionals rather than any explicit knowledge they could communicate may have informed their thinking and judgements on this occasion.

"staff would sort of tell me "your mum is declining" they wouldn't pin point how, why, in what way, just a general sort of feeling I don't think there was really any, I'm not just saying that I knew mum so well, you could argue that maybe I was a bit too close, sometimes being too close is not favourable because you don't have objectivity other people have but there wasn't really any change………" (Subject 41)

The same carer experienced unease with who communicated certain information at difficult times as noted below. The person with dementia was in a local cottage hospital for respite at this time and primary care staff had responsibility for health care for patients in this facility.

"lunch time on Monday this GP phoned me out of the blue, said to me in his view mum was dying, only had maybe 24 hours or there abouts to live…I was sort of astounded I knew mum hadn't been too well although there wasn't to me any significant change in mum…. I knew mum was running the risk of becoming dehydrated and or malnourished to go from having those concerns to suddenly somebody saying that, what this GP then said to me…. this was somebody I'd never spoken to before in my life…. he was pretty clear about it… he then said "I just need you to let your mum let her die" or words to that effect….. my response to that which on balance I know is being glad I did react in that way was "no"…" (Subject 41)

Decisions about when to initiate end of life care for people with dementia is one fraught with difficulty for primary care personnel (Grisaffi et al 2010). Predicting end of life in dementia compared to other life limiting illnesses is complex mostly due to the erratic, uncertain and unpredictable disease trajectory. Severely impaired communication and lack of capacity to make end of life decisions contribute to the difficulties encountered. Scales, end of life care pathways and guidance have been developed to support professionals in identifying the terminal phase of dementia. Reliability of these in dementia has yet to be demonstrated (Grisaffi et al 2010).

5.5.4(v) Summary

This theme has presented and discussed general literature pertaining to uncertainty and unpredictability and then focused on dementia. Quotes from transcripts have been used to demonstrate what participants and the researcher interpreted and constructed as uncertainty and unpredictability. This has been in the context of dementia and in different domains which included living with uncertainty and

unpredictability, dying with uncertainty and unpredictability, the social, physical death and sense of relief and release this brings and dying with dementia: identifying "the signs".

The following subsection will present and discuss the theme derived from the data that underpins all other themes presented previously. This pertains to communication and communicating in a world of chaos and uncertainty. Extracts from transcripts will again be used in an attempt to illustrate how informal carers and the researcher perceive and construct what the issues are.

5.5.5. Theme 5: Communicating in a world of chaos and uncertainty

"had to work it out…. I knew when she was cold she would physically put her arms together when she was too hot she would be unbuttoning her blouse I tried to get the staff to understand we had to look for non-verbal……. I mean it is easier to care for somebody when they communicate if it's limited with a stroke it's difficult… when they don't speak at all you're having to work out what their needs are…………."
(Subject 36)

The quote above enlightens us to difficulties one may encounter on a daily basis when trying to communicate with a person with dementia who may be experiencing severe impairment in this domain. This is not uncommon in dementia as the disease progresses increasing difficulty with expressive and receptive dysphasia may become apparent. Loss of concentration and poor memory may add to these difficulties (Hughes et al 2006). However, emotional receptivity and meaning do not inevitably disappear even in advanced dementia and attempts to communicate should persist (Sabat 2001) In these situations communication, maintaining well being and establishing someone's needs is usually dependent upon communication of information from informal carers or other people who may have intimate knowledge of the person with dementia.

This particular theme is the underpinning theme across the data. As will be demonstrated, all manner of communication influenced and contributed to development of this theme. As with other themes, different categories contributed to this one it will also be presented and discussed in subthemes. These include, communications with people with dementia in their last year of life, communications with informal carers of people with dementia during this period and "death talk" focusing on how people are told death is approaching and how this is interpreted. Finally, the researcher would like to present an interesting but potentially

controversial aspect of the data pertaining to language as a communication barrier as interpreted through eyes of informal carers.

Issues pertaining to knowledge and information were again present in this theme. This was in a slightly different context to themes presented previously. In this theme it pertains to a combination of tacit and explicit knowledge (Kontos 2009). That is, knowledge learned in both a formal way i.e. from a book or training and an informal way, that which comes from within and experience and is not formally acquired. Carers felt they lacked knowledge and information required to negotiate their way around what they viewed as complex health, social care and financial systems. This often resulted in feelings of frustration and disappointment and contributed to the hard work of caring and uncertainty and unpredictability of living and eventually dying with dementia.

The researcher considered it important to briefly re-visit communication theories, models, types, styles and skills in order to contextualise this theme. This was presented in chapter two and supports understanding of how the theme and issues apparent with communication contributed to its construction, interpretation and development.

5.5.5. (i) Communicating and connecting with people with dementia in their last year of life:

Communicating effectively with patients and their family is of benefit to patient, health/social care team and families. Effective communication can help the team identify patients' problems more accurately, leads to greater patient satisfaction, and can be more rewarding for the health care professional (Newton 2010). An important factor underlying patients' participation in their health care is willingness to

communicate about their health. To be actively involved in their health care, patients must talk with health-care personnel and others (e.g., their families) about their health (Wright et al 2008). In cancer care respect for autonomy will usually mean discussing treatment options, including location, with the patient (Hughes et al 2006). This is not so clear cut in dementia and becomes be more problematic for everyone involved as disease progresses. As the disease progresses impairments in many domains result in increasing dependence upon others. Professionals become more reliant upon others for information to support treatment and care choices for the person with dementia. As discussed in previous chapters, the advent of legislation in England and Wales, Mental Capacity Act, (DoH 2005) is a means to prepare for such eventualities but the uptake of this in dementia to date remains minimal. The question remains within the field of dementia as to when is the best time to initiate conversations about making provisions for what can be an insidious mental and physical decline culminating in loss of capacity to make one's own choices thus maintaining control over one's own life.

Although a biomedical approach to treatment still tends to predominate (Downs 2000, Lyman 1989) people with dementia are now being thought of less as passive recipients of care, and more as people with rights and opinions, people whom carers should be listening to and engaging with in real meaningful communication. People with dementia may experience anxiety and depression in earlier phases of their illness and as identified earlier, loose cognitive and functional abilities with resultant negative consequences for their ability to communicate effectively. Despite this, people with dementia remain potentially self aware, spiritually and emotionally mature human beings who are capable of looking illness in the eye and retaining some form of control over their own lives (Young et al 2009).

As dementia progressed in the last year of life and informal carers noted increasing dependence and limited avenues for communication with the person with dementia there was a sense of hopelessness. Informal carers searched their creative sides and knowledge of their loved ones in attempts to communicate and try to connect with them. This would involve playing music or having certain activities on a television channel they knew the person with dementia once enjoyed as the quote below demonstrates.

"there was nothing we could give him, he had a television, we put it onto what we thought he enjoyed…. in the summer he always liked to watch cricket we would tend to put that on… how much of it sunk in we don't know…. we also had a CD player …. played him his favourite tunes, he liked hymns, certain singers, we tried to do this…………." (Subject 39)

The same participant also struggled with not knowing the level of awareness of their loved one during their presence. Occasions like below led to her questioning the family's prior assumptions their father had no awareness of who they were during visits. The sense of hopelessness at the beginning of the quote above returns in the one below in the context of levels of awareness.

"it was so strange in the middle of everything, you'd go in and say "how are you?, how do you feel?" no response… nothing… suddenly he did come out with my name which was amazing, J always said, "he doesn't know who we are"… sometimes I did wonder how much did he know that we couldn't communicate with him… was always a worry for me…. I didn't know what else we could have done as regards his care…………." (Subject 39)

In the absence of communication and deteriorating communication skills "not knowing" how much the person with dementia actually understands and is aware of can be a source of anxiety for some carers. Other carers however, appear to find it

easier to embrace changes, the changing person and connect in any manner they can.

There appears to be a sense of togetherness and normality for the carer below, a kind of re-connecting with her mother within her world of dementia. This environment was part of the care home her mother was a permanent resident in but gave them both opportunity to share things together connecting and communicating in changed ways. In this quote we witness this carer attempting to understand certain communication styles and types her mother exhibits. The transactional model (Rothwell 2010) where both are engaged in communication is evident. Although through this example and dementia, maybe we can see how communication models require adaptation according to skills and needs of all engaged.

"*when I used to give her a walk round the grounds, she used to read out number plates on cars when we went round…. to me what she was trying to do was to make sense of her world… when she first started to clam in not speak so much I used to give her a paper to look at…. she would try and read out headlines… she was trying to make sense of her world….that's why she spoke……………"* (Subject 36)

Involvement of extended family and other people was common across the data. Relationships were developed with the person with dementia by a variety of people. Involvement in direct care and support of a physical nature was not necessarily their role however as demonstrated in the quote below these people were vital in maintaining a sense of well being for all concerned.

*" K (**grandson**) used to come talk to him… his girlfriend used to come…. always hold his hand….. he didn't not know us… he knew us… he knew us really the whole time until really til the end……………….. my dad used to sing to her… it were quite funny really… my dad were quite used to C… he took an instant liking to her….."*
(Subject 21)

As was demonstrated in another theme, activity and stimulation were viewed as an important part of maintaining well being for the person with dementia despite level of impairment or point in disease trajectory. Ability to participate in activity or observe someone else engaging the person with dementia in this also appeared to influence carers' sense of well-being. As dementia progresses this may not always be possible therefore other ways of engaging and connecting are sought by informal carers.

"*I started visiting…. I couldn't wait to get there… I was there every afternoon all afternoon for a fortnight….. I went in everyday I held her hand… she knew me…………..he said to me "just holding her hand makes all the difference in the world……keep that up and she'll be alright"……………I held her hand…. then I'd go home…. .. I held her hand….. talked to her………..*" (Subject 40)

Simply just "being" with the person with dementia was important to a number of participants as verbal communication skills diminished and conversations became more difficult. Touching, stroking and playing music appeared to become more meaningful and acceptable to all.

"*I'd stay right through to evening…. sit with mum just sit… talk to her… put the tv on … put some music on or I'd just sit there…. do my paperwork and things… just sit with mum……………..*" (Subject 41)

The following quote relates to the approaching death and end of life for the person with dementia. This person was cared for in the last year of life in a care home.

"***all day every day I saw him he was very still in the bed, they were coming in, talking to him, they didn't ignore him you know……….*"   (Subject 19)

The carer above continued to "be" with her husband herself until the end and placed great value on continued verbal communication by formal carers until the end of life.

The quote below is from one of four participants in the study who managed to care for the person with dementia, her husband, within their family home until he died. This was in a semi rural area and necessitated a high level of support from primary care services. There is also evidence of "being" in this quote. We get a sense of "being" by small children playing and present as death approached and by the carer as her husband died.

*"my daughter H was up from C and my other family, my other daughter was here with the children…children were playing under his bed…. it was all very nice….he'd have loved that…….last smile he ever gave was for one of S's children… he loved children……………perhaps he wouldn't have wanted strangers in the house (****PAUSE….)****I sat holding his hand….. I was very concerned about his breathing…it was about 8 o'clock I rang the surgery said "I needed a doctor right away" while I was talking to the doctor he died……."* (Subject 32)

There is evidence above of the importance of family presence and inclusion of even the youngest members as death approached. We can see this carer thinking about what the person with dementia may have wanted at this time, who he may have wished to be present and what kind of death would have been desired. This was a family who had felt out of control within the health care system and at the mercy of health care professionals for a period of time. To finally be in a position to achieve what they wanted, which appeared to be some sense of normality and regain control was immensely important to them.

Absence of the activity of "being" was noted amongst informal carers whose loved ones resided in formal care environments. Although unhappy about this, carers attributed absence of "being" to the nature and level of paid care in this type of environment. Formal carers were viewed by participants as being too busy with too

many practical tasks and residents to care for to simply just sit and "be" and spend time with a person with dementia.

Formal carers who were humanistic and kind in their approach were appreciated by carers. This pertained not only to themselves but to their loved ones. There were formal carers who appeared to have the ability to value people with dementia and treat them in an individualistic, person centred way (Kitwood 1997) despite impairments.

"nursing home staff treated me as a real person they also treated K as a real person, that's what he is… or what he was… because he doesn't make sense doesn't mean to say he's a lesser person than he was when he did make sense ……………"
(Subject 19)

One participant spoke spontaneously without prompting from the researcher, about her views regarding qualities one required to care for people with dementia. In the quote below she describes quite eloquently what, in her opinion, were some of the qualities a person required to enable them to work in a formal capacity with people experiencing dementia. During her paid career this participant had also worked in a formal capacity with older people and people with dementia.

"I think you've got to be a certain calibre of person to do that day in day out I really do…. I couldn't fault the NC it was lovely… they were very kind…..they've got to be very tolerant for a start….they've got to be able to read a situation that arises …… people with dementia are very unpredictable aren't they?....they've got to be of a what's er name where they can read the situation…. know how to handle it… I wasn't I knew when K was doing this I would never tell him when he said he was seeing something….. wouldn't say to him there's nobody there.. you've got to go along with them,….. some have got the ability, some haven't….. it's general with nursing anyway…you've got to have a natural aptitude to want to do that for people……… it's something that's within you… I could tell when I had nurses coming under me on a training programme….. you could tell who was going to be good

nurses….they didn't necessarily have to be academic… if they had the right about them you could see through the way they talk to people…. they had a certain flair I suppose…… they could connect……...." (Subject 28)

It is clear from the quote above this person felt qualities required to "care" were inherent in individuals and not necessarily something taught or learned, an issue addressed in a previous theme within this chapter.

Communicating with the person with dementia for informal carers may be considered an easier task than that for formal carers. Informal carers usually have a wealth of experience and knowledge both tacit and explicit of the person with dementia to inform their judgements, actions and choices. The carer in the quote above however does not feel this should be an issue and communication and success of this is dependent upon inherent skill. Below are examples of a carer's view of successful communication in a formal care environment. This carer distinguishes between "talking" and "communicating" supporting the view communication may involve different types at the same time and different skills.

"difference between communicating and talking to them….. on V7 they tried to put her in one…. she was having none of it…. on F2 still general nursing….different approach they sat her in one…………they communicated…… the food taken up "here's your lunch"…. "here's your dinner" they're looking at them… at the patient not "your dinners there love" **(gestured looking away from patient whilst talking)** *they're looking over there…. it's communication every one even domestics… I was so impressed………………they must provide staff to suit the patient… to communicate with the patient……....."* (Subject 13)

The above quote refers to two different caring situations in a formal care environment. An assumption is made having read the first part of this quote attempts by formal carers to seat this person with dementia in a specific chair for comfort failed. On relocation to a different ward within the same environment formal carers

269

were successful in their attempts to do this. This carer witnessed both of these situations and clearly believed initial failure was attributable to communication style. The second caring situation, meal time is of importance to this carer. Style and type of communication used is impressive to them and clearly what his loved one required at that time.

The following quote is a long example which charts an admission to a formal care environment for a person with dementia. It outlines a catalogue of events involving communication with him by a combination of formal and informal carers. This person had multiple physical health issues along with a diagnosis of vascular dementia. He had experienced deterioration in physical health necessitating a hospital admission.

" he needed proper decent care…. all through this time he just kept saying "please take me home, please would you just take me home" ….even he recognised he said "I'm going mad in this ward" there was just one light, it was dimly lit, electricity had gone, it wasn't being repaired because the ward was being closed after Christmas, it was just awful…………mum went in one afternoon… he was actually lying looking into the end of the corridor… his room door was open… he was lying on the bed… he had nothing on his bottom half….no pants, no pad, no nothing, no pyjamas, he was lying on the bed…. a nurse walked past… mum said "what's happened here?" ....dad's going "don't know, don't know" so me mum says to the nurse "what's happened here?" she's sort of scurrying past she said "I know he's showing everything he's got there isn't he" we complained…. we said "there's a lot of pyjamas there for god's sake he has vascular dementia he doesn't know what he's doing could you not have covered him up?" reaction we had…. they were sort of looking at us…. they just couldn't deal with him there……………. they'd sat him in a chair they were waiting for him to move….. it was the most distressing thing I've ever been through…….. he was ripping his drips out of his arms in total frustration….. I believe now he knew who we were…. couldn't communicate with us…. we were pinning his arms down the staff they didn't know how to deal with him…. what was going on with him me and me sister…..we were so desperately upset trying to pin him down **(gestured holding arms down)** *he was pulling at these drips…looking back now it was total frustration at not being able to communicate…. eventually he was moved down to the stroke unit where fortunately we know all staff there they said "don't worry, he'll be fine, we'll take care of him" as soon as he got in there they were "come on, you don't wanna be touching that" they got him 24 hour watch so he*

didn't do any damage he didn't get out of bed and fall…..they were trained to deal with patients like me dad there……." (Subject 20)

In the example above there appear to have been many issues with various aspects of attempts or lack of attempts to communicate with the person with dementia. We are also enlightened to the effect environment can have on a person with dementia. This poor initial environment appeared to heighten any distress about his health or what was happening to him and was possibly a barrier to successful communication. It also begs the question whether a person who was cognitively in tact and able to communicate with professionals effectively would have been placed in such an environment. Subsequent transition to a more suitable environment appears to have reduced carers' levels of stress and distress which would have impacted upon their loved one in a positive manner.

We may have a tendency to forget other allied health professionals who may be involved in care and subsequent communication with people with dementia. The situation below occurred after a few very difficult days attempting to manage some difficult behaviours exhibited by the person with dementia resulting in transfer to a formal care environment.

"ambulance drivers came… they came in like a bus ambulance…. dad thought he were going on a trip…….ambulance drivers were absolutely superb they said "come on will go for a run round" he thought he were going on his holidays… he got in no problem at all……. he got in that ambulance… they were talking to him……."
(Subject 21)

There could be a number of reasons why ambulance personnel were so successful in managing this situation. Presence of a uniform may have given an impression of authority to the person with dementia, type of vehicle used, approach and

communication styles of ambulance personnel may all have contributed in some way to this outcome.

In total contrast to the quote above the one below highlights for us a knowledge gap regarding some allied professionals.

"*one thing at the hospital… speech therapist because he couldn't communicate gave him this book of symbols…. it was so big…. they don't understand dementia do they? He'd have forgotten he had it…. he wouldn't have capability of turning pages over…… by the time he found what he wanted he'd have forgotten what he wanted in the first place………*" (Subject 32)

This was obviously a well meaning action and attempt at improving communication for the person with dementia but in absence of knowledge this failed and did not instil confidence in carer.

People with dementia are not exempt from other health issues necessitating investigations, assessments and treatments. The person with dementia in the quote below required an x-ray and issues with communication that can arise in these situations are apparent in the quote below.

"*x-ray ladies was quite nasty to him…. he couldn't do what they were asking…. he didn't know what they were asking him to do……they were all in a temper with him… I were loosing my temper with them….. I said to them "for god's sake he's got Alzheimer's he's an old gentleman you can see he's Polish as well…. he's poorly……."*"   (Subject 21)

Communication style and skills of allied professionals in the quote above are questionable. Whether this was due to lack of knowledge and experience in dealing with people with dementia was unattainable. The linear model of communication (Rothwell 2006) is evident here. Radiographers are sending instructions to the

person with dementia due to his illness and language barrier his ability to receive, decode and interpret this information is severely impaired. It would appear the radiographers are not prepared for this breakdown in the model and their response is one of anger, negative communication.

Issues relating to pain and people with dementia are prominent in the literature and have been discussed in detail earlier in this chapter within the experts theme. However the researcher feels it is important to address the issue again within this theme and context of communication. As identified earlier, the issue of pain largely pertains to it being undetected and untreated in people with dementia or pain in this group being treated and managed in a different way to those cognitively in tact. As we are aware, issues relating to pain were not a prominent feature in this study's data. This was neither in the last year of life or as death approached and issues that arose in the data relating to pain did not warrant development into an individual theme.

As dementia progresses and becomes more advanced limbs may become more contracted and people often adopt the foetal position when in the last phase of their illness and approaching death. This can give rise to issues related to procedural pain (Hedley et al 2006) and can make the task of attending to activities of daily living quite uncomfortable for the person with dementia as is evident in the quote below.

"when we moved her one day she cried out "oh!" we were ever so gentle with her… didn't know whether we'd hurt her or not we told the district nurse she said "just in case we'll notify doctor S" we had a patch put on………….just in case because she couldn't tell us….. there was just this "ow" that's what we did…. that was while she was still conscious…. we didn't know ….only person who could tell us couldn't… she'd informed us…. she'd communicated something to us we assumed rightly or

wrongly we probably hurt her somewhere… you've got to address that……..."
(Subject 25)

In the quote above severe impairment in verbal expressive communication skills of the person with dementia above necessitated use of observation by carers attending to her. Establishing what the actual problem was and what had been uncomfortable at that time was problematic. In this situation informal carer had both tacit and explicit knowledge to help inform their judgement. There appears to be a range of experts working collaboratively and successfully here with a range of communication skills and styles evident. In an attempt to reduce further discomfort and distress a collaborative choice to treat suspected pain was made.

There is a similar situation to that above in the quote below. Procedural pain or discomfort pertaining to activities of daily living appears to have been the issue. Positional change was initiated by informal carers when they felt the person with dementia was uncomfortable. This was interesting to note as formal carers who were caring for this person on a daily basis had not appeared to notice or observe this. The informal carer made an assumption the person with dementia "felt something, but very little" and was as far as they knew mostly comfortable. However, the researcher interpreted this as having a degree of uncertainty.

*"only times he didn't like was when they put him on his right side… he would move like this **(gestures a restless head)** we very quickly realised he didn't like to be put on his right side… it was just a matter of ringing the bell getting them to …………..sometimes one or two of the young ones would say to me he'll say "ow" or "pyte, don't" in the morning when they were changing him…… he must have felt something then but very little…. as far as we know he was as comfortable as we could possibly make him………."*   (Subject 39)

274

Observational and non-verbal skills appear to be crucial to identification of pain for people with dementia. The gold standard of verbal self description and reporting of pain is mostly not applicable as dementia progresses and communication skills become more impaired. In the quotes below there is evidence of a combination of communication skills being used by the person with dementia to relay the message of pain.

"every now and again you could tell you know she was in quite some pain you see other times she was fast asleep………. because she would say "ooh, ooh," **(gestured facial grimacing)***…………."* (Subject 31)

"*she was frowning, you could see the pain…. frowning at you…. her expression was there……….."* (Subject 34)

Observation and interpretation of pain by informal carers in the quotes above appear to convey with a greater degree of certainty pain was present.

5.5.5 (ii) Communicating with informal carers of people with dementia in the last year of life.

Communication difficulties with informal carers and how they perceived and interpreted aspects of this and effects upon them featured strongly across the data. There was evidence of a range of miscommunications and what appeared to be occasional inappropriate communication that heightened carers' anxieties and reduced their trust in formal carers and care environments. Transferring and relaying information via different types and styles of communication was problematic. There is evidence in the quote below of potential unreliability of transfer of information and communication via a source modern day society has become very dependent upon.

"I didn't see him on Monday I was busy I went in Tuesday evening…. one of the carers at the home met me…. they said "didn't you get my message I left a message on your mobile your grandfather's been admitted into hospital"… I rushed in…. he'd had a major bleed…. I think he was actually admitted on Monday…. he'd had a major bleed sort of early Monday morning………" (Subject 07)

It is going to be very difficult to generate solutions to the problem above. Missed messages via various means of communication will continue to occur in this advancing technological age. Perhaps the focus needs to be on developing management strategies for avoiding such occurrences, reducing the risk of such situations occurring and positive management of them when they do.

Not having opportunity to speak with formal carers about their loved ones, despite requesting this, was a source of frustration and anger often leading to formal verbal and written complaints being made. Lack of information in times of stress and distress contributed to the hard work of caring and levels of uncertainty informal carers experienced.

"I can remember one day in particular I was sitting with him… you want to know what's going on I said to this nurse "I'm going to be here for most of the day could I have a word with you for five minutes when you've got five minutes?" she said "yes that's fine"…… it was five o'clock at night she still hadn't come to me….. I was going to go home and get tea before I went back so I stopped her and said "could I have five minutes now?" she said "no you can't I'm far too tired to speak to you now I haven't had a minute all day I'll speak to you tomorrow"….I did loose me temper with her…..reported her…………" (Subject 09)

The carer above had been subjected to, what for her, appeared to be a catalogue of disasters in relation to her father's formal care. There had been transitions within a transition into the hospital environment and trust in formal carers and care environment was diminishing. In the example above she wanted information about

plans for her father's care. Having spent a whole day at his bedside waiting for an opportunity to communicate and have dialogue with formal carers about this to be informed this would not be convenient, all became too much for her.

Gate keeping to senior personnel in formal care environments can be common place. Rather than impromptu and spontaneous conversations, appointments were often required to discuss care issues with more senior medical personnel. The carer below had described during the interview many examples of what she perceived and interpreted as "battles", "fights" and "struggles" with formal carers during her care giving career. Inadvertently she felt she had become advocate for her husband and would continue in this role for as long as she was able.

"was an article in daily express that week about Risperidone? B was on a very small dose of it…. I'd read the article in the paper…. I'd got up to the hospital….I said to the sister "I need to talk to the doctor the consultant" she said "you can't do that" I could see him over her shoulder I said "watch" I just walked round her and went to him………………..." (Subject 14)

The carer's communication style in the quote above could be interpreted as aggressive. Despite this, she spoke with senior medical staff who listened to her concerns and medication was subsequently discontinued as a result. One is left to wonder what would have occurred in this situation with a less aggressive and more passive communication style and what would have happened to the well-being of the person with dementia had the medication continued.

There have been a number of issues within the data and across themes pertaining to hospital environments and people with dementia. The carer below felt quite strongly she needed to be with her husband, who had dementia, if he was transferred from care home to hospital.

"I said to staff if he has to go in hospital "I'm going with him"…. in hospital they don't understand dementia…. they understand nursing that's what they've trained for I said "I need to be there I'll fight them"…….." (Subject 19)

The carer's feelings above were based on past experiences with hospital environments that unfortunately supported her negative thinking and mistrust of such.

The following carer complained formally in writing about a situation he found himself in with his wife being discharged back to his care from hospital. We can hear in the quote below a catalogue of issues that created concern for him mostly as a result of poor communication styles and types by formal carers.

"I wrote a letter of complaint…… there'd been two things wrong one the GP doctor at northern had forgotten to sign discharge paperwork….. from I think from three o'clock or something they were just gonna pick her up……. then they weren't so it dragged on…….. I was in touch with the district nurse the care agency…. she's coming home… no she isn't…..last time I can contact the district nursing team, they finish at 4.30….. I ring their central control they then have to ring back …..when she was eventually coming home I said this was about seven "has she had anything to eat?" "erm, erm, erm, erm," and I'm stood there thinking "a little" that's general nursing, what's a little? That was neither use nor ornament to me…………………"
(Subject 13)

Lack of definitive information to enable this carer to plan for his wife's nutritional needs was another source of frustration for him contributing to his levels of stress which were already heightened as a result of events of the day and anticipation of his wife's return.

Continual requests for information by formal carers in anticipation of discharge home from hospital for her husband was a source of irritation for the carer below. Many carers of people with dementia will be elderly themselves. They may be experiencing age related health issues affecting mobility and ability to travel daily to visit loved

ones. Some elements of cognitive impairment may also be present in carers as a result of stress, poor sleep patterns and potential mood disorders due to their caring role. Retrieval of information required may be problematic.

"I had to keep seeing social worker…… can I do this…. can I do that…. all these questions……… had to go nearly everyday to see her answers hundreds of questions…. she must have got my life story in that book…………" (Subject 16)

Continual questioning and repeating of information was a source of irritation. Development of technology, information systems and software packages to manage large amounts of confidential information is supposedly reducing the need for the above repetition therefore reducing anxiety, stress and frustration felt by this carer.

Similar frustrations were felt by the same carer when they relied upon emergency services for support on one occasion.

"it's question after question she's asking me….I'm trying to tell her….. int finish she says "we'll sendt ambulance for him" I thought well I coulda done that int first place anyway it came………….." (Subject 16)

The above attempt to engage emergency support was eventually viewed as futile and a waste of her time.

It would appear verbal communication skills of the person with dementia in the quote below were preserved and he retained ability to make his needs known. The horror this carer felt at the response, of what she perceived as a senior person's response to her husband's requests to use the toilet are evident. There appear to be expectations more senior formal carers do not behave in this manner. They are

perceived by informal carers as leaders who are there to lead by example, good example. There is no information available about non-verbal communication one might expect to accompany the verbal response from formal carer. We are left to make assumptions based on informal carers response as to what this may have included or been like.

"she came in it were sister….. it wasn't a nurse….. this is what I was so disgusted at I told em when we went to this meeting at hospital I told em…. do you know what she did I was disgusted……. picks clothes up like that **(bed clothes)** *"it's alright, he's got a pad on" I mean he asked so he must have wanted to go tut toilet…………….."* (Subject 16)

The carer above was one of a few carers who had been assertive enough to make formal complaints about care their loved ones had received in certain formal care environments. Despite several stories including dissatisfaction with formal care, this was not a common occurrence in the data. Lack of formal complaint of any type is usually attributable to carers not wanting to be seen to make a fuss, fear of reprisals for the cared for and attributions they make about formal carers workloads.

As has been noted, caring for people with dementia in the general hospital environment is not without its difficulties for a multitude of reasons. Delivering palliative and end of life care to this group and their carers in this type of environment also creates problems. Privacy and dignity as death approached was something the carer in the quote below felt entitled to.

"*we knew he was passing away, I kept saying "is there a side room my dad can go in?" he was on a ward….. he died really waiting for a side room….. he died in the middle of a ward with other patients wondering what on earth was going on…… we'd been with him all day…. then the nurse said "things are coming to an end…………."* (Subject 09)

Frustration and disappointment in her voice is evident as privacy and dignity in death she sought for her father, family and other patients on the ward were out of her control and reach and in the end unachievable. This carer spoke following the recording of the interview about the lasting effect this situation had had upon her into bereavement.

Transfer from hospital environments to care homes was not without communication problems as we can hear in the quote below. To this carers horror important information about this person with dementia's needs had not been communicated to his new formal care environment in any form.

"what I did find terrible…… appalling was the hospital didn't actually inform the home one, he had MRSA and two, he needed nursing care……. when he went there they just put him in an ordinary single bed….. as soon as I got there, it was late afternoon when they moved him I said "he's going to need cot sides" they'd just put him down for residential………." (Subject 39)

The person's embodied nature requires careful attention to their physical needs (Hughes et al 2006). The person with dementia is also situated in different contexts. Without knowledge of these and their personal history they will not be fully understood in any care environment and delivery of person centred care (Kitwood 1997) becomes problematic. The following carer was surprised to discover an omission in her father's care plan of what they perceived as basic care needs.

"even his care plan didn't state he had a colostomy or he was profoundly deaf…. the deafness it means they don't hear instructions and so on…… we mentioned several things …. we had the meeting with the social worker and senior carer… she didn't bring paper or a pencil to make a note of anything suggested and said yes everything would be sorted it wasn't actually……….. one of the things you find difficult is you were not told when the GP was comin… quite by chance one day I arrived there when N was being seen………." (Subject 10)

The carer appears concerned at lack of any form of communication of her father's basic care needs and apathy of senior formal carer during a meeting to address and discuss issues of concern. This carer was also perturbed at lack of inclusion of family in her father's care. Interactive and transactional models of communication (Rothwell 2010) would support change in this area. Communication of information to support care and well-being one could argue is a two way process with all parties involved taking responsibility to communicate and share information.

Logistical issues of caring for a person with dementia at home can be extremely stressful for informal carers especially when a large care package is required to support care as dementia progresses. This frequently involves communication with a variety of sources using different styles and types. Trying to maintain a degree of control over this can be a logistical nightmare for informal carers who often feel at the mercy of other people. Care packages frequently break down for reasons beyond scope and control of informal carers. It can be argued good communication and well developed communication skills are fundamental to success.

"after a package had been set up it would just be decided they would change it without telling us…that person who was doing that has left now…. we can't do that anymore we're gonna do this instead….they'd just keep changing the package on us….. every time he went into hospital it would stop we'd have to have it started again….. me dad was in and out of hospital…..we had a care package that worked in any consistent way for about four weeks at a time? That's the longest period it was actually in place in the 12 month period……………………." (Subject 11)

The following carer made the decision early in his care giving career not to be at the mercy of and reliant upon other people. A large number of services he initiated himself and he kept a personal directory of services he felt were reliable. However,

there was one aspect of his mother's care he did have to rely upon other people for, provision of continence aids.

 "I remember it seemed to be taking a long time for these things…what's the problem?.... I had to get in touch with someone…. I had to complain…. I thought I was waiting too long… they soon arrived…. I think what happened was I threatened I would have to complain these things seemed to be taking a long time I said "mum's still incontinent where are they?" I think someone said "don't complain" I said " that's got to be the next stage I want these things" eventually I got them…. it didn't take too long once I got the right person… once you've reached the right source then things start to happen perhaps …………" (Subject 15)

There is evidence again of an aggressive communication style in the quote above. This appears to be borne out of frustration and lack of understanding by others of the needs of the person with dementia and effects caring can have on individuals who need to communicate on behalf of others.

The logistical nightmare can continue after the death of the person with dementia as the quote below demonstrates.

*"she died in the evening I rang em next morning we'd got the ripple mattress, we'd got the bed, we'd got the hoist… explained J had died night before… can we make arrangements for you to come collect the bed, the hoist and the mattress, "what district is it?" "S"…. "address?"….. "will be next" I said "pardon?" "next week" I said "I just told you my wife died last night you're now telling me I've got to sit and look at that bed, the air mattress, thank you very much" **(gestured putting down telephone)** about half an hour later the phone rang, it was someone else who said "we can come up this afternoon………………it's a case of getting these agencies to realise what is happening, what has happened…… to delay something like that is to increase pressure…. it's increasing pressure at the wrong time… it shouldn't be increasing….. it should be relieving pressure…it's dignity and respect those two words mean everything………..."* (Subject 13)

It is accepted equipment hired and loaned to support death at home has to be returned following the death. Timing of collection of this, as we can hear above, is

important. One may expect this will be an individual issue requiring a degree of flexibility, sensitive handling and management by those collecting equipment. This will be required in order to avoid the angry, aggressive response and communication style above.

Communication may not always be directed at a particular person but will be about a situation, event, people or person. It can be unfortunate when this type of communication is intercepted or overheard by those who it is not meant for as in the quote below.

"I heard care staff talking about me dad in an absolutely horrible way in the corridor when I was outside his room….they didn't know I was there ………." (Subject 11)

Frustration may be felt by formal carers about people and situations and this will be verbalised. There should be avenues for this to be addressed within organisations in order to avoid the situation above. Details about what was overheard in this situation were not divulged by this carer. Whether the person with dementia also heard this and potential effect upon them was also not divulged. Hearing or being subjected to negative communication, verbal or non-verbal can have a profound effect on well being of the person with dementia as well as their carers.

Despite long periods of confrontation and disagreements with care home in which her husband was cared for, the following carer felt a sense of disappointment her husband's death was not recognised in any form by the care home when this finally occurred.

"do you know they never rang me? HH never rang me with any sympathy, never sent a card………….." (Subject 14)

There was no communication at all about her husband's death, verbal or written. The researcher has interpreted the quote above as this carer possibly being willing to hold out the olive branch and offer some kind of forgiveness to the care home for what she perceived as neglectful care to which she attributed his death. There appears to be an expectation by this carer there would be some communication from formal carers acknowledging the death. In the absence of information from formal carers one can assume under the circumstances, considering difficulties they had experienced, it was deemed inappropriate to communicate condolences when in fact it would appear, it may have been welcomed by this carer and contributed to the healing process and resolution of their difficulties.

Extracts from the data above have tended to focus on poor, negative styles and types of communication and how these have been interpreted and perceived by informal carers. In the quote below the carer makes it explicit she saw an absence of communication and information in any form as being responsible for a decision she made about her grandfather's care she later came to regret

"*it was more lack of communication…. ironic thing is if you'd've explained clearly at the time the morphine would require an extra line I'd have said not a problem go ahead……………"* (Subject 07)

Her grandfather had a dual diagnosis of dementia and cancer and was hospitalised as he approached the end of his life. This carer is one of two participants in the study who experienced services from a hospital based palliative care team, she was extremely complimentary about this service, as will be demonstrated later. However prior to engagement of this service there appeared to be some miscommunication, misinterpretation about a treatment resulting in remorse and regret into bereavement.

Despite the negativity above, there was evidence of positive communications within the study data. These were of a verbal and non verbal type and demonstrated a kind, humanistic and compassionate person centred approach to care of people with dementia and their carers at a difficult time.

One of the things interpreted and received positively by informal carers on occasions it occurred were requests from formal carers for information about the person with dementia. Possession of this kind of information would enable them to get to know the person with dementia, hopefully facilitating better care.

"I remember when he was first moved one of the staff nurses came over to me she said "can you tell me about your dad, what he was like before he had dementia?" I thought that was the first time anyone has ever asked that…..that was lovely I was able to tell her……...." (Subject 10)

"her likes and her dislikes, I was impressed by them wanting to know all that……." (Subject 40)

There is acknowledgement in the quote below of the advantage informal carers have when caring for people with dementia. Their personal relationships sustained over many years usually, knowledge and experience of that person built up over time cannot fail to support communication and well-being. This person with dementia also experienced hearing deficits and declined the use of hearing aids which further compounded communication difficulties. What the carer below is meaning when suggesting people "wouldn't make the effort" was unclear. This could be interpreted as people not making the effort for several reasons. These could possibly relate to the age of the person with dementia, fact they have dementia and lastly, hearing impairments.

"I could often make links because I had some knowledge of what he may be talking about…… it was almost a guessing game…. I could often ascertain what he was trying to say…… as dementia progressed it did become progressively more difficult …a lot of people wouldn't make the effort…..it's very difficult…..I think I had advantage of past history…………." (Subject 07)

It can be argued fundamental to provision of good, holistic, person centred care is knowledge about a person and their history. It is imperative to establish at least their dislikes and likes. How this kind of information is generated, communicated and in what form is joint responsibility of all involved. Carers in the quotes above appeared surprised when asked about such things by formal carers and give the impression despite several transitions into various care environments this was not a common occurrence or something they had encountered previously. The researcher has interpreted from this informal carers did not appear to feel it was their responsibility to volunteer this kind of information in order to support care in formal care environments. It would appear they have a tendency to wait until they are asked for it.

We are touched by many people in the course of our lives life. Different types of relationships are developed and maintained with different people. All these will have an influence and impact upon who we are and become. Greenwood (2001) discussed the importance of relationships in care of people with dementia. This included relationships with all those involved with the person and not family alone. Brown-Wilson et al (2009) also discussed the importance of relationship centred care with a focus on development of these in care home environments. Relationships between formal and informal carers were viewed as important and in some instances there appeared to be what the researcher interpreted as mutual respect.

Communication, mostly verbal in nature, tended to be positive and this was welcomed by informal carers.

"nursing home always kept me in the know… always… they were always very friendly…. nursing home staff treated me as a real person …………." (Subject 19)

Being kept informed spontaneously about their loved one who was being care for in a formal care environment was appreciated by this carer above. Their humanistic care and approach to informal carer was also meaningful.

In the quote below we get a sense of importance and nature of a positive relationship the carer developed with key worker in her mother's care home. It gives the impression of a sense of trust and peace of mind for informal carer.

"that relationship was quite important with her key worker…. she was good I was able to learn to trust her quite quickly…. she would phone me up at home if anything was happening….. doctor or nurse was in the home to see your mum today this is what they're saying……. I don't know everybody would do that……. she would maintain contact with family…….. not just when we visited…..she would get in touch with me if I was at home or at work if there was anything I needed to know…… every time I would visit she would seek me out…just have a word…………." (Subject 26)

The situation above was not common place across the data in this kind of environment, nursing care home. It does enlighten us to the kind of things that may be valued amongst the wider group of carers. Spontaneous communication from formal carers and sharing of information and knowledge about well-being of the person with dementia and being kept up to date with events was appreciated and valued. The seeking out of informal carers at visits was also welcomed rather than informal carer having to do this with formal carers during visits.

Although the quote below is focused on formal carers within their home communicating with the person with dementia, the researcher has presented this here in order to demonstrate the apparent sense of well-being this carer has derived from witnessing the type and style of communication he prefers for his wife.

"this agency started…. absolutely superb…couldn't fault any of the carers…. they did the main thing as far as I'm concerned……communicated with her….. they didn't just talk to her……. they communicated…… they used to tell her when they were coming in next "I won't see you at lunch time I'll see you at tea time" or "I'm off for a couple of days I'll see you then"……… they always used to try and get her to smile………………" (Subject 13)

One can hear in the quote above the pleasure this carer derives from witnessing his wife being communicated with and included by what would appear to be skilled formal care workers who do have a tendency not to be qualified or specialists in dementia care. The same carer also placed immense value on the communication style he experienced with their General Practitioner.

"also listen to main carer absolutely essential I mean as I said ours did……… no more hospital… he said "alright" this is important this "I'll be guided by you" that's very important….. this is the GP listening…………" (Subject 13)

The carer above was one of four participants in the study whose death of their loved one with dementia was facilitated within their own family home. The role and communication styles of primary care staff and the GP was fundamental to this. As we can hear in the quote above, this carer did not wish any further interventions for his wife and the GP listened to his views and accepted these.

There was little evidence in the study data of the type of non-verbal behaviour from professionals exhibited below.

"doctor's stood at side of me he's got his arm around me he says "we're not gonna do nothing like that, no…." he says "what's best for F" he never called him Mr. K it were always F same as they do now when I walk in they say "hello M how are you?" "not bad" ……. Dr. W arrived he says, he were stood we his arm around me he said erm "it's alright we're not going to do anything you don't want" he said "what we don't want as well" he says "whatever we do we'll put it past you" there were nowt they wanted to do like……..(Subject 16)

The display of humanistic and empathic behaviour by quite a senior medical professional appeared to be unexpected by this carer. Use of touch and empathy by formal and informal carers as a means of communicating ones feelings and shared concerns for well-being was rarely evident and not common across the data.

As identified earlier two participants experienced the palliative care service provided within the hospital environment. One participant, whose husband had a dual diagnosis of cancer and dementia, had only one verbal communication and contact with this service. She was informed by them it was not appropriate and her husband was not unwell enough despite being told he had a life expectancy of six weeks. This participant was left confused as to what palliative care service meant.

"I saw the palliative care nurses……….. I never knew what they were I never saw them again……… one talked and talked and talked I don't think I learnt anything at all I really don't know what her role was or their role was one lady was very nice ……… saw them the once…. I've read something in the notes they'd decided not to see him again………….." (Subject 32)

The other participant had a very different experience as is demonstrated below.

"I thought the whole concept of palliative care was fantastic having seen how much he hated being moved so much… he hated having his blood pressure taken… he actually hated anything being done…. I thought that was the most dignified way of what until then had been a relatively undignified slow decline…………the way they deal with it is the person comes to chat with you about palliative care…. they act more as a bit of an advocate or intermediary between doctors and family so they can

come in there and get a good line of communication going … I think that's a fantastic idea……." (Subject 07)

It is evident the carer above had greater understanding of the concept of palliative care than the other participant. Any initial anxieties about involvement of the hospital palliative care team were dispelled and there is evidence to suggest they eased distress for this carer and helped to resolve some communication difficulties occurring between them, other formal carers and medical staff.

5.5.5 (iii) Dying and Death, "let's talk about it"

The manner and way in which professionals communicated information to informal carers about significant deterioration in their loved one's health was an issue within the data. Language used to inform people death may be imminent was not always deemed helpful. It often led to anxiety and contributed to prolonging chaos and uncertainty already present within their lives which for some, had been for a number of years.

"staff would sort of tell me "your mum is declining" they wouldn't pin point how, why, in what way…. just a general sort of feeling I don't think there was really………"
(Subject 41)

When the carer above asked formal carers about any notable deterioration in his mother prior to her death he was told she was declining, he couldn't observe what he considered any significant changes or signs. This led to further uncertainty for him as he could not see evidence suggesting she may be close to death. In the absence of anything visual for him language and words used by formal carers appears to create

some confusion. Did use of these words and language mean death was close or imminent? If so, what evidence was there to base this upon? There were no signs for the carer. Was this based upon observations and measurements they had taken of her vital signs or was this based on their experiential knowledge of death and intuition? Formal care delivered in this situation was in a specialist hospital environment and one could argue formal carers were very experienced in relation to care of the dying and end of life care in general. As such they could be considered experts in this situation over informal carer who had no experience of death at all. This particular carer was also desperate to continue in the caring role and could not envisage a time when his mother would not be there. There may have been an element of denial present and failure to recognise the end of her life was close as this final loss was far too much for him to bear emotionally.

The words "very poorly" and "not very well" were commonly used by formal carers to relay information that appeared to be about deteriorating health and imminent death.

"the doctors were saying "he's very poorly……………." (Subject 20)

"he's very, very poorly, still very poorly" they said…………..." (Subject 30)

"he did say he was very poorly…………." (Subject 18)

"J stayed there about an hour with him he was just sleeping then he got a phone call to say "your father's not very well I think you should come in" (Subject 39)

There appeared to be some hidden meaning within these words for informal carers who did actually interpret these as meaning the person with dementia was quite close to death.

Occasionally other words were used by formal carers that also appeared to have subliminal messages for carers. Upon hearing these words informal carers appeared to respond as if they had been told death was imminent.

"about half past ten the staff nurse rang me B and said "her breathing's become a bit distressed" I said "right I'll come……….." (Subject 22)

"senior nurse there told me mum was extremely ill…. I remember at the time visiting times were kept…… they wouldn't allow…..I don't know whether I should have asked them or whether they would've suggested perhaps I could go anytime to see mum that wasn't the case….. I was told the visiting times………." (Subject 15)

The carer above appears to have interpreted the words "extremely ill" as an indication his mother may die soon. However there is evidence of an element of uncertainty in the quote. He isn't quite sure how to interpret what was said and what the words used meant. Uncertainty he began to feel appeared to be related to visiting times. This carer appears to think if his mother was close to death restrictions on visiting times for him would have been lifted. This did not occur and was interpreted by him as his mother's death not being close.

People nearing the end of their life in care homes were visited by a GP unless it was a quick deterioration and subsequent unexpected death.

"she was quite comfortable at the end, my own GP rang me up the evening before she died he said "I've been to see your wife today, she's not in any pain or anything" I didn't realise he was really telling me the end was near…. I didn't realise that…

293

when I went there next morning….. they phoned me next morning said she's got worse during the night so I went there….." (Subject 24)

Very different language and words are used in the quote above to communicate information about deteriorating health and impending death. It was only on reflection after his wife's death the carer realised what words used by the GP were subsequently meaning.

There was evidence of what appeared to be a total contrast in relation to communicating information to carers about what was occurring and preparing them for the death of their loved one.

"*I said "just talk to my father about it.. I know what you're talking about… I'm not trying to explain things as well to him" I was trying to support him and my mother he said "there just comes a time there is nothing we're doing wrong there is nothing we can do her body… she's got to the age where her body just wants to stop… her systems are failing…………*" (Subject 36)

Wherein the situation above, both the carers' parents resided in a formal care environment. The informal carer was one of a few participants in the study who had experience of formal care during their careers. It was evident to her, her mother was nearing the end of her life. She requested the GP explain to her father what was happening. The burden and stressful nature of caring for two parents had begun to take their toll emotionally and physically and objective support was needed at this difficult time. The style of communication, language and words used conveying seriousness of the situation was done in such a manner it was very clear what was occurring minimising the risk of uncertainty in this situation. There is also a sense of communication of compassion and empathy by the GP in the quote above.

Language and words used by formal carers created some uncertainty for the carer below. There is an indication the carer thought she knew what palliative care was and meant, possibly in relation to end of life care and dying but no degree of certainty. It was only when formal carers were asked about this by this carer their interpretation and meanings were confirmed.

"consultant came to see him…. he said to me and mum "whatever he wants, whatever you want we're going to look after him whatever you ask for he will have…. we will look after him" he were brilliant….Friday they called a case conference told us there was nothing they could do for him they was putting him on palliative care… which were like a huge shock to us… we didn't really understand what that meant….. they told us it would be a matter of days…. it went on for 12 days………. eventually we asked what palliative care was they told us……. they was taking him off all medication off everything……… they'd no sooner told us that than the sister came wanted my dad moved from the side ward putting into a big ward….. there was somebody who had gone home for the weekend had now come back in and needed that bed because he liked to be on his own………… I refused point blank….I said "no, you've just told us you're putting him on palliative care, where is my dads dignity going into a ward with five or six other people… how are they going to feel? I said "no, you're not moving him" they asked if they could move him into another side ward rather than that one…. I agreed….. we agreed to the other side ward…………"
(Subject 21)

It seems almost unthinkable for the carer above to be told someone is dying and then be informed they will be moved out onto an open ward where other patients will witness what could be described as one of life's most private and intimate occasions.

As discussed in a previous theme and chapters, prognostication and predicting with any degree of accuracy when a person with dementia is likely to die can be more difficult than other life limiting illnesses. Formal carers appeared to be reluctant to commit to specific time scales and informal carers frequently understood why as they had been or appeared to be close to the death of their loved one on other occasions.

"he sat down with me he said he was really sorry it had fallen upon him to say what he was going to say he believed mum was dying, there were signs which he could see, for instance some discolouration in mum's skin in certain areas that suggested to him mum's body was in the process of shutting down I asked him how likely would it be mum would die sooner rather than later this evening, he said, quite rightly as a nurse with an abundance of experience of delivering palliative care and being in similar situations with patients he'd just been in with mum he said yes, occasionally there's been a patient who survived………………" (Subject 41)

Verbal communication of signs and clear evidence of what was happening was appreciated by informal carers. Despite this there was still evidence of uncertainty for those who had "been here before" both formal and informal carers.

There was one participant in the study who had experience of hospice care. His mother had a dual diagnosis of dementia and cancer. One may expect as palliative and end of life care is their main focus, they would have excellent communication skills in terms of communicating bad news and being as honest as patients have expressed a wish for them to be.

"doctor at WW (hospice) told me mum really hadn't got very long to live….. that was the summer…. I knew not to expect a long life…… doctor there was the only one that could be straight forward enough to tell me…..that stuck in me mind he was straightforward up front about it……….." (Subject 15)

Communication style and skill of the specialist above left a lasting impression upon this carer. They were grateful for communication of open and honest detailed information. One could argue in these circumstances it may have been easier to be more specific about prognosis. This could be due to the dual diagnosis and experience and information the specialist formal carer possessed about life expectancy at certain points in this type of cancer disease trajectory. Had the person with dementia not had this dual diagnosis, prognostication may have been more

difficult. One thing appears to be apparent, communication of clear, detailed information was welcomed.

Communicating and talking about deteriorating health and impending death as we have seen is not something formal or informal carers find particularly easy. Communication of information and breaking of bad news at difficult times are never going to be easy. Styles of communication and skills of those involved are of paramount importance. Timing of particular communications about some issues pertaining to death and choices that are or may be required is also important. Who is the best person to do this is also something that needs to be addressed.

Questions asked of informal carers about invasive procedures and resuscitation of their loved ones in the event of medical emergencies appeared to come as quite a shock on occasions these issues were addressed by formal carers. Definitive answers being hard to give when asked about such things quite unexpectedly.

"he did say he was very poorly…. I don't know how they put it…. did I want them to prolong his life I didn't really give a proper answer I just said "if there's any" I don't really know what I said to that I just said "it's something I can't answer that……….."
(Subject 18)

Invasive procedures, attempts at resuscitation and prolonging life were not things carers appeared to have considered when the issue was raised. Apart from one carer who opted for percutaneous endoscopic gastrostomy nutrition (PEG) for his mother, participants who described and expressed feelings of relief and release upon natural physical death of the person with dementia did not verbalise any thoughts about not engaging in life prolonging treatments in medical emergency

situations. A large number of participants had experienced hospital based care where one would expect these issues may be addressed.

*"during the week they rang up… it was the doctor he said "your wife is very seriously ill" **(tearful) (PAUSE…)** I'm sorry…….. "her heart is going to give out, have we to resuscitate her?" what a bloody thing to ask me **(cries)**…… I said "by all means", futile really…. she'd be better off dying really… nobody mentioned it… they perhaps thought anybody with any… they're going to see what's happening here………"*
(Subject 31)

The carer above was the oldest participant in the study, lived in a rural area and had to travel several miles a day to visit his wife. To be asked such a question via telephone by someone who barely knew him was a difficult position to be placed in at such a difficult time. We hear a sense of distress, anger and anxiety at being put in that position. There is also evidence of him questioning the choice he made almost instantaneously, in the absence of being given any time to consider his response at the time.

The carer below feels she has been "warned" her husband was going to die. No definitive information appears to have been communicated and she has interpreted whatever transpired as a warning, a "tip off" (Oxford Dictionary 2002). The choice to hospitalise and treat her husband, one could argue quite rightly in the absence of him being able to communicate his wishes independently, has been placed with her. Never the less it is these occasions carers appear to look to formal carers for them to support their choices and this can only be done by communicating effectively information required to enable an informed choice to be made.

"doctor said "the choice is yours, he either goes in hospital" he more or less warned me he was dying you don't believe it, he said "we can't drip him at home, he needs to go on a drip it's up to you……….." (Subject 33)

The above situations are good examples of where use of and engagement in advanced care planning (DoH 2005) for people with dementia and their carers may have been beneficial and avoided unnecessary distress at a difficult time.

When death occurred in the absence of the carer within formal care environments this information was communicated verbally via telephone by a formal carer and appeared to be done as close to death occurring as possible. There were occasions other relatives communicated this information. On these occasions this was done verbally, face to face and in a straight forward manner.

"first I knew of it me daughter rang up she said "I (wife) died in the night we've got to go over there immediately, sign papers, this, that and the other"…….. they rang me daughter….whether they'd rang her and they couldn't get through I don't know so anyway she was the one who broke the news…. perhaps they thought "we'd better tell her first……….." (Subject 31)

In the quote above the carers' daughter communicated his wife's death to him. There is a sense of the ensuing chaos that occurs with the advent of any death and need for the practicalities to be taken care of.

Having undertaken a bedside vigil and finally being persuaded to leave for a short while the following carers' wife died in his absence.

"my brother in law came with me… my son was down they persuaded me to go out for coffee…..when I went back she had died……… I just went back…. my sister in law was there outside the home when I arrived….. she just said to me "she's gone……… that's how I got to know…." (Subject 24)

As discussed in a previous chapter, no participant had an advanced care plan to refer to that would support them nor had their loved ones made specific written requests regarding what they wanted to occur in the event of their death. There was

one participant who had a pre-paid funeral plan to guide her upon the death of her mother. There was some evidence in the data suggestive of brief, superficial conversations about what people wanted or didn't want in terms of their care, death and disposal. These had usually occurred during visiting friends and relatives who were unwell in hospitals, visiting family and friends in care homes or at funerals. Participants tried to recall such conversations and adhere to them and wishes expressed wherever possible.

5.5.5 (iv) Barriers to communication: languages we speak

Dementia aside and how impaired communication skills can affect this, there are many barriers to communication we my experience. These barriers often create unnecessary gaps preventing free flow of information amongst individuals. Communication is essential in every sphere of our lives to send clear messages to people around us. It is through communication we convey our feelings, ideas and emotions to others. As identified earlier in this chapter, when we talk of communication it is not just the verbal component that matters. Non verbal messages such as body language or para-verbal messages including tone and volume of our voice have equal importance. Lack of clear communication often leads to misunderstanding and poor perception. This is mostly as a result of one or more barriers to communication at the time. There can be a number of factors that act as hurdles when it comes to effective communication. These include physical barriers within the environment, lack of and poor communication skills making communication difficult and ineffective, attitudinal barriers creating personal conflicts between individuals, emotional barriers when moods of individuals trying to communicate will influence outcomes and language barriers. Language barriers under usual circumstances can be created if a person or people use a lot of jargon or

buzz words. Unfamiliarity with those words and specialised terms by one or more of the individuals involved in communication will create a barrier. Parts or all the communication may not be understood leaving people feeling left out or marginalised. One other barrier to effective communication is cultural differences. Lack of awareness of these differences when dealing with people from different cultures also creates barriers.

Considering barriers to effective communication identified above, it is easy to understand how people with dementia and their informal carers may encounter some, if not all of these at some point in disease trajectory. As the disease progresses more and more barriers to effective communication may be encountered and will increase as dependence upon others increases and end of life approaches.

Communication and all aspects of this has been a significant issue within the study data resulting in development of this theme. However, there was a problem with communication some participants identified pertaining to language barriers. This became more common and apparent in the data as data collection progressed and a wider geographical area was included. A number of participants began to express concerns they had in relation to different languages used and effect this had in their opinions upon them and care of their loved one. The researcher is aware this is a sensitive and potentially controversial issue within the data but feels it is necessary to highlight and discuss this as it is a problem informal carers identified independently and an integral part of answering the research question.

The language barrier identified was mostly apparent in formal care environments but not exclusively. Attendance at out patient clinics for assessments and reviews could be problematic for people with dementia and their carers. Originally from Poland the

person with dementia had a good command of the English language but there appeared to be some difficulties with verbal communication when attempting to communicate with a person from another origin.

"he couldn't write his name…..my dad was Polish……. she was Indian……you can imagine…….. it were like never the twain shall meet……she wouldn't let us stop in the room with him while she asked him these questions we'd to stand outside……… we could hear what she was saying…….. she was getting quite agitated my dad wasn't responding……he didn't know how to respond….basically she wasn't interested in him…. she said there was no point giving him any tablets… he was too old…………..." (Subject 21)

There is a sense of frustration and powerlessness at this situation above. We can hear frustration of carers who desperately wanted to help but were purposely excluded. The sense of powerlessness they felt in knowing what the potential problem could be in relation to communication difficulties they were overhearing and observing from a distance but were unable to do anything about. One can only imagine what or how the person with dementia must have been feeling and experiencing having been separated from those familiar to him and questioned by a person he did not know or share a common language with. Elements of verbal and non verbal communication by this formal carer was interpreted as them not being interested in her father and dismissing him on the grounds of his age.

As discussed earlier, people with dementia will experience co-morbidities and be subject to a range of health issues requiring specialist intervention on occasions and hospital admissions as in the quote below.

"doctors there don't speak English, which I found a blooming problem……..…….. they were foreigners' "pardon? Excuse me I don't understand" I said to them when he had his throat stretched "it's no good telling him he won't remember" nurse said "well we don't even understand him what he's talking about" this was about the

*doctor….. I thought "bloody hell"……… so you're trying to take everything in ….
you're getting doctor that doesn't, can't understand talking…………"* (Subject 29)

Carers themselves also experienced some issues with language barriers and being able to comprehend information being communicated to them. This was a source of frustration and anxiety. They were the people supporting the person with dementia and as we can hear above, felt if they couldn't understand communications about their loved one's health needs wondered how on earth they were going to manage these.

One carer described a hospital visit during which her father had performed quite badly on cognitive assessments. A home visit by a community psychiatric nurse (CPN) to re-assess him in his familiar environment was subsequently arranged.

"she was lovely, she spoke W she went through this rigmarole of questions and drawing then she said "will you write me a sentence?" she was speaking in W with him I thought "what's going to happen here?" he said "of course I will" picked up the paper, he wrote a sentence in W do you know what that sentence was translated?..............."it's wonderful to have a young lady like you to come to visit me" now that to me, that was three weeks later, now there's an enormous difference between…. I'm sure he was familiar with Alzheimer's but is it pitched at the right level………….." (Subject 39)

The first language of this family was Welsh, however, they could all speak English. It would appear as her fathers' dementia progressed he was reverting more to his mother tongue to communicate verbally with people. When his level of cognitive impairment was assessed in his first spoken language, in a familiar physical environment, this appeared to be much less then when seen in a hospital clinic, an unfamiliar physical environment, by a person who could not speak Welsh.

As we can hear below, attempts at verbal communication with formal carers within care home environments who were not of British origin appeared to create some difficulties for carers. Good listening skills are crucial to effective communications and it would appear this was not a skill the carer below perceived the formal carers as being in possession of.

"they just didn't listen did they N they just looked at us as if we'd gone out the door… I think they thought we were barmy… there wasn't one of them really not even the white girls understood did they?..............." (Subject 27)

The family above had numerous issues and concerns about the formal care environment the person with dementia was cared for in. Communication difficulties they encountered related to language barriers compounded this and was a source of frustration and anger. This carer mentions communication issues with all carers and "the white girls" has been interpreted by the researcher in this situation as those carers of British origin.

There were also occasions when informal carers also became aware of language barriers for other residents within the care home their loved one was being cared for.

"I went in and said "what's the matter H?" he told me what was wrong with him…. I explained it to the girl, she got the nurse …..he couldn't….. she was English…. his first language was Welsh being from a small village………. possibly H could speak English quite fluently normally with the illness and things he'd reverted backwards to his native tongue he was using it, he wouldn't use anything else…..I complained about that I said "you should have a Welsh speaking person up there…make it easier for them……they had staff on that day the two persons upstairs were both English…. they couldn't help they can't speak W…… there were things like that which I'm talking about the home now rather than talking about my wife but it was part of her wasn't it, how she was looked after was part of her…..by this time it was part of her life……. she had a degree in Welsh………." (Subject 24)

Noticing this residents' level of distress and inability of formal carer to identify his needs via verbal communication, the carer above intervened and spoke to this resident using the same language and they were able to establish what the problem was. The problem was then resolved thus avoiding further distress for the resident and potential confrontations.

There was one informal carer who chose a particular 24 hour care environment for her father based on the ability of formal carers speaking his native tongue.

"I really wanted him to go to a Christian W speaking home I wanted there to be people there who spoke to him in his mother tongue, that was very important…….it helped…… not all of them did speak W… most of them understood W they would have enough words although a number of them also spoke E with him…………..they were really nice people….. they would take time….were absolutely excellent but they all spoke English……….." (Subject 39)

Although not all carers were able to speak in his first language, most of them could which was important for this carer. Being able to communicate with her father in his first language she perceived as something that would help maintain his well-being and quality of life for length of time he would remain alive there.

Over recent years another aspect of communication that has attracted attention is that of culture (Hargie 2006). Culture can be defined as a set of behaviours, beliefs, values and linguistic patterns relatively enduring over time and generation within a group and has been shown to have a definite influence on how interpersonal skills are enacted (Hargie 2006). Language and verbal communication styles can be directly related to a culture. This can include things such as tone and choice of words to use. Choosing the right words can be one of the most important ways of overcoming communication barriers and difficulties. The use of a single wrong word

may create a lot of misunderstanding in usual circumstances but can make matters worse for people with dementia. Use of simple understandable language is the best means of communication. The carer in the quote below felt the different tone of voice of formal carer in these circumstances created some difficulty with verbal communication.

"they're all foreigners there….. not one W person there……. mind you he could speak E as fluent as his W he could speak E ……..the tone of their voices is not the same as ours is it…… he couldn't understand what they were saying you see………….." (Subject 30)

A person with dementia experiencing impairments in communication may interpret words and tone of voice in a different manner to which they were meant if being used by a person who does not share the same first language as them. This will result in poor communication and misunderstandings which may already be problematic for the person with dementia.

One carer attributed some difficulties with language barriers to accents of non British formal carers. There are requirements for non British medical personnel working in the United Kingdom regarding English language competencies however, this does not appear to be mirrored for other formal care staff i.e trained nurses and care workers from non British backgrounds. Although formal carers' command of English language appeared good and they were competent accents apparent when they spoke it created problems. People in formal 24 hour care environments have a tendency to be elderly, have some form of dementia or level of cognitive impairment and may also be experiencing sensory deficits such as hearing loss. This will compound the problem and increase communication problems with a workforce that has a different first language.

"young girls of course were Philipino or whatever…. couldn't get through…. although their English was good patients couldn't pick it up…. they were kind as well extremely kind…….I do think patients couldn't understand accents also their age group are always anti foreigners anyway aren't they I'm convinced of that…..they were so good and so kind to them….. they couldn't always tell them what they wanted they would get the wrong end of the stick……………..." (Subject 40)

The carer above interprets communication barriers as having two dimensions. The spoken use of the English language by formal carers whose first language is not English and possible attitudes of elderly people with dementia whom she feels may have an objection to people from outside the United Kingdom caring for them.

With regards to moving on after the death of the person with dementia, there were occasions carers had felt the need to seek outside help and support the carer below was one such person.

"I did go the other week to Help the Aged for counselling…. nice bloke interviewed me…… I sat there for an hour explaining to him about the language barrier at the home and everything…… then I got a phone call on Saturday morning from a coloured lady……… I couldn't understand a bloody word she said so I had to phone him up on Monday and say it wasn't for me…… no disrespect but how can somebody who can't speak my language understand what I'm saying to them…………..." (Subject 27)

She had experienced language barriers with the care of her husband within his formal care environment and was unhappy at the prospect of support she required after his death for herself resulting in similar issues to those she had encountered there. In the event of evidence to support her negative thinking this carer chose to decline the offer of post bereavement support.

5.5.5.(v) Summary:

This theme has presented and discussed role of communication in a world fraught with chaos and uncertainty. Theories of communication, styles, types and skills discussed in chapter two have been considered. Communicating with people with dementia, their informal carers, conversations about death and dying and how language barriers affect care have been presented. Quotes from transcripts have been used to demonstrate what participants and the researcher interpreted and constructed as issues with communication and how these may or may not contribute to the chaos and uncertainty in the last year of life and events surrounding death.

This is the underpinning theme within the data. There are distinct links with all other themes derived from within the data as has been demonstrated. This theme concludes and completes the results chapter which has presented and discussed all individual themes derived inductively from within the data.

The following chapter will present a summary of results, a critical review of the study utilising the framework outlined in chapter three, strengths and limitations of the study and a discussion of findings in relation to current literature. Finally, implications for clinical practice and proposals for future research will also be presented and discussed here.

Chapter 6: Discussion

6.1. Introduction

In this chapter a summary of findings are presented initially. Rigour of the study utilising the evaluative framework outlined in chapter three will then be discussed. This is followed by a discussion of strengths and limitations of the study with regards to what it brings to the literature on end of life care and people with dementia and their informal carers. Less common issues within the data the researcher feels are of importance to note will also be presented and discussed. Findings will then be discussed in relation to models and theories of dementia and end of life care. Finally, the chapter concludes with a discussion of catalytic utility of results regarding clinical and policy implications and future research.

6.2: Summary of findings

How does this study answer the original research question:

Dementia: What care do patients and informal carers need in the last year of life and time surrounding death?

The principal aim of this study was to explore individual experiences of those informal carers who had cared for a person with dementia during their last year of life and around the time of death. The researcher investigated what was important during this period of time to this group. Through the process of analysis it was revealed whilst stories were unique and individual it was possible to organise these around five common themes:

1.) Informal carers as experts in care

2.) Humanity, kindness and compassion in care

3.) The hard work of caring

4.) Living and dying in the face of uncertainty and unpredictability

5.) Communicating in a world of chaos and uncertainty

Through this study communication has been identified as the main underlying need of people with dementia and their informal carers in the time point studied. However, as has been demonstrated, communication is not an isolated concept and there are links with this to all themes identified above. The themes were expressed in relation to subthemes illustrating how complex the last year of life and death can be for people with dementia and how all manner of communication is imperative to the quality of their experience and contributes to perception of a good death. Informal carers feel they have much to contribute to the care of their loved ones at this time and wish to collaborate in care and be included in all aspects of this. Communication by all involved is imperative in order to achieve this. Knowledge generated from this study will be used to inform both local and national models and practices regarding end of life care for people with dementia and their informal carers.

6.3. Ensuring rigour: applying evaluative framework

An important question to ask in relation to rigour is whether an appropriate method of enquiry has been adopted by the researcher to meet objectives of the study. In chapter three the researcher identified and outlined a framework for ensuring rigour developed by Guba & Lincoln (1994). Rigour of the study will be addressed and discussed below utilising this framework.

6.3. (i). Credibility

Credibility is concerned with what Guba & Lincoln (1994) refer to as "truth value". Truth in qualitative research is purported as a much more elusive goal. It is an attempt by the researcher to demonstrate confidence between their findings (reconstructions) with that of participant reports (constructed realities). The researcher feels credibility has been demonstrated in this study by the following:

1). Accuracy and credibility of interview data was ensured by using suitable digital recording equipment and conscientious, accurate transcription of interview data by the researcher herself. Each transcript was quality checked by listening to the recording again and comparing this to written transcripts. All transcripts were available for review by the researcher's supervisors. Transcripts were member checked by participants themselves in order to verify they were a true reflection and account of what had transpired during the interview. Initial interpretations of data were checked verbally by the researcher at interview. Any discrepancies were recorded in field notes. Interpretations and analysis of data as this progressed was not member checked by participants. This was mainly due to the sensitive nature of the topic and time frame under study. The researcher deemed it inappropriate and unethical to subject participants to re-visiting for some, what had been an emotional and distressing period of time and events.

2). Peer examination of data and analysis was conducted by the researcher's supervisors (Professor Mari Lloyd-Williams and Professor Ken Wilson). An outside supervisor from the funding body was also included in peer examination (Siobhan Horton, Clinical Director, St. Luke's Cheshire Hospice). In addition to the above, peer examination was also achieved via numerous presentations (Appendix 9).

3). A prolonged period of time was spent in the field. The study was ongoing for three years with 18 months of this time spent on data collection. This prolonged period of time in the field helped the researcher to acclimatise to researching an area of extreme sensitivity. It also supported development of skills that would help with conducting and understanding interviews. This prolonged period of time in the field also facilitated reflexivity. This contributed to incorporating issues and theories from previous interviews into following interviews. In addition, this prolonged period of time in the field meant the researcher was exposed to personal experiences that may have impacted on way data was interpreted such as having a close family member diagnosed with a life limiting illness.

4). During the research process and throughout interviews the researcher attempted to create a climate of openness with participants in an attempt to reduce researcher effect. All participants were fully aware of the nature and purpose of the study. Context of the study has been described in detail throughout considering any difficulties that may have arisen.

6.3.(ii). Applicability/Fittingness

As discussed in chapters three and four, in contrast to quantitative research, sample sizes in qualitative work have a tendency to be typically small. Although sample sizes appear to be increasing with time, they still do not involve large numbers seen in quantitative studies. Sampling tends to be theoretical in nature, as with grounded theory rather than based on statistics. The aim of this study was not to generalise findings but to explore personal experiences and establish any similarities.

In order to consider how findings of this study may be used to help draw conclusions about other populations it is essential to provide sufficient information to do so. This

has been done by providing rich descriptions of sample, settings and contexts. In addition to this, interpretations of data are grounded in the thesis by substantial descriptions that include contextual quotations. Evidence of these descriptions includes introduction to participants provided in chapter five. These introductions help set the scene and contexts giving information about each participating individual. In addition to data provided in the thesis other material is available for review in the form of field notes. These provide other detailed descriptions of sample, settings and other information from interviews the researcher felt significant and warranted recording including her own feelings and thoughts about her performance and influence on the interview.

Of importance to note regarding strengths of the study in relation to the applicability and fittingness aspect is recruitment of participants. All those recruited were bereaved informal carers of people with dementia. Inclusion of only such participants indicates results would be applicable to bereaved informal carers in similar circumstances.

6.3.(iii). Consistency

Qualitative research emphasises uniqueness of human situations and importance of experiences not necessarily accessible to validation through senses. Variations in experience rather than identical repetition are the objectives. Through the use of a narrative interview style in this study participants were in a position to illuminate us to their own experiences of the final year of life caring for a person with dementia and what happens to this group around the time of death. This is reported in the form of data analysis throughout the thesis and includes use of significant quotes elicited

from data. Number of codes assigned to each interview transcript and overall total of such is indicative of variations in experiences of individual participants.

6.3.(v). Neutrality

Freedom from bias in the process and end product is the objective here (Guba & Lincoln 1994). Qualitative work emphasises meaning of findings and is achieved by researcher, participant and data being closer than in quantitative studies. However, results need to demonstrate they are more than a figment of the researcher's imagination. Objectivity requires the researcher excludes biases and values. The researcher has been open and honest about potential for this to occur in chapter three. The researcher attempted to achieve neutrality and freedom from bias by being reflexive, adaptive and having an awareness of the effect one may have on the research process and participants at any time. Neutrality is demonstrated by providing a critical, reflexive account of the research process and transparency of accounts (Guba & Lincoln 1989). Reflexivity is described by Mason (2002: p5) as "thinking critically about what it is you are doing and why" and involves provision of "a methodologically self-critical account of how the research was done" (Seale 1999: p45). The researcher has already acknowledged in chapters three and four from a constructivist point of view, they are part of knowledge production and how they may impact upon this. Keeping field notes throughout the research process and engaging in discussions with supervisors, colleagues and other student peers supported reflexivity. Principles of neutrality and credibility are closely linked and demonstrate need for continued reflexivity and critique of one's actions throughout the research process in an attempt to develop and maintain rigour within the study.

6.3.(vi). Auditability

This is concerned with the underlying issue of whether the study has been consistent over time and "whether things have been done with reasonable care" (Miles & Huberman 1994). This principle is achieved when the researcher leaves a decision trail pertaining to all aspects of the study over its' duration. Anyone other than the researcher should be able to follow progress of the study and their logic. The researcher has been mindful throughout the study to document and explain details of every stage in the process in a logical systematic manner (chapter four). Regular meetings and discussions with supervisors contributed to this aspect of the framework. There has been attention to detail considering possibility of both negative and positive outcomes for participants and researcher. The researcher has taken great care to demonstrate this and maintain well being for all involved in this study.

In adhering to principles of the framework outlined above the researcher feels a credible, insightful, authentic and auditable piece of work illuminating people to experiences and needs of informal carers caring for a person with dementia in the last year of their lives and at time of death has been produced.

6.4. Strengths of study

One of the main strengths of findings is they were developed from stories told by participants from a sample not based in any clinical or 24 hour care environment. The sample was recruited via public appeals unlike previous research where samples were recruited from hospital and various care home environments. In relation to this, this study contributes something new to the dearth of literature available.

Interview technique employed was informed by narrative style of interviewing and as such offered participants opportunity to relay to the researcher what they perceived as important issues and needs rather than researcher imposing their needs upon participants. This was a unique feature of this study as previous studies have employed such methods as surveys, questionnaires, focus groups and semi and structured interviews. In this respect this study will contribute something new and valuable to existing literature. Utilising this interview technique allowed free flowing conversations with minimal interruptions from researcher. This resulted in bringing into view harm and effects, both in short and longer terms inappropriate and poor communication, neglectful management and care of people with dementia and their informal carers, within a certain time point, can have upon people.

The study offered participants the opportunity to be interviewed at a place and time convenient to themselves. This was appreciated by participants who verbalised this. In chapter three the researcher identified taking part in research discussing sensitive issues such as death can have a therapeutic function, acting as a cathartic process which may also influence the healing process. This was confirmed verbally by many participants who took part in this study following their interview and afterwards during which the researcher received thank you notes and a statement to that effect from one participant (Appendix 10).

The sample, although limited in racial and ethnic representation did include a wide age range (19-86years) and was broad with regards to socio-economic status and geography. Despite each experience being unique similar themes were identified across stories. Stories shared by participants provided a rich and emotional voice ineradicable from the researcher's mind. Through emotive recollections of these, via

the data collection process, access into their phenomenological world provided a base for the researcher to work with data lavish, reliable and grounded.

6.5. Limitations of study

Retrospective nature of this study is one limitation. A time limit of death occurring within a five year period was imposed in an attempt to address this. This also reduced risk of collecting data about things that may have already been addressed or changed in terms of caring for someone with dementia in their last year of life and around time of death. A potential limitation of using "stories" (narratives) as a data collection method is memory is a re-constructive process with memories evolving under reconstruction. Participants were being asked to recall events they had experienced within a five year time period. This could still have introduced some bias and distortion of events. Participants own prejudices may also have been brought into and been included in these events.

It is important to clarify the purpose of this study was to increase our understanding of subjective experience of caring for a person with dementia in their last year of life and around time of death. Some participants in the study were elderly themselves and as a result of the aging process, may have experienced some mild cognitive impairment. Even though there maybe some inaccurate or incomplete recall due to this and memory attrition over time, it is the actual lived experience of participants which is of most value in qualitative research and this is what the researcher obtained. There may also be problems with relying upon bereaved informal carers to relay what they feel the person with dementia required at any time. Stories were from informal carers perspectives as it was impossible to obtain accounts from the person with dementia.

317

It can be argued passage of time allows one to reflect on experiences and events. Whilst it is acknowledged some memories may have faded there were others that raised emotional responses that appeared to be entrenched and indelible in participants' memories. The fact these events were remembered and recalled so vividly offers an insight into significance of these and can also be viewed as a strength of this study.

Despite substantial efforts to recruit as diverse a sample as possible, the sample was limited in terms of racial and ethnic representation. There was one participant from Eastern European origin and one from Turkish origin. As discussed in chapter four this was not a purposeful exclusion it just occurred. Every attempt would have been made to include people from any background had they volunteered. Whilst there was a clear recurrence of issues across the sample which allowed for development of common themes, full saturation was not reached due to limited racial and ethnic representation. This limits extent to which this study's findings can be applied in populations with markedly different racial and ethnic compositions.

The majority of the sample was female. Historically females have been the main providers of care both informal and formal. However over the past three decades more males have found themselves in a care giving role (Baker 2010). Attempts were made to increase numbers of male participants by making an appeal to various organisations, Alzheimer's Society and Age Concern. However this yielded minimal responses and number of male participants in comparison to females remained low. The aim of this study was not to recruit equal gender numbers nor compare experiences across genders so this was not pursued any further by the researcher.

A further limitation is the self selecting nature of the sample. Due to this it could be argued there is bias introduced in favour of those who saw value in talking or writing about their experiences which were mostly of a difficult, problematic nature. It can be argued social status and professional backgrounds of a certain number of participants suggests voices of those carers from lower socio economic backgrounds may not have been heard. This is a potential source of bias and limitation regarding generalisability of findings. Considering the aims of the study, recruitment strategies employed were pragmatic in nature and the only way people could be recruited into this study. Participants were offered the choice to be interviewed or write their story and as such the study was able to recruit those who would not necessarily have participated had the only option available been to talk face to face about their experiences.

Interviews and process were informed by narrative style of interviewing which has also been identified as a strength of this study. Unlike narrative interviewing in its' purist form (Wengraf 2001) participants were interviewed on one occasion only and the researcher felt this was a limitation. Engaging in narrative interviewing in its purist form would have offered opportunity to return to participants on more than one occasion in order to pursue issues, emerging theories and themes in more detail thus enhancing rigour. However, the decision was made not to do this in light of the sensitive nature of topic under study and potential for this to inflict harm and distress on participants who may have already experienced this at initial interview. The only written narrative received during the study was more difficult for the researcher to interpret. There was no rapport built with this participant and there were no non-verbal cues and leads to follow as with face to face interviewing. Context of events was difficult to establish and information omitted from written narrative in terms of

demographic details, despite attempts by the researcher, proved problematic to obtain once the written narrative had been received. Whilst there was only one written narrative received in this study, the researcher could identify interpretation and analysis of this kind of data would be more difficult. If provided on a larger scale it would not have yielded the type of rich data necessary for this kind of study.

As discussed in chapter four, participants were asked to comment on transcribed accounts of interviews. This was done in an attempt to display openness within the study, enhance rigour and value placed by the researcher upon participants. Participants were not asked to comment on or confirm any aspects of data analysis and emerging themes. Reflecting on the process helped the researcher recognise doing so may have enhanced credibility of the study. Inviting participants to comment on emerging themes may have resulted in interesting and potentially informative comments and reflections on wider interpretation. It could be counter argued doing so could have been considered new data and viewed as an extension to the research rather than enhancing credibility. This would also have been extremely time consuming for both participant and researcher considering sample size. It could also be viewed as another source of potential distress. To keep returning to participants for verification on such an emotive topic was considered by the researcher unethical and inappropriate.

The researcher has reflected on all strengths and limitations of the study which will be a valuable exercise when considering and planning future projects. The experiences and limitations identified will help inform any future work.

6.6. Discussion of findings

In this section of the chapter findings will be discussed pertaining to models of dementia care, philosophy of palliative care, theories and other published work in relation to informal carers caring for a person with dementia in the last year of their lives and up to death. Some discussion has already been presented within chapter five and individual themes, these discussions will be extended here.

6.6.(i) Less common findings

Despite uniqueness of individual stories and experiences there were many elements of these that appeared to be shared experiences amongst the sample resulting in development of themes presented and discussed earlier in this chapter. There were also issues arising although not common across transcripts and sample were interesting findings and worthy of some discussion here.

Issues pertaining to spirituality and religion were not prominent in the data. Very few participants practiced or followed a particular denomination. Spirituality appeared to hold different meanings for different participants. Where it was apparent it appeared to be related to activity, things people enjoyed and valued and which contributed to their personhood and general "being" prior to onset of dementia. However, there were three participants who chose a care home for their loved one based on faith of that establishment. They felt this was important to them and person with dementia in maintaining their spiritual and religious needs and beliefs. These participants hadn't established if all formal carers in these environments were employed based on their religious following and practices or followed a particular religion or not. How this would have been policed and monitored within these establishments if they were was something that interested the researcher but was an unanswerable question

within this study. One thing all of these three participants had in common and shared was a feeling their loved ones received an improved quality and standard of care than those who resided in a none faith based care home. They instinctively thought, and felt care here would be and was delivered in a more kind, humanistic and compassionate manner. This was based on their observations whilst visiting their loved ones within these environments, observations of care being delivered and of communication styles of formal carers whilst doing this. They also had information from and communication with friends in similar positions who relayed very different stories to them regarding their experiences in none faith based care homes.

There was minimal evidence of involvement of small children within the data. On occasions younger children were present within families' involvement and inclusion of them in sustaining relationships with the person with dementia was very different. This ranged from small children being present at a death and behaving in a very natural way to small children being completely excluded and never seeing the grandparent with dementia again once they had been transferred into a care home. The participant who involved small grandchildren up to end of life felt this was a positive thing and would support normalisation of death amongst her grandchildren demystifying death and the process for them. Decisions to exclude small children, where this was evident, appeared to be borne out of a parent's fear of the impact and effect seeing a grandparent behave differently may have had upon that child. Rather than expose children to a changing grandparent, doors were closed and small children were not taken to visit them. It could be argued continuing to engage in this kind of behaviour maintains stigma around mental health and dementia, perpetuates fear amongst young and is in contradiction with objectives of the dementia strategy (DoH 2009) that advocates reducing these and raising awareness.

It is also contrary to Kellehears' (2003) ideas, beliefs and recommendations regarding whole communities' responsibilities and involvement in care, more specifically care of dying. Involving others and all the family may help to re-ignite acceptance of death and dying as a natural part of the life cycle rather than deny this and continue the quest for eternal life at all costs.

A large percentage of the sample experienced death within a formal care environment and not family home. Of this group there were some who expressed remorse at not being in a position, or feeling they were not in a position, to care for their loved one at home until the end of their lives. This resulted in emotional issues as they moved into the bereavement period. These included feelings of remorse, guilt, regret and led to questioning of choices made based on information available and communication with professionals at that time.

Western society is changing and evolving as a result composition of families is changing. The divorce rate continues to increase and less people in general commit to marriage. There are increasing one parent families and families made up of two families coming together through divorce and re-marriage. This kind of situation, although not common across the data, was apparent. This resulted in confrontations within what the researcher referred to as "non-standard families". These confrontations were mostly regarding who was now responsible or would assume responsibility for the caring role. Confrontations frequently led to severing of relationships with the person with dementia and person who assumed role of informal carer. This occurred particularly where there were disagreements over the type and kind of care the person with dementia needed or may have wanted. Hostility and anger was evident in these situations which impacted further upon caring for the person with dementia during their last year of life and into death.

It was also interesting to note participants who resided in more semi rural and rural geographical locations did not appear to have any less in terms of service provision or access to these. However, one issue apparent for these participants was access to their loved ones who were in 24 hour care environments. This would frequently be miles away from family homes resulting in transportation problems which meant reliance upon other family members or a reduction in number of occasions they visited their loved ones. This resulted in an increase in the hard work of caring, worry, anxiety and distress.

Whilst none of the issues discussed above were evident across the whole sample, one can see how difficulties with all aspects of communication, underpinning theme within the data, will also have an impact upon these.

6.6.(ii). Findings in relation to models and theories of dementia

As demonstrated in chapter one there has been an increasing amount of attention paid to end of life care and dying, dementia and dying with dementia nationally with these issues being high on the national agenda over recent years. This study sought to bring the two issues of dying and dementia together. Overall aim of this study was to explore experiences of people with dementia and their informal carers in the last year of the person with dementia's life and events surrounding time of death. This was in an attempt to identify and interpret what informal carers felt their specific needs were at this time, how these were constructed by them and what influenced this. Needs of people with dementia were reported on by their bereaved informal carers. It can be argued this may be problematic. As identified in limitations of the study, memories and ability to recall events may have been affected. What bereaved informal carers felt the person with dementia needed during this period of time may

not necessarily reflect what the person with dementia may have wished for themselves had they been in a position to express this verbally or via written communication. In the absence of any other means of identifying needs this study sought information from those who the researcher felt most appropriate.

Communication and issues with this were perceived as problematic by informal carers in this study in a range of circumstances, environments and contexts. This was the common denominator across the sample in this study. When we consider themes derived from within the data, carers as experts in care, humanity, kindness and compassion, uncertainty and unpredictability and communicating in a world of chaos it is clear to see how difficulties with communication was the link between all these and how this impacted upon them all in both a negative and positive manner. Based upon individual stories and constant comparison of these during analysis the researcher has interpreted these experiences as being mostly negative. Having a window into these experiences has helped gain insight into what the actual difficulties are from informal carers' perspectives. It has also enabled identification of good and positive examples of care and communication within a specific time frame. This has potential to inform development of a model of care for the time frame studied in this piece of work. The most common models of dementia care are presented and discussed in relation to the data initially.

There are a number of different models of dementia care consistent over time. These have supported several improvements in general care, including end of life for people with dementia and their informal carers. These models include, medical model, person centred model (Kitwood 1997), psychosocial model (Pratt et al 2003), dementia care mapping model (Kitwood 1997), biopsychosocial model (Sabat 2008), recovery (Munetz et al 2001) and the relationship centred care model (Nolan et al

2006). All these models of dementia care incorporate different aspects of care and are applicable to different care settings. Apart from the medical model, it can be argued all these to some extent incorporate a sense of individualised and person centred care taking into account contexts. One thing all these models have in common is need for well developed communication styles and skills for their implementation in any environment, circumstance or context to be successful.

The reductionist nature of the medical model of dementia has possibly received most criticism over recent years (Kitwood 1988, Bond 1992, Gillard 1995). In this model of care the person with dementia is reduced to an organic being with a focus on cause, symptomology, treatments and potential cure. There is minimal consideration for the person within and how dementia may be affecting them and those around them. There was evidence of this model in the data as illustrated in chapter five. It was particularly apparent where people with dementia had dual diagnosis requiring interventions from medical personnel. This was not in isolation however, there was evidence of the medical model being applied for those with a diagnosis of dementia alone. This kind of approach was a source of distress and anxiety for participants when it occurred and left them feeling the person with dementia had been de-humanised. The basis for construction of this was interpreted as being communication styles and skills of those formal carers delivering care at the time and interactions between them and participants.

One of the earliest, if not the first model to acknowledge the person within was the person centred model described by Kitwood (1997). He argued neurological causes, as described in the medical model, alone could not account for the devastating effects of dementia. Instead Kitwood (1997) proposed cultural values, social and emotional history of people with dementia and daily practices of caring for patients

exacerbate disease process and dementia was socially constructed. Kitwood's (1997) subsequent model of malignant social psychology supported his thinking in this domain. Kitwood's (1997) model acknowledges the person with dementia as a whole person and focuses on maintaining personhood of that person until they die. There was also evidence of attempts to do this within the data and across themes. Different people appeared to have differing abilities and methods of achieving this in different contexts and environments. Participants who experienced faith based care homes appeared to perceive they were in receipt of a more person centred type of care. This was difficult to establish or confirm within this study.

One could counter argue without the medical model we would not have diagnosis, awareness of symptoms or how to manage these for the person with dementia and their informal carers. A lot of work has been undertaken in this area and has been identified across the themes presented in this work. These are most apparent in the hard work of caring, living with uncertainty and unpredictability and communicating in a world of chaos themes. Identifying specific symptoms and origins has been instrumental to development of management strategies and interventions to support people with dementia and their informal carers. This has no less significance in the last year of life and as end of life approaches. Neurological origins of symptoms may be different to other life limiting illnesses and as such require different assessment, management and treatment strategies. One such example of this is the issue of pain and its possible different neurological origins and pathways in different types of dementia, identified by Scherder et al (2003). This is a good example of the role and value of the medical model and how this may be applicable in palliative and end of life care for people with dementia.

Worthy of note is the recovery model. This has mainly been applied to other severe and enduring mental health conditions but is an interesting concept in terms of dementia care. There has been criticism of application of this model (Martin 2009) in relation to dementia particularly by those who feel dementia is a progressive degenerative brain disorder offering no hope of recovery. Kitwood (1997) would counter argue this and purports in earlier phases of the disease process with the right kind of help, support and environment there will be evidence of what her viewed as an element of recovery. People with dementia were seen to improve or appear to improve, Kitwood (1997) referred to this as "re-mentia". However, Martin (2009) does acknowledge in the latter part of the dementia disease trajectory, informal carers, as people who usually know the person with dementia best, may be the most appropriate people to consult with regards heath care and end of life decisions and the recovery model is appropriate at this time. Application and value of this model is limited in dementia and is dependent upon disease trajectory and where the person is within this at any point in time.

The person centred model of care advocated by Kitwood (1997) has been enhanced over recent years by development of the relationship centred model (Greenwood et al 2001, Brown-Wilson 2009). Greenwood et al (2001) identified the importance of many different relationships the person with dementia may engage in and how these can influence a sense of well being. Brown-Wilson (2009) however, focused more on 24 hour care environments, residential and nursing home care and formal carers. It was apparent in the data this not only applies to the person with dementia, but also to carers who valued occasions when they were, or appeared to be, respected for their contributions, what they could bring to the caring context and were treated in a humanistic, kind and compassionate manner by those professionals around them.

There was evidence in the data of a variety of the models discussed above being applied together forming what could be described as a more biopsychosocial approach to care. However, it appeared individual professionals and formal carers were applying their own individual models of care rather than any conscious effort being made to consider the whole person and wider contexts as a biopsychosocial model would do. There was also evidence of relationship and person centred approaches to care in the data. This was in varying degrees and whether formal carers were aware of this and purposely or naturally interacted in this way was unclear. Issues pertaining to whether the ability to do this is an inherent or learned quality have been addressed in the humanity, kindness and compassion theme.

A limited number of participants (4) in this study experienced death of their loved one within their family home. Relationships of many different people around them at that time were interpreted as being extremely important thus supporting relationship centred and biopsychosocial models of care. These participants had vivid memories of help and support they received from different kinds of people, some of whom were strangers. These memories were not necessarily always positive, vividness with which they were recalled is indicative of the influence and impact this had upon them. This also supports the notion how people die and what they experience lives on in the memories of those left behind. This can influence how people grieve and whether there are any complications experienced with this.

Participants in the study who experienced death within formal care environments, with the exception of some nursing and residential care homes, appeared to be mostly subjected to the medical model of care. Whilst this had an important role to play in identification, assessment and management of some symptoms, people with dementia appeared to receive aggressive and invasive procedures as the end of

their lives approached. There also appeared to be occasions where because the person with dementia did not fit into the model of care that environment was used to they were neglected and subjected to what informal carers interpreted as poor, substandard care. This was attributed by informal carers to lack of knowledge of formal carers, provision of limited information and poor communications between them and professionals.

Hospitals in general do not have models of care that support or assist people with dementia and their informal carers (Ghatak 2011). Day-to-day coping with the disease often continued within hospital environments for carers in this study who frequently worried about nutritional status, medication administration and general care and well being of their loved one whilst they were in hospital. There were occasions in the data when informal carers felt unable to leave the person with dementia in the care of formal carers within hospital environments. Fearing for their loved one's safety, families would negotiate shifts of care between themselves.

Increasing interest in dementia, palliative and end of life care for this group has brought about an increase in developments in this area including exploration of different models in different contexts. This is in an attempt to implement directives and strategies identified in chapter one and improve experiences at end of life for people with dementia and their families.

Ghatak (2011) proposed an interesting general "supportive" model of care for people with dementia and their families based on a continuum of care that included supporting care in any context or environment. Supportive care being advocated along a continuum of care from diagnosis to longer term. The dementia support programme (DSP) proposed by Ghatak (2011) is described by them as a unique

integrated approach aimed at education, information, behavioural management, training of informal caregivers, long-term care planning, and general support for people with dementia and informal carers living with dementia. Although not mentioned, good communication is integral to the above and fundamental to its successful implementation. Whilst this model is not end of life specific, the principles of it may be applicable and transferrable into end of life care.

Identifying the correct time point to intervene in dementia with such a model above may prove difficult if it was to be applied to the last year of life. Identifying when death maybe approaching or if a person with dementia may be in their last year of life can be problematic. As highlighted in earlier chapters, prognostication in general in life limiting illness can be fraught with difficulties and is not always simple. Accurately estimating life expectancy of a person with advanced dementia is difficult and may hinder delivery of palliative and end of life care for this group (Mitchell et al 2004). This was illustrated well from within the data in the uncertainty and unpredictability and hard work of caring themes presented in chapter five.

Prognostic information is important for guiding end of life decision making. In the USA this can still be used to determine eligibility for admission to hospice care. It could be argued in dementia this is even more problematic due to the uncertain and unpredictable nature and course of disease trajectory unlike other life limiting illnesses such as cancer.

As previously identified in the literature review, (chapter 2) one of the tools advocated in the End of Life Care Strategy (DoH 2008) to support prognostication is

the Gold Standards Framework. This tool was originally developed in 2000 and was the grass roots initiative to improve primary palliative care from within primary care. It was developed by a General Practitioner with a special interest in palliative care supported by a multidisciplinary reference group of specialists and generalists. From its first pilot in 2001 the tool and its popularity have grown. It has now been introduced into a variety of care environments with support of local facilitators who enabled its implementation via overseeing training, audit and developing further adaptations to the tool and resources. It has developed and changed since its inception to meet needs and recommendations of the End of Life Care Strategy (DoH 2008) and challenges faced in provision of end of life care across disease areas. In relation to dementia and end of life care in residential and nursing care environments, formal carers receive training and education on a range of issues faced in dementia as end of life approaches. This training also includes a tool that supports analysis of death when it has occurred and a review and critique of performance by the establishment itself. To support prognostication there is a question integral to the tool called the "surprise question". This question encourages people to ask themselves and acknowledge based on their observations and knowledge, if they would be surprised if the person they are caring for would still be alive within a certain time frame. Answer to this question depends on type and level of care implemented for the person in receipt of care.

On completion of training, depending upon performance of care establishments as judged by GSF facilitators and monitoring, these environments are awarded eventual accreditation by the GSF Centre. This has potential to improve their rating amongst local authorities and is now something informal carers may choose or be advised to

look for when choosing care environments. Having this accreditation supposedly demonstrates an ability of that establishment to provide a good standard of end of life care for people with dementia.

Prognostic indicators from this tool (GSF) pertaining to frail elderly, including those with dementia have been outlined in chapter five in the uncertainty and unpredictability theme. However, evaluation of its usefulness and sustainability within certain groups, including those with dementia, needs further research and evaluation as highlighted in the literature review (chapter 2). There were no reports or mentions of this tool amongst participant stories.

There were two occasions where participants, without prompting from researcher, spoke about the Liverpool Care Pathway (Ellerhsaw 2003) discussed in chapter 2. The quote below informs us how this is interpreted by informal carers, more certainty time of death is approaching. There appears to be a sense of urgency to take her husband home to die, preferred place of death once this tool had been implemented. Some potential difficulties identified by another member of the family with doing so appear to have informed her choice not to do this. Moving into bereavement this informal carer appears to have accepted positive aspects of care delivered at the end of her loved one's life by formal carers. However, she appears to remain reticent still about context and environment in which death occurred.

"*half way through treatment more or less they put you on the pathway….. I forget what it's called…. is it the pathway to death?....................I thought "I want him home" … my daughter said to me "he could die in the ambulance if you take him home"…. she said "also mum every three hours they come and turn him" and they did…. the*

bed was spotless…..couldn't wish for a better ward….. except he was in a normal ward………….." (Subject 33)

The participant above spoke again about the LCP following recording of the interview and expressed some reservations regarding her interpretation of this, "the pathway to death". Ultimately implementation of the LCP is indicative death is approaching it is a pathway of "care" rather than a pathway to "death". If this is to be used within a model of end of life care for people with dementia and their carers, sensitivity, care and caution needs to be exercised by those communicating meaning of this emphasising the positive "care" aspect of this pathway.

Mitchell et al (2004) undertook a retrospective cohort study of people with dementia in nursing and hospice care in the USA. In an attempt to predict mortality within a six month period for people with dementia they used the Functional Assessment Staging scale (Reisberg 1988). The FAST scale is used to assess functional change among patients with dementia. It consists of seven major stages and has a total of 16 successive stages and sub stages. Stage seven represents the most advanced stage of dementia and consists of six sub stages, seven (a) to (f). These are defined as follows:

7a, speech is limited to 1 to 5 words

7b, all intelligible vocabulary is lost

7c: non-ambulatory

7d: unable to sit independently

7e: unable to smile

7f: unable to hold head up.

In the USA stage seven (c) of the FAST scale has been suggested by the National Hospice Organization as an appropriate cut off to enrol people with a primary diagnosis of dementia into hospice care. Possibly answering the surprise question in the GSF identified and discussed earlier. Whilst there are similarities with the GSF, physiological changes noted in the prognostic indicators are omitted from stage seven in the FAST. These physiological changes can be an indication the person with dementia is in the last year of their life or approaching death as illustrated on occasions in this study's data. This study's' data has also demonstrated how people with dementia may live for many years in the terminal phase of the disease. Presenting in accordance with stage seven of the FAST, making it problematic to apply the above in isolation in terms of life expectancy and any planning. Mitchell et al (2004) however reported in their study the results of the seventh stage of the FAST were a reliable measure of determining mortality within a six month period in dementia which supported prognostication.

With advances in technology increasing novel models for supporting people with dementia and their carers will be developed. One such innovation in practice was described by Judge et al (2011). This was a care co-ordination service for older people with dementia and their carers based in America. Assessment of need, co-ordination of care, treatment and monitoring by a trained professional took place over the telephone. Information and advice was given over the telephone and actions were also decided by this means. These were mostly acted upon by informal carers of people with dementia. This service appeared to be well received by people with dementia and their informal carers and was evaluated positively. Whilst this was not a model focusing on end of life care, nor did it appear to be an out of hours

service, of note is apparent increased level of involvement, collaboration and control carers felt they had over their care within this model.

Issues pertaining to involvement, collaboration and control were raised by participants in this study. There were also a number of participants who felt an out of hours service would have been beneficial. This included participants in suburban and semi rural locations. Ability to communicate with a professional verbally via telephone to seek advice and re-assurance was something they felt would have been of value to them in times of crisis.

Historically NHS based community services for people with dementia have been organised on a 9-5 office hours basis with limited out of hours services available and usually limited to those in need of support on discharge from hospital care. Voluntary organisations such as the Alzheimer's Society provide a limited service which is more inclined to provide information about dementia in general. What participants in this study felt was lacking was communication with formal carers in times of what they interpreted as crisis. This included time when end of life was approaching for those who managed to care for their loved ones within the family home. This tended to be related to concerns regarding breathing changes not expected by informal carers being a source of anxiety and fear for them. This need was addressed usually by primary care out of hours personnel, including GP's. Informal carers also contacted emergency services resulting in inappropriate admissions into district general hospitals. Future consideration needs to be given to development of a model of 24/7 support for people with dementia and their informal carers nearing the end of their lives. Provision of such a service would help support implementation of

objectives in the Dementia Strategy (DoH 2009) focusing on reduction of inappropriate admissions into district general hospitals. If more people identify family home as their preferred place of death, as is expected and intended provision of such a model of service will be crucial to supporting this.

6.6.(iii) Proposed model of care arising from data

Addington-Hall (1998) described palliative care as forming a spectrum. At one end of this spectrum lies palliative care supportive in nature and at the other end is palliative care that is specialist and applicable to more complex cases. In chapter two an argument was presented as to where this fits in relation to dementia and dementia care. In their guidance on dementia care the National Institute for Clinical Excellence (2006) advocate a palliative care approach from diagnosis to death. Hughes et al (2006) however advocate a more supportive approach. It is clear from this study's' data there are issues that set dementia apart from other life limiting illnesses regarding palliative and end of life care. These include differences in communication skills and abilities making the expression of one's wishes more problematic and disease trajectory which creates a lot of uncertainty and unpredictability.

It appeared difficult for most participants to commence their stories at the time point under study. There was a need for participants to set the scene for the researcher in the context of where most journeys through dementia had commenced. The beginning in a number of stories, influencing what occurred towards the end. Within these stories there appeared to be a need for varying levels of supportive care throughout the journey including information, knowledge and communication on a variety of levels and from different people. This appeared to change and transfer to a

need for something interpreted as more urgent and involved than supportive care towards end of life. This seems to align with what Addington-Hall (1998) described above. The question of who provides this type of care, context in which palliative and end of life care is delivered and how specialised this needs to be remains unanswered and a source of debate across life limiting illnesses (Hughes, 2004, Zarit 2004, Pace 2009) not dementia alone.

With regards to this Kellehear (2009) suggests end of life care is a public health issue and as discussed in the humanity, kindness and compassion theme, purports we need to return to a time when death is viewed again as a natural part of the life cycle with communities taking an active and supportive role in this. There was evidence of this within the data for those participants who experienced death within their family home but this was minimal.

The act of death and dying generally across the data appeared to be viewed as the responsibility of health care professionals and formal carers. On occasions this was at the exclusion of informal carers. Kellehear (2009) is critical of this so-called medicalisation of death and dying that began to occur in the mid-20th century. He suggests there is now abundant evidence of a professionalisation of death and dying that effectively performs the same function. As health deteriorates and death approaches there appears to be an increase in number of professionals involved resulting in professionalization of death and dying.

Heath (2009) asked the question:

> "*how is it at the beginning of the 21st century we have forgotten how to die and have even forgotten that death can be a gift itself?*" (Heath 2009 p503)

One of the simplest answers to this question one could argue, apart from the unrealistic and increasing quest for eternal life in today's' Western society, lies with communication and apparent inability and reluctance to talk about death and dying and plan for this in an open manner.

Since introduction of the Mental Capacity Act (DoH 2005) there has been increasing focus on advance care planning and treatment directives. This is in anticipation of loss of capacity and ability to make informed choices regarding treatments and wishes as capacity is lost and death may be approaching. As identified in an earlier chapter, (chapter 2) uptake of this in dementia care has been minimal to date. Potential reasons for this have been discussed in previous chapters. Boyd (2011) suggests exercising caution with people with dementia when addressing issues pertaining to end of life care and advanced care planning. In his study he discovered amongst participants information pertaining to prognosis and potential course of disease was minimal. As such people with dementia and their informal carers had not considered what treatments they may or may not wish to undergo in the future and were not ready to commence discussions about death. This would indicate unlike cancer and possible other life limiting illnesses, communications regarding full implications of diagnosis and prognosis had probably not occurred. This may have been out of choice by person with dementia and their informal carers or as a result of potential paternalistic reasons of clinicians.

Levels of knowledge and information giving were also issues across the data and sample. How this differed across themes in terms of knowledge has been addressed in individual themes. Knowledge can not be developed nor information imparted

without some means of communication. How and whether or not this is done can impact upon and influence informal carers as with this study. Babrow (2001) discussed how information and knowledge are communicated impacts upon construction, management and resolution of uncertainty. He purports communication as being essential to resolution of uncertainty. Living and dying with uncertainty and unpredictability was a major issue for participants in this study. This was influenced by lack of information and knowledge. This was evident around time of dying and more so for those participants who had been close to death with their loved one on a number of occasions. Open, honest information and knowledge shared with participants about difficulties with prognostication may have supported resolution of some issues faced with uncertainty and alleviated some anxiety and distress.

Brijnath et al (2008) highlighted what they perceived as the challenge in dementia. He saw this challenge as the moving away from practice and research based on privileging ideas of self, mind and cognizance at the expense of the power of the body. Brijnath et al (2008) felt in understanding how power is enacted in, by and through bodies that are social, biological, medical and political in particular cultural contexts, we can begin to increase our understanding of how dementia is not only a neurodegenerative disorder but a set of social anxieties about how to create discipline in chaos.

Social anxiety and chaos that ensues within the lives of people with dementia and their informal carers was evident in the data and illustrated in the themes. Little appears to be stable in this world with many things potentially changing. This can

create new challenges and anxieties for people on a daily and sometimes hourly or less basis.

Different models of care can be viewed as attempting to maintain order and discipline within this chaos Brijnath et al (2008) identified. Before embarking upon developing new models to support this group or considering transfer of existing models of care, it is worth considering dementia and end of life issues in terms of chaos and complexity theories. It is evident from the data this world can be chaotic and fraught with complexities. This does not alter greatly in the last year of life or time surrounding death.

Let us consider the dementia caring dyad in terms of a system. System is simply the name given to an object studied in some field and might be abstract or concrete, elementary or composite, linear or nonlinear, simple or complicated, complex or chaotic (Rickles et al 2007). Complex systems are highly composite ones, built up from very large numbers of mutually interacting subunits whose repeated interactions result in rich, collective behaviour that feeds back into behaviour of individual parts. Chaotic systems can have very few interacting subunits, but they interact in such a way as to produce very intricate dynamics (Rickles et al 2007). Simple systems have very few parts that behave according to very simple laws. Complicated systems can have very many parts too, but they play specific functional roles and are guided by very simple rules. Complex systems can survive removal of parts by adapting to change, to be robust, other systems must build redundancy into the system (eg by containing multiple copies of apart). For example, a large healthcare system will be robust to removal of a single nurse because the rest of the

members of the system will adapt to compensate however, adding more nurses does not necessarily make the system more efficient. In comparison to this, a complicated piece of medical technology, such as a positron emission tomography scanner, will obviously not survive removal of a major component (Rickles et al 2007). Dementia care giving dyads can fulfil criteria for either simple or complex systems depending upon individual responses to progression of disease process, support services in place and point in disease trajectory. However, based on the above we can see how health care in general and more specifically caring and dementia can be associated with these two theories. It is also clear to see how issues with communication can impact upon the system (care giving dyad) resulting in chaos. Chaos theory (Lorenz 1960) suggests a very small occurrence can produce unpredictable and sometimes drastic results by triggering a series of increasingly significant events. Inability to recognise signs and symptoms death is approaching for a person with dementia can be applied here. Inability of formal carers to identify this time may lead to inappropriate admissions into hospital for people with dementia when end of life care is what is required and not invasive, investigative procedures. Chaos theory would appear to predict a seemingly insignificant influence in initial conditions can dramatically affect long term behaviour of another system, informal carers.

Resnicow et al (2008) discussed chaos and complexity theory in terms of public health, viewing this as a new challenge for this discipline. They suggest public health research and practice has been guided by a cognitive, rational paradigm where inputs produce linear, predictable changes in outputs. This perspective does not account for non linear and quantum influences on human behaviour suggesting as such underlying statistical assumptions of this paradigm may be flawed. In terms of

health behaviour change, they propose this would be better understood through the lens of chaos and complexity theory and systems. Key relevant principles including behaviour change, is often as a result of a quantum event, resembles a chaotic process sensitive to initial conditions, is highly variable, difficult to predict and occurs within a complex adaptive system with multiple components where results are often greater than sum of their parts. Dementia has been identified as a public health issue in terms of future predictions regarding incidence and prevalence (DoH 2009). As discussed earlier, Kellehear (2003, 2009) also identified dementia and end of life issues as a public health concern.

It can be argued the philosophy and principles of a palliative care approach and model outlined in chapter two, are easily transferred into end of life care and people with dementia and their carers. Scott et al (2009) reported on one of the first pilots of such a model applied to people with dementia. Their aim was to investigate palliative and end of life care needs of people with advanced dementia and their informal carers, clarify the role of specialist palliative care for this group and examine usefulness of one model of working within their geographical locality. Initial evaluation from this project indicates a high level of unmet needs amongst this group, as with this study's' data. They also identified a number of unmet needs for formal carers which included knowledge of dementia and end of life symptoms. The model of care they chose appeared to meet needs of participants included in their pilot.

Geographical location and available resources will impact greatly upon any model or pathway of care developed in an attempt to meet needs of people with dementia and

their informal carers. A one size fits all will not be appropriate. Individual patient and carer needs should also be considered. Developing and piloting different models and pathways that draw upon others may be more successful and influential. Models described earlier in this section have a role to play. The philosophy of palliative care it can be argued is aligned with the relationship and person centred models (Greenwood 2001, Nolan et al 2006).

Any model or care pathway needs to consider the person with dementia at the heart of it and extend this out to wider relationships affecting and influencing this person at that time. There needs to be acknowledgement of what different people, communities and multi professionals can do to support people. Communication is an integral aspect of relationship and person centred models. Education and information for informal and formal carers about end of life issues should be fundamental to any model. Knowledge on different levels and knowledge base of different people has been raised as a problem in this study's data. Informal carers themselves should be encouraged to contribute towards development and delivery of these for formal carers enabling examples of good and poor communications and practice to be shared and learned from.

Crucial to any educational work within a model pertaining to end of life for this group is inclusion of information regarding symptoms one may expect to observe during last year of life and as end of life approaches. This is particularly pertinent for informal carers of people with dementia. How people with dementia may present physically needs to be included in this. Data from this study has illustrated how distressing symptoms relating to physical presentation, caceaxia and nutritional

issues can be when they present unexpectedly with little knowledge of or anticipation or preparation for this. Congedo et al (2010) argue lack of evidence to suggest artificial hydration and nutrition in dementia is efficient supports the need for advanced care planning. These kinds of issues need to be addressed with informal carers in an open and honest manner. Boyd (2011) suggests these kinds of issues are best communicated by a person who already has an ongoing therapeutic relationship and involvement with the person with dementia and their informal carer. These kinds of conversations and communications are best undertaken by someone with well developed communication skills and may facilitate conversations about advanced care planning.

Advanced care planning may remain a contentious issue for some time to come in dementia care. Issues surrounding problems with this have been addressed and outlined in previous chapters. Never the less it could be one way of opening up talk of death and dying and guidance is available to support formal carers in doing so helping society move towards inclusion of wider communities in planning for and acceptance of death Kellehear (2003) aspires to. Conversations of this nature tended to be tongue in cheek and on a superficial level within the data with no advanced care plans being made amongst participants. Levi et al (2010) explored what influenced people to undertake advance care planning in an attempt to help health care professionals engage in these conversations with patients. Participants in their study experienced a range of medical conditions and were mixed in gender and age. Interestingly, "concern for selves" was the most influencing factor they discovered.

Communication with informal carers about management of what they interpret as a crisis as end of life approaches needs to be developed. Offering re-assurances and advice informal carers are doing all and the best they can is often all that is required to allay fear and anxiety. If efforts are put into communicating information in verbal or written form regarding prognosis and symptoms to be alert for then anxiety and distress may be reduced and managed more positively.

Integral to a model supporting people with dementia and their informal carers in the last year of life and surrounding time of death needs to consider bereavement issues and ability to move on with life post dementia. As identified in the study data, bereavement and loss are also something else different for this group to other life limiting illnesses. The ability to move on with life after physical death of the person with dementia was a very individual thing for participants. Each drew upon different inner and external resources to support them. Identification of individual preferences, needs and resources will be required.

6.7. Catalytic utility: clinical and policy implications

The researcher has identified several ways in which findings from this study could impact upon practice and policy. This is both on a local level, satisfying needs of funders of the project and potentially on a national level. Clinical utility and policy implications of the study's findings are outlined and discussed below.

Both carers strategy (DoH 2008) and dementia strategy (DoH 2009) advocate need to take care of carers health. The carers' strategy and subsequent review of this (DoH 2010) recommend regular health reviews for informal carers. These recommendations could be targeted at specific groups including carers of people

with dementia. Findings from the project have demonstrated how informal carers of all ages, for people with dementia have a tendency to sacrifice their own health needs (chapter five). This can be over a long period of time and not necessarily in last year of life and is done in order to maintain support for person with dementia. This can have dire and sometimes fatal personal consequences and also further impacts upon the economy of care. It can also impact upon the future for informal carers and ability to move on with their lives post dementia. Taking care of informal carers health needs, physical and mental, by developing more supportive and preventative carer health strategies will have positive effects generally. Data from this study could help inform projects local to the funders focusing on carers health. Developing a service that involved longer term assessment, monitoring and treatment of carers health needs would be supporting implementation of both strategies identified above. It also has potential to inform a model of best practice nationally.

Issues of loss, grief and anticipatory grief were identified and discussed in chapter five. As we are aware, carers of people with dementia may experience many different losses as the disease progresses. The person with dementia may change, on occasions beyond recognition for the informal carer and generally becomes more dependent upon them and others on a daily basis. Carer burden and stress are also factors that may contribute to and complicate the grief process when eventual physical death of person with dementia occurs. Tremont (2011) suggest caregivers with greater depression and burden leading up to and during the end-of-life period are at increased risk of prolonged grief. Data from this study could support identification of carers more at risk of prolonged or complicated grief reactions. Information from the data could inform development of an assessment tool

specifically for this. This kind of work could be considered by funders of the project who have provided a bereavement service for informal carers of people with dementia in the past. In collaboration with local counselling services and such organisations as Age UK and Alzheimer's Society this could be specifically tailored to informal carers of people with dementia. Identifying informal carers who may be at risk of complicated grief reactions through careful assessment is crucial to accessing the appropriate kind of help and adjusting to life without dementia. One could argue even more so when the journey or end of journey through dementia has been traumatic, as has been demonstrated in the study data.

Study data could inform development of a training package focused on end of life care for people with dementia. This would be for clinician's and allied professionals employed in the field of dementia care. The data has demonstrated a need for this and there is clear evidence of lack of knowledge, information and communication skills. Some examples of problems informal carers have faced can be found throughout chapter five. There were issues with different levels of care provided by different groups of people. The underpinning theme in the data, communication, affected this. A large component of this training package should consist of communication and communication skills development. Informal carers themselves should contribute to this as their accounts can be extremely powerful when shared with professionals and those formal carers in the position of delivering care. This kind of work would be useful on a local level again, satisfying needs of the study's funders and local service provision. It could also be developed for use on a national level and tailored to meet individual resource needs.

In developing interventions to support carers in the last year of the person with dementia's life and around time of death carers needs and perspectives may be understood and given more consideration. Collaborations in care at this difficult time are crucial and key to positive outcomes, effective communication is fundamental and necessary. The researcher feels this study contributes to this effort. This study is based on the assumption of existence of multiple realties and does not aim to give an account of one universal truth. However, it does offer valuable insights into experiences of a group of people in similar circumstances. Despite their uniqueness, participants did appear to experience the same or similar things. Knowledge generated from this study can be used to inform professionals working with such groups as well as carers in similar situations.

6.8. Future research

In light of this study's findings there are particular aspects that have highlighted a need for further investigation. Some areas for further research have been mentioned in the discussion. The researcher would like to bring attention to areas of interest arising from the study as interpreted by her.

Despite efforts, inclusion of participants from different ethnic groups and cultures was limited in this study. Therefore views on needs of people from different ethnic origins and cultural backgrounds were limited. Numbers of people migrating into the UK have increased as the European Union has expanded. As the aging population, migration and re-settlement continue to increase so too will incidence and prevalence of dementia and numbers of people dying with dementia. Limited information is available about needs of different populations and there are many unanswered questions. Society in the UK is now a multi-cultural contemporary

society it is therefore crucial research also focuses on experiences and needs of ethnic minorities in relation to living and dying with dementia. Establishing if needs are different can be addressed through attempting to answer the following questions: What kind of experiences have people from different origins and cultural backgrounds had in the UK to date? Is this different? Do they access services currently provided? If not what are possible reasons for this? How could this be changed? The possibility of a comparative study comparing experiences of across groups would be a way of beginning to identify and address differences. Data from this current study could form the basis of this as we now have data pertaining to British people. Exploring experiences and identifying needs of people from different origins and cultural backgrounds is necessary in order to provide equitable services and support everyone in the manner they feel they need at this difficult time. There could be practical and ethical implications to such research and these will need further consideration and debate.

Similar to above, there needs to be an exploration of an older population dying with dementia that includes a range of sexual orientations such as gay, lesbian, transgender and bi-sexual. As with any other part of the population these groups will be living and dying with dementia. The researcher is unsure as to whether anyone from these groups was included in this study. Specific questions pertaining to sexuality were not asked of participants in this study and this would have been inappropriate. There appeared to be no same sex relationships amongst participants, spousal relationships tended to be, or appeared to be, heterosexual. Similar questions to those above would begin to identify and address needs of these groups. The researcher envisages one of the main issues could be practicalities with recruitment for such a project. There is stigma attached to differences in sexual

orientation which will be compounded further by having dementia and being an older person. Elderly people belonging to any of these groups may not volunteer for such a project and may be difficult to identify and access.

There were issues apparent in the study data pertaining to younger informal carers. These were adult carers who had added responsibilities in terms of their own families, partners and paid employment. There are specific initiatives aimed at younger informal carers but these are mainly children. For the younger adult informal carers in this study the "juggling of plates" was an issue for them. They felt constantly torn between their own families and those responsibilities and those they felt they had for a parent living and dying with dementia. This was more apparent in those who felt reciprocity was important. Stressors for this group and effects of these appeared to be different than those of older informal carers in the study. Some of these carers wanted to support care for their loved ones with dementia at home until their death and this appeared to them an impossible task mainly due to lack of service provision to support this. There may be similar issues for older informal carers as opportunities and expectation we will remain in paid employment further into older age are presented. It has long been established the contribution informal carers make with regards to the economy and cost of care (DoH 2008, DoH 2009). If we are to continue relying upon such groups as an unpaid workforce there needs to be systems in place to facilitate this. Exploring and identifying best ways to support these groups would facilitate a greater understanding of their needs and help inform service and policy developments.

Connected to the above is the fact dementia is predominantly seen as a disease of older age. There are increasing numbers of younger people diagnosed with dementia (DoH 2009) and the number of younger spousal and sibling informal carers

will increase. People will not necessarily be caring for and supporting an older person with dementia but a younger person who may still have responsibilities. This study chose to include informal carers of people with dementia who were over the age of 65 years when they died. We already know needs of younger people and their informal carers are completely different in terms of living with dementia. We now need to explore whether these needs are different as end of life and death approaches.

Male participants in the study were limited, despite efforts of the researcher to increase numbers of these. Almberg et al (1998) highlighted differences in male and female informal carers of people with dementia. They discovered females experienced more stress and burden and males had a less positive outlook on life and need for social support. This was not addressed in the study but anecdotally the researcher was aware of a calmer and less stressed approach to caring and end of life issues exhibited by males. This could possibly indicate different needs in terms of type and kind of support required across genders. A comparative study exploring these differences, if any, at end of life would help inform support strategies that could be tailored to meet gender specific needs if it was demonstrated via research this was a an issue. Issues with recruitment of males may be one of the main problems with such a study and would need careful consideration and planning.

6.9. Conclusion

Drawing upon frameworks of grounded theory and phenomenology this study enabled the researcher to be an integral part of the research process. This has offered opportunity to gain insights into the world of the last year of life and events surrounding death of bereaved informal carers for people with dementia. This has

facilitated development of a theory and model/pathway of care to support those in a similar position in the future based upon their perceptions and the researchers' interpretations. The interpretive approach used in this study has given a voice to bereaved informal carers of people with dementia. It has offered opportunity for them to express what they interpret their needs as being within a certain time frame. Valuable insights into the meaning of caring for a person with dementia in their last year of life and surrounding death have been portrayed. This is now intelligible evidence that has potential to inform professionals working with this group. This will facilitate improvements in this area and ultimately informal carers of the future's experiences.

Stories reflected the complex, diverse and negotiated experience of living and dying with dementia. Results have demonstrated the profound effects caring for someone with dementia during this period of time can have upon informal carers in this situation in many different contexts.

Results strongly demonstrate communication of all types and kinds are at the fore front of informal cares concerns. Difficulties encountered with communication and everything involved in this, including knowledge and information transfer can act as barriers to provision of palliative and end of life care for this group. The results enlighten us to how informal carers perceive and interpret care and interactions with formal carers and professionals and effects this has upon them into bereavement and engaging in a life post dementia.

This study contributes to ongoing debates regarding the who, what, where when and how to deliver palliative and end of life care for this group. Palliative care skills should be common for formal carers across caring environments. As incidence and

prevalence of dementia increase one could argue so should ability to care for people with dementia and their informal carers. The results inform us this is the expectation of informal carers. They expect an equitable service and person with dementia to be treated in same manner as those with other life limiting illnesses, for them to be included and collaborated with, regarding all aspects of care as they near the end of their journey.

Finally, this study provides insight into the ethics of researching what can be interpreted as a sensitive topic with a vulnerable group.

References:

Abel, E. K. (1998). The Caregivers Perspective. In: *Health Illness, Society, Social Context & Self: An Anthology.* Eds. Charmaz. K., Pattennitis. Oxford. Oxford University Press.

Addington-Hall. J., (1998). Reaching Out: Specialist Palliative Care for Adults with Non-Malignant Disease. Occasional Paper 14. *National Council for Hospice and Specialist Palliative Care Services.* 8.

Addington-Hall, J., Walker. L., Jones. C., Karlsen. S., McCarthy. M., (1998). A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring the satisfaction with, and use of, services received in the year before death. *Journal of Epidemiology and Community Health.* 52. 802-7.

Agar, M., Currow, D., C., Shelby-James, T., M., Plummer, J., Sanderson, C., Abernethy, A.,P. (2008). Preference for place care and place of death in palliative care: are these different questions? Palliative Medicine. 22(7). 787-795.

Ahronheim, J. C., Morrison. R. S., Morris. J., Baksin. S., Meier. D. E. (2000). Palliative Care in Advanced Dementia: A Randomised Controlled Trial and Descriptive Analysis. *Journal of Palliative Medicine.* 3(3). 265-73.

Allcock, N., McGarry, J., Elken, R., (2002). Management of pain in older people within the nursing home: a preliminary study. *Health and Social Care in the Community.* 10(6). 464-71

Almberg, B., Jansson, W., Grafstrom, M., Wimblad, B. (1998). Differences between and within caregiver strain: a comparison between caregivers of demented and non-demented caregivers of elderly people. *Journal of Advanced Nursing.* 28(4). 849-858.

Andrews, S., McInnery. F., Robinson. A. (2009). Realising a palliative approach in dementia care: strategies to facilitate aged care staff engagement in evidence based practice. *International Psychogeriatrics.* 21. 64-8.

Aronson, M.K., Lipkowitz, R. (1981) Senile dementia, Alzheimer's type: the family and the health care delivery system. *Journal of the American Geriatrics Society.* 29(12). 568-71.

Ashton, S., McClelland. B., Roe. B., Mazhindu. D., Gandy. R. (2009). An end-of-life care initiative for people with dementia. *European Journal of Palliative Care.* 16(5). 240-3.

Babrow, A. (2001). Incertainty, value, communication and problematic integration. *Journal of Communication.* September 2001. 553-573.

Baker, K., L., Robertson, N., Connelly, D. (2010). Men caring for wives or partners with dementia: Masculinity, strain and gain. Aging and Mental Health. 14(3). 319-327.

Baldwin, C. (2006). Difficult Decisions for Family Carers at the End of Life. In: *Palliative Care in Severe Dementia: in association with nursing and residential care.* (Ed). Hughes. J. UK. Ashford Colour Press Ltd.

Baldwin, C., Capstick. A. (2007). *Tom Kitwood on Dementia: A reader and critical commentary.* England. Open University Press.

Ballinger, C., (2004). Writing up rigour: Representing and evaluating good scholarship in qualitative research. *British Journal of Occupational Therapy 67 (12).* 540-46.

Bamford, S. (2010). Tackling dementia across the channel. *Community Care.* 1815

Barnett, M. (2001). Interviewing terminally ill people: is it fair to take their time? *Palliative Medicine:* 15(2) 157-158.

Bell, C., Araki, S., Neumann, P. (2001). The Association between caregiver burden and caregiver health related quality of life in Alzheimer's disease. *Alzheimer's Disease and Associated Disorders.* 15. 129-136.

Beauchamp, T.L, Childress. J.F. (2001). *Principles of Biomedical Ethics.* New York.Oxford Universities Press.

Benner, P. (1984). *From Novice to Expert: Excellence and Power in Clinical Nursing.* California. Addison-Wesley Publishing Company.

Benner, P., Tanner, C. (1987). Clinical judgment: how expert nurses use intuition. *American Journal of Nursing.* 87(1). 23–31.

Bingley, A.F., Thomas. C., Brown. J., Reeve. J., & Payne. S. (2008). Developing narrative research in supportive and palliative care: the focus on illness narratives. *Palliative Medicine.* 22. 653-658.

Birch, D., Stokoe. D. (2010). Caring for people with end stage dementia. *Nursing Older People.* 22(2). 31-36.

Bond, J. (1992). The Medicalisation of Dementia. *Journal of Aging Studies.* 6(4). 397-403.

Bourdieu, P. (1977). *Outline of a Theory of Practice.* Cambridge. Cambridge University Press.

Bourdieu, P. (1990). *The Logic of Practice.* Cambridge: Polity Press.

Bowling, A. (2002). Research Methods in Health: *Investigating Health and Health Services.* 2nd Edition. UK. Oxford University Press.

Boyd, R. (2011) Discussing end-of-life care with people with dementia: a word of caution. *Mental Health Nursing.*31(11). 14-17.

Brashers, D. E., Neidig, J. L., Russell, J. A., Cardillo, L. W., Haas, S.M., Dobbs, L. (2003). The medical, personal, and social causes of uncertainty in HIV illness. *Issues in Mental Health Nursing. 24.* 497–522.

Brazil, K., Howell, D., Bedard, M., Krueger, P., Heidebrecht, C. (2005). Preferences for place of care and death among informal caregivers of the terminally ill. Palliative Medicine. 19(6). 492-299.

Brijnath, B., Manderson, L. (2007). Discipline in Chaos: Foucault, Dementia and Aging in India. Culture, Medicine and Psychiatry. 32. 607-626.

Brown-Wilson. C., Davis. S. (2009). Developing relationships in long term care evironments: the contribution of staff. *Journal of Clinical Nursing.* 18. 1746-1755.

Brown-Wilson, C. (2009). Developing community in care homes through a relationship centred approach. *Health and Social Care in the Community.* 17 (2). 177-186.

Bruce, E., Schweitzer, P. (2008). Working with Life History. In: *Excellence in Dementia Care. Research into Practice.* Eds. Downs. M., Bowers. B. England. Open University Press.

Bryant, A., (2003). A constructivist response to Glaser. Forum: *Qualitative Social Research.* (online journal). 4(1). http://www.qualitativeresearch.net/fqs-texte/1-03/1-03bryant-e.htm.

Buff, R. (2005) Grounded Theory: the methodology. In: *Qualitative Research in Health Care.* Holloway. I. (Ed). Buckingham: Open University Press. 335-348.

Buffum, M., Haberfelde, M., (2007). Moving to new settings: Pilot study of families' perceptions of professional caregivers' pain management in persons with dementia. *Journal of Rehabilitation, Research and Development.* 44(2). 295-304.

Burt, J., Shipman. C., Richardson. A., Ream. E., Addington-Hall. J. (2010). The experiences of older adults in the community dying from cancer and non-cancer causes: a national survey of bereaved relatives. *Age and Aging.* 39(1). 86-91.

Cahill, S., Shapiro. M. (1998). "The Only One You Neglect is Yourself": Health Outcomes for Carers of Spouses or Parents with Dementia; Do Wives and Daughter Carers Differ? *Journal of Family Studies.* 4(1). 87-101.

Caron, C.D., Griffith. J., Arcand. M. (2005). Decision making at the end of life in dementia: how family caregivers perceive their interactions with health care providers in long term care settings. *Journal of Applied Gerontology.* 22.1-17.

Carlson, L. (2004). Emotional issues complicate life for carers. http://www.Benefitnews.com. Accessed 25.06.2011.

Carlsson, G., Drew. N., Dahlberg, K. Lutzen, K. (2002). Uncovering tacit caring knowledge. *Nursing Philosophy.* 3(2). 144–51.

Cayton, H. (2004). Telling stories: Choices and challenges on the journey of dementia. *Dementia.* 3 (1). 9-17.

Chambliss, D. F. (1998). What It Means to Be a Nurse. In: *Health, Illness & Healing, Society, Social Context and Self: An Analogy.* Eds. Charmaz. K., Paternitis. D. A. Oxford. Oxford University Press.

Charlesworth, G. (2001). Reflections on using Cognitive therapy with depressed family caregivers of people with dementia. *PSIGE Newsletter.* No.78.

Charlesworth, G. (2001). Reviewing psychosocial interventions for family carers of people with dementia. *Ageing and Mental Health*. 5(2). 104-106.

Charmaz, K. (1995). Grounded Theory. In: *Rethinking Methods in Psychology.* Smith, J.A., Harre, R. & Van Langenhove, L. (Eds). London. Sage Publications Ltd. 27-49.

Charmaz, K. (2003). Grounded theory: Objectivist and constructivist methods. In: Denzin, N.,K., Lincoln, S., Y. (Eds) *Strategies of Qualitative Inquiry.* London. Sage Publications. 249-81.

Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis.* London. Sage Publications Ltd.

Cheston, R., Jones. K., Gilliard. J. (2004). "Falling into a hole": narrative and emotional change in a psychotherapy group for people with dementia. *Dementia.* Sage Publications.

Chiesa, M., Hobbs. S. (2006). Making sense of Social Research: how useful is the Hawthorne Effect? *Journal of Social Psychology.* 38 (1). 67-74.

Christkais, N. A., Lamont, E. B. (2000). Extent and error in doctor's prognosis in terminally ill patients: prospective cohort study. *British Medical Journal.* vol. 320.

Chui, H. F., Lee. Chung. W.S., Kwong. P.K. (1994). Reliability and Validity of the Cantonese version of the Mini Mental State Examination - a preliminary study. *Journal of Hong Kong Psychiatrists.* 4 (2). 25-28.

Clarke, C. (1999). Family care-giving for people with dementia: some implications for policy and professional practice. *Journal of Advanced Nursing.* 29 (3). 712-720.

Clayton, M., F., Mishel, M. H., & Belyea, M. (2006). Testing a model of symptoms, communication, uncertainty and well-being in older breast cancer survivors. *Research in Nursing and Health. 29.* 18–39.

Closs, J., Casj, K., Barr, B., Briggs, M. (2004). Cues for the identification of pain in nursing home residents. *International Journal of Nursing Studies.* 42 (1). 3-12.

Congedo, M., Causarano, R., I., Alberti, F., Bonito, V., Borghi, L., Colombi, L., Defanti, C., A., Marcello, N., Porteri, C., Pucci, E., Tarquini, D., Tettamanti, M., Tiezzi, A., Tiraboschi, P., Gasparini, M. (2010). Ethical issues in end of life treatments for patients with dementia. *European Journal of Neurology* 2010. 17. 774–779.

Cooper, C., Seiwood. A., Blanchard. M., Livingstone. G. (2010). Abusive behaviour experienced by family carers from people with dementia: the CARD (caring for relatives with dementia) study. *Journal of Neurology, Neurosurgery and Psychiatry.* 81 (6). 592-6.

Corbin, J., Strauss, A. (2008). *Basics of Qualitative Research.* (3rd ed) London, Sage Publications Ltd. 297.

Cotrell, V., Hooker. K. (2005). Possible selves of individuals with Alzheimer's disease. *American Psychological Association.* 20 (2). 285-94.

Cowdell, F. (2010). The care of older people with dementia in acute hospitals. *International Journal of Older People's Nursing.* 5 (2). 83-92.

Coyle, N. (2006). The Hard Work of Living in the Face of Death. *Journal of Pain and Symptom Management.* 32. 266-274.

Coyne, I.T. (1997). Sampling in qualitiative research. Purposeful and theoretical sampling: merging or clear boundaries? *Journal of Advanced Nursing.* 26. 623-630.

Dartington, T. (2008). Dying from Dementia – a patient's journey. *British Medical Journal.* 337. 1712.

Davies, R. (1989). *My Journey into Alzheimer's disease: helpful hints for family and friends.* U.S.A. Tynsdale House Publishers.

Dawson-Goodey, E. (2011). Simple Kindness. *Nursing Standard.* 25(37). 26-27.

Denzin, N.K., & Lincoln, Y.S. (2000). Introduction: The discipline and practice of qualitative research. In, Denzin, N.K., Lincoln, Y.S. (Eds.) *Handbook of Qualitative Research.* (2nd ed.). London. Sage Publications Ltd.

Department of Health, (1983). *Mental Health Act. An Act to Consolidate the Law Relating to Mentally Disordered Persons.* UK. Reed Elsevier.

Department of Health, (2003). *Information sheet on Palliative Care and Hospices.* London. The Stationary Office.

Department of Health, (2005). *Research Governance Framework for Health and Social Care. (*2nd ed.) U.K. Department of Health.

Department of Health, (2005) *Mental Capacity Act. (England & Wales).* London. The Stationary Office.

Department of Health, (2005). *Mental Capacity Act: Code of Practice.* London. DoH Publications.

Department of Health, (2008). *Carers at the heart of 21st-century families and communities: "A caring system on your side. A life of your own".* London. DoH Publications.

Department of Health. (2008). High Quality Care for All: NHS next stage review, final report. London. DoH Publications.

Department of Health, (2008). *End of Life Care Strategy: Promoting high quality care for all adults at the end of life.* London. DoH Publications.

Department of Health, (2009). *The NHS Constitution: The NHS belongs to us all.* http://www.dh.gov.uk. (Accessed 17.06.2011)

Department of Health, (2009). *Living Well with Dementia: A National Dementia Strategy. Putting People First.* London. DoH Publications.

http://www.dh.gov.uk/en/policyandguidance/healthandsocialcaretopics/cancer/DH.4001753 Accessed 13.01.10

Dewey, M. E., Saz. P., (2001). Dementia: cognitive impairment and mortality in persons aged 65 and over living in the community: a systematic review of the literature. *International Journal of Psychiatry.* 16. 751-61

DiBartolo, M. (2000). Caregiver burden: Instruments, challenges, and nursing implications for individuals with Alzheimer's disease and their caregivers. *Journal of Gerontological Nursing.* 26. 46–56.

Doka, K., J. (2004). Grief, multiple loss and dementia. Bereavement Care. 9. http://dx.doi.org/10.1080/02682621.2010 Accessed 22.07.2011.

Donaldson, C., Tarrier. N., Burns. A., (1998). Determinants of Carer Stress in Alzheimer's Disease. *International Journal of Geriatric Psychiatry.* 13. 248-56.

Done. D. J., J. A. Thomas (2001).Training in communication skills for informal carers of people suffering from dementia: a cluster randomised clinical trial of therapist led workshop and a booklet. *International Journal of Geriatric Psychiatry.* 16. 816-821.

Downs, M. (2000). Dementia in a socio-cultural context: An idea whose time has come. *Ageing & Society*, *20*, 369-375.

Downs, M., Clibbens. R., Rae. C., Cook. A., Woods. R. (2002). What do general practitioners tell people with dementia and their families about the condition? *Dementia: The International Journal of Social Research and Practice.* 1 (1). 47-58.

Einstein, A. J. (1966). *Evolution of Physics: from early concepts to avanta.* New York. Touchstone.

Ellershaw, J.E., Wilkinson, S. (2003). *Care of the Dying: A Pathway to Excellence.* Oxford. Oxford University Press.

Ellis, R. (1980). Simulated social skill training for the interpersonal professions. In W. Singleton, P. Spurgeon & R. Stammers (Eds), *The analysis of social skill.* New York: Plenum.

English Dictionary and Thesaurus. (2000). Glasgow. HarperCollins Publishers.

Fallon, M., Hanks. G. (2006). *ABC of Palliative Care* 2nd Ed. Oxford. Blackwell Publishing Ltd.

Ferrell, J. (2006). Understanding the moral distress of nurses witnessing medically futile care. *Oncology Nursing Forum.* 33(5). 930-992.

Fitzpatrick, A.L., Kuller. L.H., Lopez. O.L. Kawas. C.H., Jagust. W. (2005). Survival following dementia onset: Alzheimer's disease and vascular dementia. *Journal of Neurological Science.* 229-30: 43-9.

Foley. M. K., Duck. S. (2006). Relational communication. In: The handbook of communication skills. 3rd ed. London. Routledge.

Foulger. D. (2004). Models of the communication process. www.davis.foulger.info/research/unifiedModelOfCommunication.htm Accessed: 16.08.2011

Frank, L., Lloyd. A., Flynn. J., A. Kleinman. L., Matza. L., S., Margolis. M., K., Bowman. L., Bullock. R. (2006). Impact of cognitive impairment on mild dementia patients and mild cognitive impairment patients and their informants. *International Psychogeriatrics Association* 18(1). p.151-162

Franke, R.H., Kaul, J.D. (1978). The Hawthorne experiments: First statistical interpretation. *American Sociological Review*. 43. 623-643.

Freels, S., Nyenhuis. D.L., Gorelick. P.B. (2002). Predictors of survival in African American Patients with AD, VaD or stroke without dementia. *Neurology.* 59. 1146-53.

Friel, N. (2003). *The Validation Breakthrough: Simple Techniques for Communicating with People with Alzheimer's-Type Dementia.* 2nd Ed. Maryland. Health Professions Press Inc.

Freshwater, D., (2000). Transformatory Learning in Nurse Education: A Reflexive Action Research Study. *Nursing Praxis International*: Southsea. Hants.

Gabriel, M. S. (2011). Trajectories of Chronic Illnesses. In: Qualls, S., Kasl-Godley, J., E. (Eds). *End of life issues: Grief and Bereavement, what clinicians need to know.* New Jersey. John Wiley & Sons.

Gasset, J. O. (2002). *What is Knowledge?* Eds. Gomez. J. G. USA. State University of New York Press.

General Medical Council. (2010). Guidance for Doctors: Treatment and Care Towards the End of Life: Good Practice in Decision Making. London. GMC.

George, L. Gwyther L. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *American Gerontological Society.* 26. 253–259.

Georges, J., Jansen, S., Jackson, J., Meyrieux, A., Sadowskas, A., Selmes, M. (2008). Alzheimer's disease in real life – the dementia carers survey. *International Journal of Geriatric Psychiatry.* 23. 546-551.

Ghatak, R. (2011). A Unique Support Model for Dementia Patients and Their Families in a Tertiary Hospital Setting: Description and Preliminary Data. *Clinical Gerontologist.* 34. 160-172.

Gilbert, P. (2005). Compassion and cruelty. A biopsychosocial approach.
In P. Gilbert (Ed.).*Compassion: Conceptualisations, research and use in psychotherapy.* 9-74. London. Routledge.

Gilbert, P. (2009). *The compassionate mind.* London: Constable.

Gilliard, J. (1995). Dementia. The Lancet. 346. 440-441.

Glaser, B. G., Strauss, A. L. (1966). *Awareness of Dying.* London. Weidenfeld & Nicholson. 108.

Glaser, B., Strauss, A. (1967). *The Discovery of Grounded theory: strategies for qualitative research.* Chicago. Aldine.

Glaser, B. (1978). *Theoretical Sensitivity.* Mill Valley CA. The Sociology Press.

Glaser, B., (1992). *Basics of Grounded Theory Analysis: emergence versus forcing.* Mill Valley. Sociological Press.

Glaser, B. G. (1999). Keynote address from the 4th annual qualitative health research conference: The Future of Grounded theory. *Qualitative Health Research.* 9 (6). 836-45.

Glaser, B.G. (2002). Constructivist Grounded Theory? Forum: *Qualitative Social Research.* (online journal): 3(3). http://www.qualitative-research.net/fqs-texte/3-02/3-02glaser-e.htm

Godwin. B., Waters. H. (2009). 'In solitary confinement': Planning end-of-life well-being with people with advanced dementia, their family and professional carers. Mortality. 14(3). 265-285.

Goffman. E. (1959). The Presentation of Self in Everyday Life. New York. Anchor/Doubleday.

Goldsmith, D. J. (2001). A normative approach to the study of uncertainty and communication. *Journal of Communication. 51.* 514–533.

Goulding, C. (1999). Consumer Research, Interpretive Paradigms and Methodological Ambiguities. *European Journal of Marketing.* 33. 7-8.

Grafstrom, M. Winblad, B., (1995). Family burden in the care of the demented and non-demented elderly: a longitudinal study. *Alzheimer's Disease and Associated Disorders.* 9. 78-86.

Grant, G., Keady. J. (2003). *Partnerships in Family Care: understanding the caregiving career.* England. Open University Press.

Greenhalgh. T. (2001). How to Read a Paper. The basics of evidence based medicine. 2nd Ed. London. British Medical Journal Publishing Group.

Greenhalgh, T. (2002). Intuition and Evidence: uneasy bedfellows. *British Journal of General Practice.* 52. 395-400.

Greenwood, D., Loewenthal. D., Rose. T. (2001). A relational approach to providing care for a person suffering from dementia. *Journal of Advanced Nursing.* 36 (4). 583-590.

Grisaffi, K., Robinson, L. (2010). Timing of end-of-life care in dementia: difficulties and dilemmas for GPs. *Journal of Dementia Care.* 18(3). 35-39.

Guehne, U., Angermeyer, M.C., Riedler-Heller, S.(2006). Is mortality increased in mildly cognitively impaired individuals? A sytematic literature review. *Dementia and Geriatric Cognitive Disorders.* 21. 403-10.

Guba, E., Lincoln, Y. (1989). *Fourth Generation Evaluation.* Newbury Parks. CA. Sage Publications Ltd.

Guba, E., Lincoln, Y. (1994). Competing paradigms in Qualitative research In: (eds) Denzin, H., Lincoln, Y. *Handbook of Qualitative Research.* California. Sage Publications Ltd.

Hargie, O., Dickson, D. (2004). *Skilled interpersonal communication: research, theory and practice*. London: Routledge.

Hargie. O. (2006). Ed. *The handbook of communication skills*. 3rd ed. London. Routledge

Harris, J. (1985) *The Value of Life.* London: Routledge & Kegan Paul.

Hasson. F., Kernohan. W.G., McLaughlin M., Waldron. M., McLaughlin. D., Chambers. H., Cochrane. B. (2010). An exploration into the palliative and end of life experiences of carers of people with Parkinson's disease. *Palliative Medicine*. 24 (7). 731-736.

Heath, H., Cowley, S., (2004). Developing a grounded theory approach: A comparison of Glaser & Strauss. *International Journal of Nursing Studies.* 41. 141-50.

Heath, I. (2009). Momento Mori. *InnovAiT*. 2 (8). 503-504.

Heath, H. (2010). Improving quality of care for people with dementia in general hospitals. *Nursing Older People: Quality Care Supplement.* 1-16.

Hedley. K., Hughes. J. (2006). Aspects of holistic terminal care in severe dementia. In: *Palliative Care in Severe Dementia in association with Nursing and Residential Care.* Ed. Hughes. J. London. MA Healthcare Ltd.

Heidegger, M. (1962). *Being and Time.* Macquarie, J., Robinson, E., (trans) New York. Harper and Row.

Hennings, J., Frogart, K., Keady, J. (2010). Approaching end of life and dying in care homes: the accounts of family carers. *Clinical Gerontology.* 20.114-127.

Hertogh, C.M.P.M., (2006). Advance care planning and the relevance of a palliative care approach in dementia. *Age and Aging.* 35(6). 553-555.

Holst, G., Hallberg, I.R. (2003). Exploring the meaning of everyday life for those suffering from dementia. *American Journal of Alzheimer's Disease and other Dementias.* 18(6). 359-65.

Holley. C. K., Mast. B. T. (2009). The Impact of Anticipatory Grief on Caregiver Burden in Dementia Caregivers. *The Gerontologist.* 49(3). 388–396.

House of Commons Public Accounts Committee. (2008-2009). End of Life Care: Nineteenth Report of Session 2008-2009. London. Stationary Office.

Hudson, P., (2003). The experience of research participation for family caregivers of palliative care cancer patients. *International Journal of Palliative Nursing.* 9(3).

Hughes, J. C., Robinson, L., Volicer, L. (2005). Specialist palliative care in dementia. *British Medical Journal.* 330. 57-58.

Hughes, J. (2006). Palliative Care in Severe Dementia: in association with nursing and residential care. UK. Ashford Colour Press Ltd.

Hughes, J., C., Hedley, K., Harris, D., (2006). The practice and philosophy of palliative care in dementia. In: Hughes, J., C., (ed) *Palliative Care in Severe Dementia in association with nursing and residential care.* London. Ashford Colour Press Ltd. p1-9

Hughes, J., C., Lloyd-Williams, M., Sachs, G., A., (2010). (Eds). *Supportive Care for the Person with Dementia.* Oxford. Oxford University Press.

Hughes, L. (2004). Palliative care in the community. *Primary Health Care*. 14(6). 27-31.

Hunter, C. (2004). *Hermeneutics and Phenomenology in Research.* http://jmm.aaa.net.au/articles/13625.htm. Accessed 12.11.09

Husserl, E., (1931). *Ideas: general introduction to pure phenomenology.* (trans) Boyce-Gibson, W. R. London. George Allen and Unwin.

Husserl. E. (1969). General Introduction to pure Phenomenology. 5th ed. (trans.) Boyce-Gibson, W. R. London. George Allen & Unwin.

Husserl, E., (1970). *The crisis of European Sciences and transcendental Phenomenolgy.* Evanston, Ill: North Western University Press.

Husserl, E., (1970). *Logical Investigations.* (trans.) Carr, D. New York. Humanities Press.

Hutchinson, C., Foster, J. (2008). *Best Interests at End of Life: Practical Guidance for Best Interests Decision Making and Care Planning at End of Life.* UK. Social Care Institute for Excellence.

Irvine, C., Devlin, K. (2009). Daughter claims father wrongly placed on NHS end of life scheme. www.telegraph.co.uk Accessed 10.09.2011.

James, A. (2010). Show a little kindness. *Australian Nursing Journal.* 17(8). 3.

Jasper, M. A. (1994). Expert: a discussion of the implications of the concept as used in nursing. *Journal of Advanced Nursing.* 20. 769-776.

Johnson, L. M., Zautra, A. J., Davis, M. C. (2006). The role of illness uncertainty on coping with fibromyalgia symptoms. *Health Psychology. 25.* 696–703.

Jordan, A., Lloyd-Williams, M. (2009). Distress and pain in dementia. In: *Supportive Care for the Person with Dementia.* (eds) Hughes, J., Lloyd-Willliams, M., Sachs, G., (2009). Oxford. Oxford University Press.129-31.

Judge, K., S., Bass, D., M., Snow, A., L.,Wilson, N., L., Morgan, R., Looman,W., J., McCarthy, C., Kunik, M., E. (2011). Partners in Dementia Care: A Care Coordination Intervention for Individuals With Dementia and Their Family Caregivers. *The Gerontologist.* 51 (2). 261-272.

Jurgens, C. Y. (2006). Somatic awareness, uncertainty, and delay in careseeking in acute heart failure. *Research in Nursing and Health. 29.* 74–86.

Karabos, A. (2009). *Definitions of Palliative Care.*
http://www.avert.org/palliative-care.htm. Accessed 14.01.10

Katz, E. (1957). The Two-Step Flow of Communication. Public Opinion Quarterly. 21.61-78

Kellehear, A. (2005). *Compassionate Cities. Public health and end-of-life care*. Oxfordshire. Routledge.

Kellehear, A. (2009) Dementia and dying: The need for a systematic policy approach. *Critical Social Policy.* 29(1) 146-157.

Kiely, D. K., Volicer, L. Teno, J., Jones, R. N., Prigerson, H. G., Mitchell, S.L. (2006). The validity and reliability of scales for the evaluation of end of life care in advanced dementia. *Journal of Alzheimer's Disease and Associated Disorders.* 20. 176-181.

Kitwood, T. (1988).The technical, the personal and the framing of dementia. *Social Behaviour.* 3(2). 161-179.

Kitwood. T. (1992). Quality assurance in dementia care. *Geriatric Medicine.* 22(9). 34-38.

Kitwood, T. (1997). *Dementia Re-considered: the person comes first.* Buckingham. Open University Press

Koch, T. (2006). Establishing Rigour in Qualitative Research: the decision trail. *Journal of Advanced Nursing.* 53(1) 91-103.

Koefoed, I. (2007). The Smallest Kindness. *American Journal of Nursing.*107(5). 72.

Kontos, P.C., Naglie, G. (2009). Tacit knowledge of caring and embodied selfhood. *Sociology of Health & Illness.* 32(5). 688-704.

Kovach, C., Weissman, D., Goffie, J. (1999). Assessment and treatment of discomfort for people with late stage dementia. *Journal of Pain and Symptom Management* 18. 412-19.

Knight, B., Lutzky, S., Macofsky-Urban, F. (1993). A Meta-analytic Review of Interventions for Caregiver Distress: Recommendations for Future Research. *The Gerontologist.* 33(2). 240-248.

Kumar, R. (2005). *Research Methodology: A Step by Step Guide for Beginners.* London. Sage Publications Ltd.

Lamont, E. B., Kristakis, M. A. (1999). Some elements of prognosis in terminal cancer. *Oncology.* 13 (8). 1165-1170.

Lampert, K. (2006). Traditions of Compassion: *From Religious Duty to Social Activism. London.* Palgrave-Macmillan.

Lee, R., Renzetti, C. (1993). *Researching sensitive topics.* London. Sage Publications Ltd.

Leini-Kilpi, H., Tuomaala, U. (1989). Research Ethics and Nursing Science: an Empirical Example. *Journal of Advanced Nursing.* 14(6). 451-8.

Lester, S. (1999). *An Introduction to Phenomenological Research.*
http://www.devmts.demon.co.uk/resmehty.htm. Accessed 12.11.09

Levi, B., H., Dellasega, C., Whitehead, M., Green, M. J. (2010).What Influences Individuals to Engage in Advance Care Planning? *American Journal of Hospice and Palliative Care.* 27(5). 306-312.

Littlejohn. S. W., Foss. K. A. (2008). Theories of human communication. 9th Ed. Belmont. Thomson Wadsworth.

Lloyd-Williams, M., Payne, S., Dennis, M., (2005). Specialist palliative care in dementia: Patients with dementia are unable to access appropriate palliative care. *British Medical Journal.* 330(7492). 671-672.

Lyman, K. A. (1989). Bringing the social back in: A critique of the biomedicalisation of dementia. *The Gerontologist. 29.* 597-605.

Mace, N., Rabins, P. (2006). *36 Hour Day: A Family Guide to Caring for People with Alzheimer Disease, Other Dementias, and Memory Loss in Later Life.* 4th Ed. U.S.A. John Hopkins University Press.

Mahon, M., Sorrell, J. (2008). Palliative Care for People with Alzheimer's Disease. *Nursing Philosophy.* 9.110-20.

Marie Curie Palliative Care Institute. (2009). Liverpool Care Pathway version 12. Liverpool. Mari curie Palliative Care Institute.

Marriott, A., Donaldson, C., Tarrier, N., Burns, A. (2004). Effectiveness of cognitive-behavioural family intervention in reducing the burden of care in carers of patients with Alzheimer's Disease. *British Journal of Psychiatry.* 176. 557-562.

Martin, G. (2009). Recovery approach to the care of people with dementia: decision making and "best interests" concerns. *Journal of Psychiatric and Mental Health Nursing.* 16. 654-660.

Martin, D., (2010). Dementia disgrace: Ministers break promise on making Alzheimer's a national priority. *Mail online.* http://www.mailonline.com. Accessed 01.09.10.

Mays, N., Pope, C. (2000). Quality in Qualitiative Health Research. In: *Qualitative Research in Health Care.* (eds). Pope, C. Mays, N. London. BMJ Books. 89-101

Mason, J. (2002). *Qualitative Researching.* London. Sage Publications Ltd.

Mast, B. T. (2009). Uncertainties in Dementia: What Do People with Dementia Experience? *Journal of the American Society on Aging.* 33(1). 31-36.

McCarthy, M., Addington-Hall, J., Altmann, D. (1997). The experience of dying with dementia. *International Journal of Geriatric Psychiatry.* 12.

McConaghy, R., Caltabiano, M., Cook, J. (2005).Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping and well-being. *Nursing and Health Sciences.* 7. 81-91.

McCurry, S. M. (2006). *When a family member has Dementia: steps to becoming a resilient caregiver.* Oxford. Greenwood World Publishing.

McDaid, D., Sassi, F. (2001). The burden of informal care for Alzheimer's Disease: carer perceptions from an empirical study in England, Italy and Sweden. *Mental Health Research Review.* 34-38.

Medical Research Council. (2000). *A framework for development and evaluation of RCT's for complex interventions to improve health.* London. MRC.

Meller, A. E., Caplan, G. A. (2009). Let someone else decide: Development of an advanced care planning service for nursing home residents with advanced dementia. *Dementia.* 8. 391-406.

Merleau-Ponty, M. (1962). *Phenomenology of Perception.* London. Routledge & Kegan-Paul.

Mishel, M. H. (1981). The Measurement of Uncertainty in Illness. *Nursing Research.* 30(5). 258-263.

Mishel, M. H. (1988). Uncertainty in illness. Image: *Journal of Nursing Scholarship. 20.* 225–232.

Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. Image: *Journal of Nursing Scholarship. 22.* 256–262.

Miles, M., Huberman, A. (1994). *Qualitative Data Analysis. An Expanded Source Book.* 2nd ed. U.S.A. Sage Publications Ltd. 278

Mills, J., Bonner, A., Francis, K. (2006). Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice.* 12(1). 8-13.

Mills, P., Ancoli-Israel, S., Kanel, R., Muasbach, B., Aschbacher, K., Patterson, T., Ziegler, M., Dimsdale, J., Grant, I. (2009). Effects of gender and dementia severity on Alzheimer's disease caregivers' sleep and biomarkers of coagulation and inflammation. *Brain, Behaviour and Immunity.* 23(5). 605-10.

Mitchell, S., L., Kiely, D., K., Hamel, M., B., Park, P. S., Morris, J., N., Eries, B., E.(2004). Estimating Prognosis for Nursing Home Residents With Advanced Dementia. *Journal of the American Medical Association.* 291(22). 2734-2740.

Mitchell, S., L., Miller, D., K., Connor, S. R., Teno, J., M. (2007). Hospice Care for patients with dementia. *Journal of Pain and Symptom Management.* 34(1). 7-16.

Moore. S., Sherwin. A., Medina. J., Ream. E., Plant. H., Richardson. A. (2006). Caring for carers: A prospective audit of nurse specialist contact with families and carers of patients with lung cancer. *European Journal of Oncology Nursing.* 10.207–211.

Morris, J. C. (1997). Clinical dementia rating scale: a reliable and valid diagnostic and staging measure for dementia of the Alzheimer type. *International Psychogeriatrics.* (suppl 1). 173-6.

Mosby's Medical Dictionary. (2009) 8th Ed. London. Elsevier.

Mulkay, M. (1993) Social death in Britain. In: Clark, D. (ed) *The Sociology of Death: Theory, Culture, Practice.* Oxford: Blackwell.

Munetz, M., R., Frese, F., J. (2001). Getting ready for recovery:reconciling mandatory treatment with the recovery vision.*Psychiatric Rehabilitation Journal* 25. 35–42.

Murray, M. (2003). Narrative Psychology. In: Smith, J. (Ed). *Qualitative Psychology.* 111-131. London. Sage Publications Ltd.

Murray, S. A., Sheikh, A. (2008). Care for all at the end of life. *British Medical Journal.* 336. 958.

National Audit Office. (2008). *End of Life Care.* London. The Stationary Office.

National Audit Office. (2010). *Improving Dementia Services in England: an interim report.* London. The Stationary Office.

National Council for Hospice and Specialist Palliative Care Services. (2002). *Definitions of Supportive and Palliative Care.* Briefing paper 11*.* London: NCHSPCS.

National Council for Palliative Care. (2009). *Out of the Shadows: End of Life Care for People with Dementia.*Suffolk. Lavenham Press.

National End of Life Care Programme. (2004). National Health Service. http//:www.endoflifecareforadults.nhs.uk. Accessed on numerous occasions between 2009-2011.

National End of Life Programme. (2010). Supporting people to live and die well: a framework for social care at the end of life. London. National End of Life Care Programme.

National End of Life Care Programme. (2011). Support Sheet 18: Preferred Priorities for Care (PPC): a tool for discussing and recording end of life wishes and preferences. National Health Service. http//:www.endoflifecareforadults.nhs.uk. Accessed 14.09.2011.

National Gold Standards Framework Centre. *National Gold Standards Framework.* http://www.goldstandardsframework.org.uk Accessed on several occasions between 2009-2011.

National Institute for Clinical Excellence, (2004). Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer. London. NICE.

National Institute for Health and Clinical Excellence. (2006).(amended 2011). Dementia: supporting people with dementia and their carers in health and social care. London. National Institute for Clinical Excellence, Social Care Institute for Excellence.

National Welsh Assembly Government. (2009). *Consultation on a National Dementia Plan for Wales.* National Welsh Assembly Government.http//:www.wales.gov.uk

Netto, N. R., Gyn, J., Ylk. P. (2009). Growing and gaining through caring for a loved one with dementia. *Dementia.* 8 (2). 245-61.

Newton. T. J. (2010). Reactions to cancer: communicating with patients, family and carers. Oral Oncology. 46. p.442-444.

Nolan, M. R., Grant, G., Keady, J. (1996). *Understanding Family Care. A multidimensional model of care and coping.* Buckingham. Open University Press.

Nolan, M., Lundh, U., Grant, G., Keady, J. (2003). *Partnerships in Family Care: understanding the caregiving career.* England. Open University Press.

Nolan, M.R., Brown, J., Davies, S., Nolan, J., Keady, J. (2006) The Senses Framework: Improving Care for Older People Through a Relationship Centred Approach. *Getting Research into Practice Report.* 1. University of Sheffield, Sheffield.

Nuffield Council on Bioethics. (2009). *Dementia: ethical issues.* London. Cambridge Publishers Ltd.

Oonagh, S., Koppel, B., Dallos, R. (2007). The development of memory difficulties: A journey into the unknown. *Dementia.* 193-213. http://dem.sagepub.com/6/2/193 Accessed: 15.07.2011.

Ouldred, E., Bryant, C. (2008). Dementia Care: Part 3: end-of-life care for people with advanced dementia. *British Journal of Nursing.* 17(5). 308-13.

Oxford Dictionary. (2002). Oxford. Oxford University Press.

Oxford Mini Dictionary Thesaurus & Wordpower Guide. (2002) Oxford. Oxford University Press.

Paterson, R. (2011). Can we Mandate Compassion?. *Hastings Center Report.* 41(2). 20-23.

Patterson, L., Grant, I. (2003). Interventions for caregiving in dementia: physical outcomes. *Current Opinion in Psychiatry.* 16. 629-633.

Pautex, S., Herrmann, F. R., Le, L. P., Ghedira, M., Zulian, G. B., Michon. A., Gold, G. (2007). Symptom relief in the last week of life: is dementia always a limiting factor? *Journal of the American Geriatric Society.*55(8). 1316-1317.

Payne, S., Hudson, P., Grande, G., Oliviere, D., Tishelman, C., Pleschberger, P., Ewing, G., Hawker, S., Kerr, C. (2010). White Paper on improving support for family carers in palliative care: part 1. Recommendations from the European Association for Palliative Care (EAPC) Task Force on Family Carers. *European Journal of Palliative Care.* 17 (5). 238-245.

Pearson, A., Nay, R., Taylor, B. (2003). Relatives' experience of nursing home entry: meanings, practice and discourse. p.185. In: Nolan. M., Lundh.U., Grant, G., Keady, J. Partnerships in Family Care. England. Open University Press.

Phillips, A., Taylor, B. (2009). On Kindness. England. Penguin Books.

Pinner, G., Bouman, W., P. (2003). What should we tell people about dementia? *Advances in Psychiatric Treatment.* 9. 335-341.

Pratt, R., Wilkinson, H. (2003). A psychosocial model of understanding the experience of receiving a diagnosis of dementia. *Dementia.* 2 (2). 181-199.

Polanyi, M. (1966). *The Tacit Dimension.* Garden City. NY. Doubleday & Co.

Potkins, D., Bradley, S., Shrimanker, J., O'Brien, J., Swann, A., Ballard, C. (2000). End of Life Treatment Decisions in People with Dementia: Carers views and factors which influence them. *International Journal of Geriatric Psychiatry.* 15. 105-108.

Powell, T. (2011). Life Imitates Work. *Journal of American Medical Association.* 305(6). 542.

Powers, B. A. (2008). Meaning and Practice of Palliative Care for Nursing Home Residents with Dementia at End of Life. *American Journal of Alzheimer's Disease and Other Dementias. 23* (4). 319-25.

Qureshi, H., Walker. A. (1989). The Caring Relationship: *Elderly People and their Families.* London. Macmillan Education Ltd.

Racher, F., Robinson, S. (2003). Are phenomenology and Postpositivism Strange Bedfellows? *Western Journal of Nursing Research.* 25(5). 464-481.

Rando, T. A. (1986). A comprehensive analysis of anticipatory grief: Perspectives, processes, promises, and problems. In: Rando, T. (Ed.), *Loss and anticipatory grief* 1 – 36. New York. Lexington Books.

Reaney, P. (1988). What is Knowledge: Science Mysteries. *Arizona Journal of Natural Philosophy.* 2. 7-14.http://ajnpx.com/html/AJNP.html. accessed 21.03.2011

Regnard. C., Reynolds. J., Matthews. D., Clarke. C. (2007). Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *Journal of Intellectual Disability Research.* 51(4) 277-292.

Reisberg, B. (1988). Functional assessment staging (FAST).*Psychopharmacology Bulletin.* 24.653-659.

Reissman, C. K. (1993). *Narrative Analysis.* 18-19. London. Sage Publications Ltd.

Reynolds, K., Hanson, L., DeVellis, R., Henderson, M., Steinhausser, K. (20008). Disparities in Pain Management Between Cognitively Intact and Cognitively Impaired Nursing Home Residents. *Journal of Pain and Symptom Management.* 35.

Riches, G., Dawson, P. (1996. Making stories and taking stories. *British Journal of Guidance and Counselling.* 24(3). 357-365.

Rickles, D., Hawe, P., Shiell, A. (2007). A simple guide to chaos and complexity. *Journal of Epidemiology and Community Health.* 61:933–937.

Rothwell, D., J. (2010). *In the Company of Others: An Introduction to Communication.* 2nd Ed. New York. The McGraw-Hill Companies.

Royal College of General Practitioners. (2003). GP's rely on intuition rather than guidelines to diagnose meningitis. *Royal College of General Practitioners.* www.rcgp.org accessed 26.01.2011

Royal College of General Practitioners, Royal College of Nursing. (2011). End of Life Care Patient Charter: A charter of care for people who are nearing the end of their life. London. RCGP.

Sabat, S. (2008). A biopsychosocial approach to dementia.In: Excellence in Dementia Care: Research into Practice. Eds. Downs, M. Bowers, B. England. Open University Press.

Sampson, E., Ritchie, C. W., Lai, R., Raven, P. W., Blanchard, M. R. (2005). A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *International Psychogertiatrics.* 17(1). 31-40.

Sampson, E., Gould, V., Lee, E. (2006). Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Ageing*. 35(2).187-189.

Sampson, E., Jones, L., Thune-Boyle, I., Kukkastenvehmas, R., King, M., Leurent, B., Tookman, A., Blanchard, M. (2010). Palliative assessment and advance care planning in severe dementia: An exploratory randomised controlled trial of a complex intervention. Palliative Medicine. 0(00). 1-13.

Sampson, E. (2010). Palliative care for people with dementia. *British Medical Bulletin*. 96. 159-174.

Sandalowski, M. (1986). The Problem of Rigour in Qualitative Research. *Advances in Nursing Science.* 8. 27-37.

Schachter, R. (2011). Can Kindness be Taught? *Instructor.* 120(4).

Shea, S. Lionis, C. (2010). Restoring humanity in health care through the art of compassion: an issue for the teaching and research agenda in health care. *Rural and Remote Health.* 10. http://www.rrh.org.au Accessed 12.06.2011.

Scherder, E., A., Sergeant, J. A., Swaab, D., F. (2003). Pain processing in dementia and its relation to neuropathology. The Lancet: Neurology. 2(11). 677-686.

Scholtens, M. (2011). Kindness. *Canadian Medical Association Journal.* March 8th. 23-24.

Schultz, R., Beach, S. (1999). Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study. *Journal of American Medical Association*. 282 (23). 2215-2219.

Schultz, W. T. (2003). The Prototypical Scene: a method for generating psychobiographical hypotheses. In: *Up Close and Personal: the teaching and learning of narrative research.* 156-176. (Eds). Rosselson, R., Lieblich, A., Dan, M. Washington DC. American Psychological Association.

Schwandt, T. A. (1994). Constructivist, Interpretivist Approaches to Human Enquiry. (1994) In: N.K. Denzin & Y.S. Lincoln (eds) *Handbook of Qualitative Research.* 194. Thousand Oaks. Sage Publications Ltd.

Scott, S., Pace, V. (2009). The first 50 patients: A brief report on the initial findings from the Palliative Care in Dementia Project. *Dementia.* 8(3). 435-441.

Seale, C. (1999). *The Quality of Qualitative Research.* London. Sage Publications Ltd.

Seale, C. (2002). Qualitative issues in qualitative inquiry. *Qualitative Social Work.* 1(1).   97-110.

Shuster, J. (2000). Palliative Care for Advanced Dementia. Geriatric Medicine. 16(2). 373-386.

Small, N., Barnes, S., Gott, M., Payne, S., Seamark, D., Gariballa, S., (2009). Dying, death and bereavement: a qualitative study of the views of carers of people with heart failure in the UK. *BMC Palliative Care.* 8 (1). 6.

Smith, D. (2007). Assessing pain in people with dementia 1: The challenges. *Nursing Times.* 103(29). 28-31.

Stationary Office (2000). *Adults with Incapacity (Scotland) Act.* The Stationary Office. Norwich.

Sterin, G.J. (2002). Essay on a word: A lived experience of Alzheimer's disease. *Dementia.* Sage Publications Ltd.

Stone, M. A., Jones, C., L. (2009). Sources of Uncertainty: Experiences of Alzheimer's Disease. *Issues in Mental Health Nursing.* 30. 677-686.

Strang, P. (2000). Qualitative research methods in palliative medicine and palliative medicine. *Acta Oncologica.* 39(8). 911-739.

Strauss, A., L. (1987*). Qualitative analysis for social scientists.* New York. Cambridge University Press.

Strauss, A., Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park CA. Sage Publications Ltd.

Strauss, A., Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques* (2nd ed). Thousand Oaks, CA, Sage Publications Ltd.

Sudnow, D. (1967) Passing On: The Social Organisation of Dying.74. Englewood Clifts. N.J. Prentice Hall Inc.

Sussman, T., Regehr, C. (2009). The Influence of Community-Based Services on the Burden of Spouses Caring for Their Partners with Dementia. *Health & Social Work.* 34(i) 109.

Svanstrom, R., Dahlberg, K. (2004). Living with Dementia Yields a Heteronomous and Lost Existence. *Western Journal of Nursing Research.* 26(6). 671-687.

Sweeting, H. N., Gilhooly, M. L. M. (1990). Anticipatory grief: a review. *Social Science and Medicine.* 30. 1073-1080.

Sweeting, H. N., Gilhooly, M. L. M. (1992) Doctor, am I dead? A review of social death in modem societies. *Omega.* 24(4). 251-69.

Sweeting, H. N., Gilhooly, M. L. M. (1997). Dementia and the phenomenon of social death. *Sociology of Health and Illness.* 19(1). 93-117.

Takan, M., Arai, H., (2005). Gender difference and caregiver's burden in early onset Alzheimer's disease. *Psychogeriatrics.* 5(3) 73-6.

Thomas, C., Morris, S. M. (2002). Carers and families in distress. *European Journal of Cancer Care.* 11(3). 178-182.

Thomas, K. (2009). RCGP End of Life Strategy. *Clinical Innovation and Research Centre.* Royal College of General Practitioners.

Tonks, A. (2009). Advanced dementia is a terminal illness. *British Medical Journal.* 339(7727). 944.

Torti, F., Gwyther, L., Reed, S., Friedman, J., Schulman, K. (2004). A Multinational Review of Recent Trends and Reports in Dementia Caregiver Burden. *Alzheimer's Disease and Associated Disorders.* 18. 99-109.

Tremont, G. (2011). Family Caregiving in Dementia. *Medicine & Health*. 94 (20). 36-38.

Valentine, C. (2008). *Bereavement narratives: continuing bonds in the twenty first century.* Oxon: Routledge.

van der Steen, J.T., Gijsberts, M.J., Knol, D.L, Deliens, L., Muller, M.T. (2009). Ratings of symptoms and comfort in dementia patients at the end of life: comparison of nurses and families. *Palliative Medicine.* 23. 317324.

van der Steen, J., T. (2010). Dying with Dementia: What we know after more than a decade of research. *Journal of Alzheimer's Disease*. 22. 37-55.

Waring, S. C., Doody, R.S., Pavlik, V.N., Massman, P.J., Chan, W. (2005). Survival among patients with dementia from a large multi-ethnic population. *Alzheimer's Disease and Associated Disorders.* 19. 178-83.

Warner, G., (2009). The Liverpool Care Pathway may be the slippery slope to backdoor euthanasia. www.blogs.telegraph.co.uk: Accessed 04.09.2011.

Watson, M. Lucas, C., Hoy, A., Back, I. (2005). *Oxford Handbook of Palliative Care.* Oxford. Oxford University Press.

Waugh, A., Marland, G., Hendrson, J., Robertson, J., Wilson, A. (2011). Improving the care of people with dementia in the acute hospital. *Nursing Standard.* 25(32). 44-49.

Wiemann, J. (2003). Foreword. In J. Greene & B. Burleson (Eds), *Handbook of communication and social interaction skills*. Mahwah, NJ: Lawrence Erlbaum.

Weinstein, B. (1993). What is an Expert? *Theoretical Medicine.* 14. 57-73.

Wengraf, T. (2001). *Qualitative Research Interviewing.* London. Sage Publications Ltd.

Williams, S., Keady, J., (2006).The narrative voice of people with dementia. *Dementia.* 5(2). 163-166.

Winslow. L. (2007). http://EzineArticles.com/experts. accessed 28.02.2011

World Health Organisation. (1990). *Technical Report Series 804.* World Health Organisation.

Wolf-Klein, G., Pekmezaris, R., Chin, L., Weiner, J. (2007). Conceptualising Alzheimer's disease as a terminal medical illness. *American Journal of Hospice and Palliative Care*. 24 (1). 77-82

Wright. K. B. Frey. L. R. (2008). Communication and Care in an Acute Cancer Centre: The Effects of Patient's Willingness to Communicate About Health, Health Care Environment Perceptions, and Health Status on Information Seeking, Participation in Care Practices and Satisfaction. *Health Communication.* 23.369-379.

Xie, J., Brayne, C., Matthews, F. (2008) Survival times in people with dementia: analysis from population based cohort study with 14 year follow up. *British Medical Journal*. 336. 258-62.

Young. T., Manthorp. C. (2009).Towards a Code of Practice for Effective Communication With People With Dementing Illnesses. *Journal of Language and Social Psychology.* 28(2). 174-189.

Zarit, S., Todd, P., Zarit, J. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *American Gerontological Society.* 26: 260–266.

Zarit, S. (2004). Family care and burden at the end of life. *Journal of the Canadian Medical Association.* 170(12). 1811.

Zwakhalen, S., Kooperman, R., Geels, P., Berger, M., Hamers, J. (2008). The prevalence of pain in nursing home residents with dementia using an observational pain scale. *European Journal of Pain.* 13(1). 89-93.

Appendix 1: Distress Protocol

Dementia: what care do patients and carers need in the last year of life?

<u>**DISTRESS PROTOCOL**</u>

In the event of a study participant becoming distressed the following courses of action will be taken:

- Distress exhibited by participants prior to the interview will be sensitively addressed by the researcher. The cause of the distress will be established and discussed if participant wishes. The researcher, in collaboration with the participant, will establish whether to proceed with the interview, re-schedule or continue inclusion in the study.

- If participants demonstrate any signs of distress during the interview, the process will be suspended by the researcher, (tape switched off). Participants will be allowed to ventilate feelings/emotions if desired. Researcher and participant will collaboratively decide upon their ability to continue the interview following a "time out" period.

- If researcher and participant agree, interview will proceed.

- If the level of distress exhibited necessitates complete suspension of the interview, both will discuss the appropriateness of re-scheduling. If both agree the level of distress warrants withdrawal from the study, this will occur.

- If the interview is re-scheduled, the researcher will be aware of the potential for distress and act accordingly on the future visit.

- If distress occurs following the interview, researcher to sensitively address this in collaboration with participant.

- Researcher to establish if participant wishes any data obtained to be used in the final analysis. Wishes of participant will be respected.

- Researcher and participant to collaboratively identify ways of seeking support with distress regarding any issues that arose. This may include a referral to their G.P., supportive groups or counselling services.
  The researcher will have list of potential sources of help.

Appendix 2: Appeal for volunteers poster

Appeal for volunteers to take part in a study

Little is known about what care people with advanced dementia and their carers need during the last year of life. This is the subject of research being carried out at the University of Liverpool by the Academic Palliative and Supportive Care Studies Group within the Division of Primary Care.

Researchers are keen to hear from people over the age of 18 (no upper age limit) that have cared for a person with advanced dementia. This can have been as a family member, friend, paid carer, male or female. To protect those who may be vulnerable, those experiencing the death of the person with dementia within a six week period may not be eligible. Through listening to personal experiences, the research team hopes to gain a better understanding of what this group may need to improve the quality of life at this difficult time and beyond. The knowledge gained will add to the lack of evidence we currently have on this topic. It will also be used to inform services at a local and national level so they can be tailored better to meet individual needs.

Participation in this study is voluntary and anonymous. Any data collected will be kept in the strictest of confidence.

If you are interested in taking part in this study and would like further information please contact:

Jackie Crowther (project researcher, PhD student)

Academic Palliative and Supportive Care Studies Group

Division of Primary Care

Whelan Building, 2nd Floor

Brownlow Hill

Liverpool, L69 3GB

crowther@manchester.ac.uk Tel: 0151 794 8047

Appendix 3: Covering letter for participants

Jackie Crowther

PhD Student,

Room 201, Floor 2,
Whelan Building,
Brownlow Hill,

Liverpool L69 3GB

Tel:01517948047
Fax:0151 7945604
crowther@liv.ac.uk

Date: (insert details)

Name: (insert details)

Address: (insert details)

Dear (insert potential participant name)

Re:Research Study

Dementia: what care do carers and people with dementia need in the last year of life and time surrounding death?

Thank you for responding to our appeal for volunteers for the above research study. Please find enclosed, as discussed via telephone, copies of the information sheet for you to read. Please take your time to read this and discuss it with family, friends and/or your General Practitioner if you wish.

I will contact you via telephone in a few days to discuss the study and answer any questions you may have. If you wish to participate in the study, we can make an appointment to meet then.

I look forward to speaking with you in the near future, in the meantime should you have any questions about the study, please do not hesitate to contact me on the number above.

Yours sincerely,

Jackie Crowther,

Project Researcher, PhD Student.

Version 1 November 2008

Appendix 4: Participant Information Sheet

UNIVERSITY OF
LIVERPOOL

Academic Palliative and Supportive Care Studies Group,

School of Population, Community and Behavioural Sciences,

2nd Floor, Whelan Building,

Brownlow Hill,

Liverpool, L69 3GB.

Participant Information Sheet

Title of the Study: Dementia - what care do patients and carers need in the last year of life and time surrounding death?

Invitation:

You are being invited to take part in a research study. Before you decide to participate, it is important that you understand why the research is being undertaken and what it will involve for you. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. You may also wish to discuss this with your family, friends and/or your General Practitioner. We would like to stress that you do not have to accept this invitation and should only take part if you wish to do so.

Thank you for reading this information.

What is the purpose of this study?

We know very little at the moment about what happens to people with advanced dementia and their carers in the last year of life. The purpose of this study is to find out more about this by talking to people about what happened to them during this time. If we can gather information about this and what people feel they need it will help to decide what services people may benefit from and how best to provide these in the future. Jackie Crowther is a researcher working with the Principal Investigator Professor Mari Lloyd-Williams at the University of Liverpool. Jackie will be working on the project for three years as part of a PhD.

This study is being funded by St. Luke's Hospice in Cheshire and has been reviewed by the University of Liverpool Research Ethics Committee.

Why have I been chosen to take part?

You responded to our appeal for people who had cared for someone with advanced dementia in the last year of their life to take part. We would like to hear about your experiences to help us understand yours and the needs of others in a similar situation better.

Do I have to take part?

It is up to you whether you decide to take part. This information sheet is yours to keep. If you decide to take part, the researcher will ask you to sign a consent form first. It is entirely voluntary and you can decide to withdraw from this study at any time. You do not have to give a reason and you will not be affected in any way should you wish to withdraw. If you decide to withdraw, the project researcher will ask for permission to use the information collected from you to this point but you do not have to agree to this.

What will happen to me if I do take part?

If you decide to take part, please contact Jackie Crowther. She will discuss the study with you in more detail over the telephone and will make an appointment to come and see you at a time and place convenient for you so you can tell her your "story".   Jackie will talk to you again about the study when she visits and ask you to sign the consent form before the interview begins. You will be given a copy of the information sheet and consent form to keep for your records. Jackie will record the interview, with your consent and permission. This will mean she can concentrate fully on what you are telling her without having to take notes. The meeting will last about an hour but this depends upon you and what you have to tell her. If your interview seems to be taking a long time, this can be discussed at the time and if you wish, an appointment to carry it on, on another day can be made. If you do not meet Jackie in your own home, any travel costs or those associated with taking time from work to meet her will be refunded to you. A receipt will be needed for us to this.

If you prefer, you can write your story down in your own words and send it to Jackie in the pre-paid envelope she provides. You will also be asked to sign and return a copy of the consent form should you choose to tell your story in this way.

What are the benefits of taking part?

There are no direct benefits to you in taking part in this study. If you decide to take part in this study you will help us to find out more about what happens to carers and people with advanced dementia in their last year of life. In addition, other research has suggested that talking (or writing) about past experiences can be helpful to people.

Are there any disadvantages to taking part?

It is possible that telling/writing your story may be upsetting to you. You may be recalling a traumatic event. If you become upset during the interview, if you wish, Jackie will stop the recording and discontinue the interview. You may feel able to continue after a short break. If you prefer, the interview can be arranged for another time or you may decide not to continue at all. If you have chosen to write your story and you become upset, it is up to you if and when you choose to continue. If anything untoward happens to you, this study is covered by the University of Liverpool indemnity scheme.

What if I am unhappy or there is a problem?

If you are unhappy at all please contact Professor Lloyd-Williams, 0151 794 5605 or Jackie Crowther, 0151 794 8047 and we will try to help resolve the problem. If you remain unhappy please contact the University Research Governance officer on 0151 794 8290. When contacting the Research Governance Officer please tell them the name of the investigators, what the study is called which is at the top of this page and the nature of your complaint.

Will the information I give be kept confidential?

The stories that you tell will be kept confidential. Jackie will make sure that the tape and transcript from your interview are anonymous and kept safe at the University in a lockable cabinet. The only people who will be able to see these are Professor Lloyd-Williams and Jackie Crowther. If any of the contents of your interview are used for publications in journals, presentation at conferences or similar, please be assured that these will be anonymous and you will not be identified at all. Any personal details you give to enable us to send information and to contact you will also be confidential and kept securely.

What will happen to the findings from this study?

The findings will be published in international and national journals and may be presented at conferences and research meetings. This is so as many people as possible can hear about the findings and take action in the future. A summary of the findings will also be available to you if you wish. The findings will also form the basis of Jackie's PhD thesis for examination by the University of Liverpool.

What will happen if I decide I do not want to continue taking part?

If at any time you decide you do not want to carry on taking part in the study it is not a problem. Your participation is voluntary and your withdrawal will have no consequences for you whatsoever. You will need to contact Jackie Crowther, 0151 794 8047 or Professor Lloyd-Williams, 0151 794 5605 to tell them you have changed your mind.

Who do I contact if I have further questions?

If you have any more questions about this study, please contact Jackie Crowther, 0151 794 8047, crowther@liverpool.ac.uk or Professor Lloyd-Williams, 0151 794 5605, mlw@liverpool.ac.uk.

Version 1 November 2008

Appendix 5: Consent form

CONSENT FORM

Title of Research Project:

Dementia: what care do patients and carers need in the last year of life and time surrounding death?

Researcher(s):

Professor Mari Lloyd Williams, Honorary Consultant in Palliative Medicine, Academic Palliative and supportive Care Studies Group, School of Population, Community and Behavioural Science.
mlw@liverpool.ac.uk Tel: 01517945605
Jackie Crowther, PhD student. Crowther@liverpool.ac.uk Tel: 01517948047

PLEASE

INITIAL BOX

1. I have read and understood the participant information sheet version 1, dated November 2008 for this study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw from this study at any time without giving a reason or my statutory rights being affected.

3. I understand that under the Data Protection Act, I can ask at any time to access the information I provide. I can also request the destruction of this information if I wish.

4. I understand that my interview will be audio recorded. I agree to this and the use of any information I give being used in anonymous form in publications, conference presentations or similar events.

5. I agree to take part in the above study.

_____   _____   _____

Participant Name   Date   Signature

_____   _____   _____

Person taking consent   Date   Signature

_____   _____   _____

Researcher Name   Date   Signature

Version 1, November 2008

Appendix 6: Demographic information table template

UNIVERSITY OF
LIVERPOOL

Study Title: Dementia: what care do patients and carers need in the lat year of life and time

      surrounding death?

Participant Details:

NAME	ADDRESS	CONTACT NUMBER	GENDER M/F	INFORMAL FORMAL CARER	TIME CARING (YEARS)	TIME SINCE DEATH	PLACE OF DEATH

Version 1, November 2008

Appendix 7: Aid memoir (interviews)

UNIVERSITY OF LIVERPOOL

Study Title:

Dementia: what care do carers and people with dementia need in the last year of life and time surrounding death?

Aid memoir for initial interviews

1) Diagnosis and illness trajectory – what were the problems and how were these addressed?
2) What support was offered – how effective was that support in the last year of life; what was good, what was not so good?
3) Were palliative care needs addressed – if so how, when and where?
4) What happened in last few weeks of life?
5) Bereavement support.

Appendix 8: University Research Ethics Committee (UREC) favourable opinion notification

Dear   Mari and Jackie

I am pleased to inform you that the Sub-Committee has approved your application for ethical approval. Details and conditions of the approval can be found below.

Please ensure that you send a signed copy of the final version , with all supporting documentation, to the Research Governance Officer, Contract Services, Legal Services, Foresight Building, Liverpool, L69 3GL.

Ref:	RETH000206
Sub-Committee:	Non-Invasive Procedures
PI:	Professor Mari Lloyd-Williams
Title:	Advanced Dementia: What Care to Patients and Carers Need?
First Reviewer:	Prof Helga Drummond
Second Reviewer:	n/a
Date of initial review:	17/12/08
Date of Approval:	06/01/09

The application was APPROVED subject to the following conditions:

Conditions

1	Mandatory	M: All serious adverse events must be reported to the Sub-Committee within 24 hours of their occurrence, via the Research Governance Officer (ethics@liv.ac.uk).

This approval applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Sub-Committee should be notified. If it is proposed to make an amendment to the research, you should notify the Sub-Committee by following the Notice of Amendment procedure outlined
at http://www.liv.ac.uk/researchethics/amendment%20procedure%209-07.doc.

If the named PI / Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore please contact the RGO at ethics@liverpool.ac.uk in order to notify them of a change in PI / Supervisor.

Many thanks

Sarah

Appendix 9: Study outputs

Study outputs February 2009-April 2011:

- Community Integrated Care (March 2009) Carlisle, oral presentation to senior managers and CE of organisation on project

- National Council for Palliative Care (April 2009) London, joint oral presentation of workshop on: **Care Pathways in Dementia** and the project

- Cheshire Hospice Education Team (Sept 2009) Winsford, **"Defining a Research Question"** training for undergraduate students, incorporating dementia project

- Royal College of GP's (Sept. 2009) Liverpool, presentation of 4 consecutive   workshops on: **End of Life issues in Dementia** incorporating project and data

- Staffordshire University (March 2010) Stafford, oral presentation from main platform on: **Pain Assessment and Dementia**, incorporating project data

- Transpennine Research Meeting (May 2010) Sheffield, poster presentation: **Advanced Dementia: what care do patients and carers need?**

- St. Luke's Cheshire Hospice (May 2010) Winsford, **"Dementia Awareness Training"** for hospice clinical staff (two 2 hour sessions)

- European Association of Palliative Care (June 2010) Glasgow, poster presentation on project: **Dementia: what care do patients and carers need in the last year of life and time surrounding death?**

- Royal Society of Medicine (July 2010) London, oral presentation from main platform of project and emerging themes: **Palliative and End of Life Care for People with Dementia**

- Admiral Nurses, North West Team and CE of Dementia UK (August 2010) Bolton, oral presentation of project and potential emerging themes

- LOROS (July 2010) Leicester, oral presentation from main platform on project and emerging themes

- Stirling Dementia Development Centre (Oct 2010) London, poster presentation on project: **Dementia: what care do patients and carers need in the last year of life and time surrounding death?**

- St. Luke's Cheshire Hospice (Jan 2011) Winsford, oral presentation to hospice trustees and clinical on project and transfer of results into practice

- University of Liverpool Post Graduate Research Day (March 2011) Liverpool, poster presentation: **Dementia: what care do patients and carers need in the last year of life and time surrounding death? Whole project and conclusions.**

- Cancer Experience Collaborative, (April 2011) Manchester, poster presentation: **Dementia: what care do patients and carers need in the last year of life and time surrounding death?** Whole project and conclusions.

Appendix 10: Participant statement

November 1st 2010

My Father suffered from Alzheimer's disease and spent the final year of his life between a care home and hospital.

Last year I was able to take participate in a study entitled "Advanced Dementia: what do carers and people with dementia need?" In particular looking at the end of life needs and experiences.

My interview was held at my home in a relaxed setting by a project researcher who asked me to tell the story of my dad's last year of life. There were times during the interview which were emotional interspersed with some happy memories too, and always the interviewer was sensitive to these feelings and offered to discontinue the session if I so wished.

I realised how much I needed to tell this period of his life and found the whole process cathartic.

Christine Breathen