Restoration following personalised, residential respite for patients with neurodegenerative conditions and their carers: A grounded theory study.

BY
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A thesis submitted for the Doctorate in Clinical Practice

THESIS PART ONE

Faculty of Health and Medical Sciences
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University of Surrey
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**Overview of the integration of knowledge, research and practice**

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**Research Log**

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Statement of Originality

This thesis and the work to which it refers are the results of my own efforts. Any ideas, data, images or text resulting from the work of others (whether published or unpublished) are fully identified as such within the work and attributed to their originator in the reference/bibliography or in footnotes. This thesis has not been submitted in whole or in part for any academic degree or professional qualification. I agree that the University has the right to submit my work to the plagiarism detection service TurnitinUK for originality checks. Whether or not drafts have been so-assessed, the University reserves the right to require an electronic version of the final document (as submitted) for assessment as above.

D. V. Laverty

Diane Laverty

12th December 2014
ABSTRACT

**Aim:** This study aimed to develop a grounded theory to explain the experience of patients with neurodegenerative diseases and their carers, following an episode of residential respite care.

**Background:** Neurodegenerative diseases are incurable, debilitating and result in progressive deterioration of the patient which present as problems with cognitive functioning (dementias) and/or physical functioning (ataxias). To allow quality of life and purpose for the patient and caregiver, as well as providing value for money, respite is an area of care which could offer the patient rehabilitation, maximisation of functionality and quality of life; relief from caregiving duties for the carer and signposting for additional assistance and support.

**Methods:** This was a qualitative, grounded theory study conducted across south east England. An initial audit, attendance at support groups and specialist clinics provided scoping of the scale of the problems encountered by this patient population. Data collection included 17 semi structured interviews conducted with patients and carers who had recently received residential respite, non-participant observation at a hospice offering dedicated respite care and 4 hospice staff interviews.

**Findings:** A successful respite depended on the patient and carer identifying the need for respite and the information required to determine where, what, when and how respite could be accessed. The logistics of the referral process, preparation for respite and the handover of care needs to professionals were key factors for a therapeutic admission.

**Conclusion:** The outcomes from the respite admission should be mutually acceptable to both the patient and carer and be able to demonstrate acceptance and adaptation to a new normalcy, influenced by disease progression and reflecting on time present and time past. The onward journey sees a transitioning which involves restoration and building up a level of resilience for the carer, which all contribute to sustainability and being able to continue in the caring role.
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I would like to dedicate this thesis to my husband, Cliff and son, Ben. They have been my rock and motivated me throughout this journey, for which I am indebted to them.

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GLOSSARY

Categories
- group of concepts that are used to create a theory

Carer / Caregiver
- terms used interchangeably to describe someone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support

Codes
- identifying anchors that allow key points of data to be gathered

Concepts
- collection of codes of similar content that allows data to be grouped

CNS
- Clinical Nurse Specialist

Constant Comparison
- constantly comparing incoming data with data, codes and categories to determine ‘fit’

Constructivist Grounded Theory
- a method of conducting qualitative research which assumes that there are no absolute truths and realities are made through multiple interpretations and the people who experience them

Epistemology
- the study of knowledge

Induction
- a type of reasoning that emerges from the data

MDS
- Minimum Data Set – national statistics provided by the NCPC

MNDA
- Motor Neurone Disease Association

NCPC
- National Council Palliative Care
Neuro-degenerative diseases
- incurable, debilitating diseases which affect the neurones in the brain and result in progressive deterioration. Examples include, Motor Neurone Disease (MND), Huntington’s Disease (HD) and Multiple Systems Atrophy (MSA).

Ontology
- the study of the nature of reality

Palliative Care
- an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness

Reflexivity
- the researcher’s scrutiny of their own experience, decisions and interpretations

Respite care
- the temporary physical, emotional or social care of a dependent person in order to allow the informal carer to take a break from caregiving duties. It can also have a benefit for the patient by providing an opportunity for review of care needs.

Rigour
- ensuring and demonstrating processes employed to explain all factors that have been followed and adhered to in order to avoid bias and threaten the validity of the research findings.

Symbolic Interactionism
- a theoretical perspective which assumes people construct selves, society & reality through interaction and they assign their meaning to it

Theory
- a collection of explanations that explain subject of research

Theoretical Sampling
- sampling is focused on people, places and events which will illuminate the data emerging.

Theoretical Sensitivity
- the ability to recognise and extract from the data elements that are relevant to the emerging theory.
CHAPTER 1: INTRODUCTION

1.1 Introduction

This thesis is the conclusion of the doctorate in clinical practice (DCP) programme which was commenced in January 2010. This introductory chapter serves to contextualise and situate the researcher to gain an understanding of the context of the research and to provide an overview of the thesis. Each chapter will be briefly presented with a resume of its content.

1.2 The researcher

The researcher is a nurse with 30 years experience, twenty five of which have been in palliative care. The majority of her clinical work has been in oncology where she considers she possesses a high level of specialist expertise. On gaining a nurse consultant post in a hospice she was placed in a position where she had to consider the needs of patients with chronic and life limiting non-malignant diseases. The researcher was working at an East London hospice that had recently reviewed its strategic direction and was exploring avenues to widen access to a diverse population of patients as well as extend the service to the non–malignant agenda. The consultant post was new and the first time the hospice had heavily invested in its senior nursing posts, as previously the hospice had been medically dominated. The primary aim was to establish a nurse led unit, focusing on respite services as a neglected area but a service desired by the local population. The researcher had only minimal knowledge and understanding of respite
from a previous role so this was a new field of practice for her. It also felt very ambitious as the nurses in the hospice were very traditional and did not fully understand the concept of nurse leadership. Most importantly, the vast majority of patients that were cared for at the hospice had a cancer diagnosis.

As part of the appointment of the consultant post the researcher was to embark on a doctorate programme. This felt timely to challenge her existing knowledge and apply it to her interest in non-malignant palliative care. Although the nurse-led respite unit provided background context and information about the service and an opportunity to explore concepts of respite, she was keen to conduct research relevant to her immediate working area. This resulted in exploring new found connections and contacts to establish a study of patients with neurodegenerative illness in other services in the south east of England and to provide alternative avenues to conduct the research.

1.3  Background to the study

1.3.1  Neurodegenerative diseases

Neurodegenerative diseases consist of a variety of conditions which primarily affect the neurons in the central nervous system. They are incurable and debilitating and result in progressive deterioration of the patient. This results in problems with either/and cognitive functioning (dementias) or physical/movement (ataxias). The disease can progress over months or years which places a heavy burden on the patient; seeing their personal deterioration and knowing the end result and the caregiver (usually a family
member); who has to continue caring whilst witnessing this slow journey of a loved one to death. To allow quality of life and purpose for the patient and caregiver, as well as providing value for money, it is an area of study which meets a need for change, particularly pertaining to respite care which could offer several avenues of care related to rehabilitation, maximisation of functionality and quality of life as well as signposting for additional assistance and support.

The scale of the problem varies depending on the neurological disease. Motor Neurone disease (MND) has an incidence of 1-2 per 100,000 and a prevalence of 4-6 per 100,000 (Woodward & Waterhouse, 2009). The cause is unknown and the life expectancy is 2-5 years after onset of symptoms. Similarly, Multiple Systems Atrophy (MSA) has an incidence of 3 per 100,000 and a prevalence of 6 per 100,000 and the cause is also unknown. The life expectancy is slightly longer at 5-9 years. In contrast Huntington’s disease (HD) has a smaller incidence and prevalence of less than 0.1 per 100,000 and it is a genetically inherited disease. It has a much longer life expectancy of 15-20 years (Woodward & Waterhouse, 2009). See Appendix 1 for an overview of neurodegenerative diseases. The burden of caregiving is significant and an issue that is becoming more problematic. The next section will briefly explore the increased caring role for informal carers.
1.3.2 The role of informal carers

The Office of National Statistics (ONS) states that by 2033 there are predicted to be in the region of three million people who make up the population of the over 85 year olds and approximately a quarter of the population will be over retirement age. These people will experience ill health as they age and will be supported by informal carers who are usually close family members (ONS, 2009).

The National Institute for Clinical Excellence (NICE, 2004, p155) define informal carers as “lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management”. The role has long been associated with a significant burden including physically, emotionally, socially and financially (e.g. Payne et al. 1999; Payne et al. 2010a & 2010b), although there is some literature to support elements of satisfaction with the caregiving role (e.g. Hogstel et al. 2005). Greater emphasis is now placed on keeping patients in their own homes in order to address their personal wishes but also reduce hospital / institutional costs (DH, 2008a; DH, 2010b; DH, 2012). One way of achieving this is for patients and carers to receive regular respite, which is the topic of this thesis.

1.4 Synopsis of the chapters

1.4.1 Literature review

Most research projects begin after a thorough literature review has been completed (Bryman, 2008). Grounded theory differs in this respect as the hope is that existing
literature will not taint the research focus or results and cause the researcher to come to
the study with preconceived ideas (Glaser, 1998). Chapter two outlines the rationale
behind the researcher performing an early literature search, followed by the later review
when the theory begun to emerge from the findings. The search findings are presented
under specific headings to attempt to make sense of the place that literature held within
this research as well as data to support the results.

1.4.2 Methodology and methods
Chapter three presents the rationale for, and mechanics of, the chosen methodology
which is grounded theory. It presents the background to the choice and why grounded
tooly theory suits this research study. It then explores the methods chosen to gather data and
the theoretical underpinnings of the research. The theoretical framework chosen for this
study is symbolic interactionism which is placed in context with the researcher’s aims
and objectives. Finally the process of the research is scrutinised, including the data
analysis technique.

1.4.3 Findings
Chapter four presents the results of the findings which were reached after analysis had
occurred. The three core categories or themes:

- Procuring the commodity of respite
- The order and chaos of respite
- Respite as restoration and biographical reconstruction for the carer
are shown which demonstrate the breakdown of subcategories and categories and how they were attained through the three stages of coding.

### 1.4.4 Discussion and emerging theory

Chapter five focuses on the conceptual thinking achieved through analysis and discussion of the findings. The research literature is examined and used as additional data to inform the emerging theory. Finally, the model of the theory generated from the research is disclosed with explanation of the tenets behind its conception.

### 1.5 Summary of the chapter

This chapter has provided an introduction to the thesis and the rationale for the original research concern. Respite has recently become a neglected area of care, especially in light of cost implications and the scarcity of bed provision. However, with the government’s health agenda shifting to emphasizing care in the community, respite may need to be reconsidered as an alternative to support patients and their carers. This introduction has also briefly discussed each chapter to contextualise it within the research frame as well as the researcher’s credentials and position.
CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This literature review aims to provide an overview of current research relating to respite care for patients with neurodegenerative diseases and their carers. Respite care will be examined in the broader sense, including consideration of adults with cancer, those with neurodegenerative diseases, mental health needs, learning disabilities and paediatrics as well as care services for older people. It is explored in relation to different groups of people and their care needs, thus reflecting the ethos of current respite provision.

Funding of respite provision will also be examined. A description of the search strategy is included along with the search findings. The overview will explore the current knowledge and intelligence and it will reveal gaps in the research. Finally an audit, carried out by the researcher, will be discussed which contextualises the beginnings of the research and the aim and objectives of the study will be introduced.

2.2 Search strategy

The search strategy was conducted using key words / text, in addition to utilising Boolean operators and MESH terms:

- Respite
- Respite care
- Carer and/or break
- Neurological / neurodegenerative disease(s)
Funding

Numerous databases were searched:

- Cinahl
- Cochrane
- Medline
- British Nursing Index
- ProQuest Nursing and Allied Health Source.

These were supplemented with hand searching and review of journal reference lists. Over 4000 references were found (see Appendix 2) but many of these were not specific to respite (i.e. the word ‘respite’ might be used as a general term and not as an intervention). Due to the large volume of literature identified, specific methods were employed in order to limit the search to more relevant articles, for example:

- a specific time period (1990 – 2014)
- identifying themes (listed below)
- seminal work was searched for relevant (and recurring) articles
- titles and abstracts were briefly reviewed and
- only scholarly articles and dissertations were included.

Further examination resulted in a division between research articles and review articles which were then summarised in grids to provide a quick reference guide for those pieces of work that were considered relevant and demonstrated key ideas or concepts.

An example of the research grid is shown in Appendix 3. To ensure the quality of
studies examined, the Critical Appraisal Skills Programme (CASP) framework was utilised to critically appraise the research studies (Appendix 4).

In addition, text books, including seminal work, were located and utilised with reference to (constructivist) grounded theory and symbolic interactionism.

The search strategy was developed around the following themes:

- Patient group of neurological / neurodegenerative diseases
- Neurodegenerative diseases and their palliative nature
- Concerns regarding access, availability and barriers of respite care
- Types / models of respite care available
- Funding of respite care

Inclusion criteria included:

- Written in English
- Studies / reports for children and adults accessing respite
- All research designs

### 2.2.1 Search results

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2.3 The literature review in grounded theory

2.3.1 The early literature review

Early thoughts on grounded theory stipulate that the researcher must begin with as few preconceived ideas as possible and that a literature review should be delayed until analysis of data has taken place (Glaser, 1978). It was felt that literature should be used to support and constantly compare data and then integrate into theory (Glaser, 1992) although Glaser later acknowledged that preliminary ‘reading’ would place any prospective study in context (Glaser, 1998). The fear is that a deductive stance will be taken with data if preceding knowledge is thought to be in existence (Cutcliffe, 2000) and this avoids speculation (Glaser, 1998). However, Dey (1999) points out that research should be approached with an open mind, not an empty head and previous knowledge should be used to inform our analysis but not direct it (Dey, 1999). In a similar vein, Cutcliffe (2000, p. 1481) alludes to the benefit of conceptual awareness if the literature is explored before the research, on which the remaining “emergent theory can be built”. Strauss cautioned against blocking ‘creativity and familiarity’ but welcomed “enhanced sensitivity to subtle nuances in data” (Corbin & Strauss, 2008, p. 37).

A brief literature review was initially conducted by the researcher prior to the study which served to highlight what was already known about respite provision, the chasms in current thinking and thereby inform the direction of this research (Hutchinson, 1993; Walls et al. 2010). Birks & Mills (2011, p. 22) refer to this as “a limited and purposive review which can assist the researcher”. A preliminary scan of the literature may be
considered essential in order to inform the original research proposal for the purposes of ethical approval and to ensure similar work has not been undertaken previously (McGhee et al. 2007). The researcher acknowledged her expertise within this area which was a reason to further explore any gaps in intelligence. It is not felt that the early literature review hindered or jeopardised a transparent approach to the research, but instead afforded the opportunity to study pertinent, previously unexplored areas related to respite care.

2.3.2 The later literature review

The initial review was widespread whereas the later review was much more focused on surfacing concepts and took on a much different angle; a process Charmaz describes as “travelling to new substantive terrain and scaling unimaginative theoretical heights”, which, if ‘thorough and sharply focused’ can ‘strengthen your argument and add credibility’ to the study (Charmaz, 2006, p.166). A grounded theory study creates theory from raw data as opposed to extant literature (Hallberg, 2010) but the literature can also be used as data (Walls et al. 2010).

A more comprehensive, thorough literature review was conducted towards the later stages of analysis as the theory was emerging. This served to weave into the theory generation and provide more data to compare (Glaser, 1998; Rintala et al. 2014) as well as providing a vehicle for engagement (Walls et al. 2010). As each new core category / theme evolved, the literature was searched to explore possible connections and
relationships. This was an exciting period of time as thoughts and ideas unfolding could be proved accurate, consistent or otherwise with existing literature. The harmony between conducting an early review to establish previous studies and the later review to add data to the emerging theory provided an appropriate balance and understanding of the literature (Giles et al. 2013).

2.4 Findings of the literature review

2.4.1 The differing models of respite

Informal caregiving involves ‘roles and tasks provided by the family and friends who give unpaid assistance to people in the community who are unable to fully care for themselves’ (Williams et al. 2009, p. 790). Respite care has acquired many definitions over the last decade. As people live longer (Gomes & Higginson, 2008) and medical care improves, the ongoing needs of the informal carers who provide 24 hour unpaid care to their loved ones should be considered. It has been referred to as the ‘cornerstone of care’ (McGrath et al. 2006, p. 147) and Lindsay (1996, p. 80) commented that respite care should “match the (patient’s) way of life and enhance it – not clash with it and create disharmony”.

The most frequently adopted (and adapted) definition of respite care is that proposed by Miller (1991) as “the temporary physical, emotional or social care of a dependent person in order to provide relief from care giving to the primary provider” (p.599) which is also supported and reiterated by Gilmour, 2002; Payne et al. 2004 and Skilbeck et al.
2005. Theoretically it can refer to ‘a pause, a temporary cessation or an interval of rest’ (Chappell et al. 2001, p. 202). The beneficiary of respite care is usually considered to be the informal carer (although there may also be benefits for the care recipient) (McNally et al. 1999; Ingleton et al. 2003; Mason et al. 2007; Ryan et al. 2008) by decreasing carer burden (McNally et al. 1999), promoting carer wellbeing (Horsburgh et al. 2002; Thurgate, 2005; Corkin et al. 2006), preventing breakdown of the caring home situation (Heaton, 1999; McGrath et al. 2006) and providing ongoing carer support (Heaton, 1999; Corkin et al. 2006; Green & Wakefield, 2006). The primary aim of providing respite support is for the patient to remain at home for long periods of time (Pomeroy et al. 1999; Chappell et al. 2001; Green & Wakefield, 2006; Russell, 2010) by providing the carer with time away from the caring role (Harding & Higginson, 2003; MacDonald & Callery, 2004; Dixon & Caradoc-Davies, 2005).

Respite has also been described as both a ‘service’ (depending on the setting) as well as an ‘outcome’ (relief from care giving) (Hanson et al. 1999; Chappell et al. 2001; Ingleton et al. 2003) where the benefits of additional therapeutic services (such as physiotherapy and occupational therapy) and interventions can also be accessed (Thurgate, 2005; Russell, 2010). Patients who receive respite care are generally not considered to be medically complex, (i.e. requiring significant medical intervention and symptom control) but more emphasis is put on rehabilitation of the patient and maximising functionality. Flexibility is considered crucial to the services offered (Corkin et al. 2006).
There has been minimal attention paid to, or studies looking at, respite services for patients living alone despite this being acknowledged as an area of increasing need (Payne et al. 2004; Barrett et al. 2009). Kristjanson et al. (2005) conducted a national descriptive survey of patients and carers of people with neurodegenerative conditions using numerous assessment tools (e.g. Symptom Assessment Scale (SAS), Hospital Anxiety and Depression Scale (HADS), General Health Questionnaire (GHQ)) in order to identify and compare the needs for supportive and palliative care services. One finding was the significant proportion of multiple sclerosis patients who were living alone with no carers at all. The benefit of receiving respite care when living alone would be from the context of their usual place of care and the opportunity for sign-posting them to ongoing alternative support such as befriending services and day services.

Respite care is notoriously associated with ‘crisis intervention’ when the caring role breaks down at home (Hanson et al. 1999; Thurgate, 2005). Lack of general availability of services results in situations becoming extreme which will then activate emergency support. In their quantitative survey, McConkey et al. (2011) looked at a national database of 4000 families in the Republic of Ireland who had an intellectually disabled child. The purpose of the survey was to explore the proportion of carers who had access to ‘respite’, which was identified as a break outside of the family home. Results indicated that one in four carers had access to respite but the national database where this was extracted from had limitations relating to the amount of data available and
recorded. It demonstrated that carer crisis admissions were low if respite breaks were able to be planned in advance.

2.4.2 The interventions and elements of respite

Respite services may not necessarily be a ‘discrete intervention’ (Mason et al. 2007) (i.e. one defined area of care) but are frequently a range of services in a variety of settings, for example, day care in a centre on a weekly basis, intermittent care in the person’s home, which may be a few hours at weekly intervals or residential care in an institution, which can be from a few days to two weeks (Horsburgh et al. 2002; Gilmour, 2002; MacDonald & Callery, 2004; McGrath et al. 2006; Mason et al. 2007). It is important that the correct service is used in a timely fashion in order to provide the appropriate support needed for the carer (Albinsson & Strang, 2003; Payne et al. 2010a & 2010b). McCabe et al. (2008) conducted a study which looked at the services accessed by 41 carers of people with multiple sclerosis (MS), motor neurone disease (MND), Parkinson’s disease (PD) and Huntington’s disease (HD) and their level of satisfaction. The study provided a balanced view of patients, carers and professionals. All of the groups of participants acknowledged the need for all different types of respite care in order for the carers to cope with their individual needs which ranged from basic practical services (e.g. home help) to more specialised services (e.g. support groups).

In one study of 296 carers for dependent older people, (Carretero et al. 2007), intermittent care (home respite), which provided infrequent and minimal spare time to
carers, (a few hours on an infrequent basis) was not considered adequate to allow caregivers any significant benefit. Contrary to this, overnight support was looked at in different areas of care (paediatrics and palliative care) and different settings (institution and home), and was felt to be very beneficial in order to enable caregivers to continue their role during the day with minimal professional input. It provided regular, longer episodes of time when the caregiver could achieve a period of rest (MacDonald & Callery, 2004; Kristjanson et al. 2004; Green & Wakefield, 2006). Skilbeck et al. (2005) prospective study explored the experiences of 25 carers whose relative had been admitted to the local hospice for planned inpatient respite care. One finding was that the carers were extremely satisfied with the high standard of nursing care and rehabilitative opportunities provided by the hospice and over half of them commented that it was superior to that perceived by the carers to be given in the local nursing homes which were the only other alternative for respite care available. A review demonstrated that residential respite care did not meet the expectations of either professionals or patients. Many patients access residential respite in nursing homes where there is a lack of understanding relating to mobility and behavioural problems as well as little or no access to specialist advice and support (Ward et al. 2003).

A study by Jones et al. (2007) identified access to appropriate and timely respite care as being an area of concern for adults with an acquired neurological condition. Respite care came from residential and nursing homes with standard basic nursing care and no additional therapeutic or rehabilitative assessments or interventions (Ward et al. 2003).
Unlike the care homes, hospice was felt to offer continuity of care and rehabilitation facilities which the carers felt were very important and offered in a positive atmosphere (Skilbeck et al. 2005). Access to therapeutic interventions, such as physiotherapy, dietetics and occupational therapy was felt to be beneficial to patients in order to prevent further deterioration of functional capacity (Pomeroy et al. 1999; Kersten et al. 2002; Russell, 2010). The study by Pomeroy et al. (1999) looked at 81 elderly people from 12 clinical centres that had dementia and experienced a mobility problem. The findings showed that there was only a small level of improvement in walking distances for those patients accessing regular physiotherapy intervention which was not statistically significant. It must be remembered that this is only one aspect of rehabilitation and therapeutic services and these patients had a diagnosis of dementia which may affect their functional ability. Similarly, Gilmour’s study (2002) explored 9 family caregivers’ experiences using critical discourse analysis. The results demonstrated that patients may decline in performance and ability to perform activities of daily living after a residential stay in a care home.

For long term conditions such as multiple sclerosis (MS), residential care was considered to be essential for the carer due to the physical burden of caring and the need for a rest (Russell, 2010). Flexibility and being responsive to individual needs were considered important in the provision of services, relating to settings, timings and frequency (Twigg & Atkin, 1994; Ashworth & Baker, 2000; Damiani et al. 2004; MacDonald & Callery, 2004; Dawson et al. 2004; Thurgate, 2005; McGrath et al. 2006; Jeon et al. 2007; Arksey
& Glendinning, 2007; Shaw et al. 2009; Russell, 2010; Mutch, 2010). Providing regular respite was key to avoiding crises in children with complex health needs (Thurgate, 2005).

An increased focus on providing respite care in the home setting on a regular basis for those considered to be at the end of their life was noted in Skilbeck et al. study (2005). The amount of respite time offered was sometimes limited to yearly which was of minimal use for patients felt to be nearing death. In addition, ‘coordination, collaboration and integration between sectors’ were thought to be essential to meet the patients / carers needs and identify shortfalls in service provision (Horsburgh et al. 2002; Aoun et al. 2006). Carers felt that a health care professional who had a coordinating role would be beneficial in providing timely and accessible advice and information (Brown et al. 2006; Jones et al. 2007). The involvement of patients and carers in service design and development was felt to be essential to achieve high quality, responsive, individualised care (Brown et al. 2006), although there is scant evidence of this happening in practice. Information about the services available was considered to be vital (Nolan & Grant, 1992; Damiani et al. 2004; Skilbeck et al. 2005; Arber et al. 2010; Stockwell-Smith et al. 2010). Poor communication and information were identified as very stressful and a barrier to accessing respite care (Twigg & Atkin, 1994; Thurgate, 2005).

Payne et al. (2004) sent a structured questionnaire to 242 clinical service managers to explore specialist palliative respite provision in the UK. This survey showed that planned
admission for respite care is very rarely offered in favour of symptom control or terminal care, however Barrett et al. (2009) conducted a study (n=41) looking at the implementation and evaluation of an at-home palliative care respite service which showed that patients were five times less likely to be admitted to an acute hospital if they accessed the service. It can be concluded that the benefits of offering this type of service are potentially cost effective.

Respite care is felt to be more likely to keep patients in their own home, thus avoiding long term placement, so should be considered an essential component of palliative and end of life care services (Chou et al. 2008; Lyons et al. 2009; Bamford et al. 2009; Downes, 2013; Geiger & O’Neal, 2014). In the study by Chou et al. (2008) 116 family carers living with an adult with intellectual disabilities were surveyed regarding the respite programme they had utilised. The carers were able to comment that before they accessed respite, 60% of them had been considering placing their relative in full time residential care due to their inability to continue with the caring role. In a similar vein, the study by Lyons et al. (2009) used an interactive research methodology to gain an understanding of how service users with mental health issues and their carers define a crisis and what range of services is available. Two hundred and twenty questionnaires and group meetings were the methods of data collection and they showed that the patient and caregiver situation had to deteriorate to a point of crisis (inability to sustain care at home) in order for services to be mobilised. This could be said to demonstrate reactivity as opposed to proactivity (Hanson et al. 1999). A service which responds to the
needs of the patients and carers is ultimately much more preferable to that of the users having to ‘fit’ into a service that is available which may not suit their needs (Thurgate, 2005). Furthermore, Evans (2013a) implied that respite could be seen as a complex intervention and any framework devised would not suit everybody as people were unique in their needs and likely outcomes.

2.4.3 Rationale for accessing respite

The literature showed several reasons for possible uptake and need for respite care. One of the main reasons for palliative patients to be admitted to hospital towards the end of their lives is due to the carers being unable to maintain the caring role (Hinton, 1994; Payne et al. 2004; Faithfull et al. 2005; Lyons et al. 2009). Regular respite would allow a pre-planned opportunity to give carers a break from the role of caring which would aid their ability to continue (Boeije et al. 2003; Kristjanson et al. 2004; McGrath et al. 2006; Russell, 2010; Downes, 2013) and equally important was the chance to allow carers to manage other routine aspects of their life (Payne, 2006). Younger carers are often parents to children and dividing their time between their responsibilities can be stressful and wearing (Skilbeck et al. 2005). This was a particular issue with carers of those with neurodegenerative diseases, for example, MND, HD and MS, who were more likely to be younger.

Patients are more able to stay at home, if that is their preferred place of care, if their carers receive regular respite (Kristjanson et al. 2004; Barrett et al. 2009). An interesting
study by Grande & Ewing (2008) showed that if carers did not concur with the patients’ preference to die at home, it was considerably less likely to happen.

Carer burden was a frequent feature in the literature. It can manifest itself in many ways – physically (e.g. fatigue, insomnia, ill health), psychologically (e.g. stress, anxiety, anger, depression) and by becoming socially isolated from usual normal activities (MacDonald & Callery, 2004; Kristjanson et al. 2004; Faithfull et al. 2005; McGrath et al. 2006; Corkin et al. 2006; Carretero et al. 2007; Chou et al. 2008; Barrett et al. 2009; Payne et al. 2010a & 2010b). Cope (2003) conducted a survey of 1005 caregivers and identified that most of them assisted patients with four or more activities of daily living. They requested the need for respite but this has never been considered a priority for health care insurance companies in America. In another study 77.6% (n=90) of carers reported dissatisfaction with their lives which improved considerably after accessing different forms of respite services depending on their individual needs (Chou et al. 2008). A high level of burden may lead to carers being unable to sustain the caring role (Kristjanson et al. 2004). Psychological morbidity was seen in the study by Payne et al. (1999). They used the General Health Questionnaire (GHQ) and the Caregiver Strain Index (CSI) which showed 84% (n=33) of carers scored highly in relation to distress and 41% (n=16) scored over the average for strain. Other studies reviewed by McNally et al. (1999) and Thurgate (2005) showed that an improvement in psychological well-being was not congruent with respite care, though, conversely, Salin et al. (2009) felt that respite care had a major positive influence on informal carers’ quality of life. In addition, if carers do
get benefit from respite it may only be short lived (McNally et al. 1999). One clearly identified aspect was that carers’ needs should be assessed on an individual basis (i.e. not in conjunction with the patients’) (Payne, 2006; Grande et al. 2009).

Several studies of patients with neurodegenerative conditions noted that carers identified specific benefits from accessing respite care. Kersten et al. (2001) conducted 61 face to face interviews with disabled patients and their carers who reported that the most unmet needs included short breaks and respite care which were so beneficial in reducing social isolation for both carer and patient. Ashworth & Baker (2000) undertook a qualitative study with 23 carers of patients with various conditions in order to ascertain their experiences of respite care. Themes were identified from the transcripts and respite care emerged as an opportunity to escape and be ‘normal’. Other studies showed respite care as beneficial in creating a distance from their caring role (de la Cuesta-Benjumen, 2011) and in keeping them motivated to care (Mutch, 2010).

Research surrounding the respite needs of children’s carers highlighted the importance of considering the non-affected siblings in a family. Time out offered by respite services was needed to continue to be a family and residential respite for the ill child was preferred for this reason (Horsburgh et al. 2002; Damiani et al. 2004; MacDonald & Callery, 2004; Thurgate, 2005; Corkin et al. 2006). Additionally, the sick child was also able to meet children in similar situations and this enhanced the social dimension for them (Damiani et al. 2004).
If patients have increased physical care needs (e.g. higher disability, increased dependency, incontinence) then respite services are more likely to be accessed (Damiani et al. 2004; Barrett et al. 2009; Takai et al. 2013) than those who have lower dependency needs due to the increased physical burden on the caregivers. In addition, if the patient had advancing disease and / or the carer was older there was a more identified need for respite. Conversely, if patients or carers did not request services it might be (wrongly) assumed that they were coping and did not require further support (Aoun et al. 2006). Furthermore Mast (2013) conducted a literature review of factors influencing family caregivers’ use of support services and noted that respite was deemed beneficial especially in the early days because it decreased carer burden and improved their mood and quality of life.

There were no significant age or gender differences in access to respite although it was noted that the majority of informal carers are women, especially as a longer life expectancy means they maybe more accepting of this role (McNally et al. 1999; Payne et al. 2010a & 2010b).

2.4.4 Respite for the patient and / or carer

When planning for respite services, it should be considered who the services are for, the carer and/or the patient. Both need to be sure and trusting of the facilities and services available and how they might meet their individual needs (Jeon et al. 2007; Greenwood et al. 2012). There is no significant evidence to support the benefits of respite care for
caregivers, especially in quantitative research. This may be due to the carer experiencing an increased workload in preparation for the respite stay, disruption to their and the patient’s normal routine and an overwhelming feeling of guilt at ‘letting go’ of the caregiver role. Knight et al. (1993) reported in their meta-analysis of randomised controlled trials that respite care did not show a significant benefit to the carer except for a moderate improvement in caregiver distress. Conversely, Ashworth & Baker (2000) interviewed 23 carers about their experience of caring and respite care and overall they report it was felt to be intrinsically beneficial and brought some normality back into their lives. Similarly Shaw et al. (2009) acknowledged that respite is an unmet need but there is no economic analysis and minimal research available at the present time. It might be difficult to cost the benefit(s) of respite care. Potential indicators may be too subjective and difficult to measure such as an improvement in functioning and preventing repeated hospital admissions.

Harding & Higginson (2003) commented on the ‘unique position’ of the carer being seen to ‘provide and need support’ and conducted a literature review which addressed the varied ways in which carers could be supported. There were questions about the need to provide additional clarity regarding the outcome of the intervention / support services and what was trying to be achieved by offering interventions such as respite care. If there were answers to these concerns this could provide an appropriate benchmark for respite to be measured against.
Overwhelmingly the literature highlights that the majority of carers are women (McNally et al. 1999; Carretero et al. 2007; Payne et al. 2010a & 2010b). This may be due to women historically being seen in the caring role (McNally et al. 1999; Payne et al. 2010a & 2010b). In a study looking at carers of patients with Huntington’s disease, male carers found the caring role particularly difficult and required time out and more practical support (Dawson et al. 2004), although there do not appear to be any studies looking at aspects such as differences in expectations related to gender. Respite services are more likely to be used by middle class families as they tend to be more aware of their rights and are willing to ask for support (Chou et al. 2008) although conversely Thurgate (2005) stated that in children’s care it was considered that more people from social class III accessed respite care. This was not written about in the literature but anecdotally those accessing hospice respite care are noted to be either of a higher social class or those from a younger age group (Personal communication, 2012). There is little mention of ethnic minorities or diverse groups accessing respite.

In some cases patients might be the main beneficiaries of respite. In large cities it is not uncommon to find a big proportion of society to be living alone and this is significant when considering respite care services. There are occasions when respite may provide an intervention for the patient from the context of their usual care and also help reduce social isolation (Kristjanson et al. 2004; Payne et al. 2004; Payne, 2006). The patient may need the opportunity to have a general overview of their current condition without major identified symptom problems (Kristjanson et al. 2004; McGrath et al. 2006).
Accessing interventions, functional and medication reviews can be valuable whilst still promoting routine and well-being.

The research does not look in depth at what respite care is for the patient. One paper commented that some activities made available for patients in respite were childlike and meaningless (Stockwell-Smith et al. 2010; McConkey et al. 2011) and one paper mentioned the need for a rehabilitation focus (Jones et al. 2007).

Neville et al. (2014) conducted a literature review of the use of respite by carers and commented on the benefits to the patient by providing assessment, socialisation and stimulation and also for the carer who could rest and attend to their own self care needs but a prerequisite for the carer was knowing their loved one was receiving good care. Finally, Evans conducted a concept analysis and proposed a model that suggested respite was of potential benefit for both the patient and the carer and the outcome consisted of much more than a break from caring (Evans, 2013a). He also referred to the relationship between the patient, carer and professional that could influence the overall outcome depending on how strong and mutually effective the developing partnership was (Evans, 2013a).

### 2.4.5 Desirability and legitimacy

A study by Nolan & Grant (1992) looked at how successful residential respite care could be, depending on the ‘desirability and legitimacy’ of the patients. This refers to the
patient’s perception of the move to respite being to their advantage and a worthwhile thing to do. If the patients were willing to go in and understood the ‘concept’ (the reason for the admission), the respite care would be more successful and anticipated in a positive fashion, as opposed to patients who really did not want to enter the facility and were nervous of the potential outcomes (e.g. permanent institutionalised care).

It is noted that in the literature pertaining to neurodegenerative conditions, there is scarce mention of the patient. The focus is on the carer and their need for respite. It is acknowledged that patients with neurological conditions have carers who may be younger and there may be young children to be cared for, especially in diseases such as Huntington’s disease (Aubeeluck, 2005) where onset may occur at a younger age. In addition, there may be a role reversal relating to the main breadwinner of the family and this brings with it the potential for significant financial difficulties (Aoun et al. 2006; McCabe et al. 2008; Mutch, 2010). Tailored respite (i.e. access to services which addresses individual psychological and physical needs, as well as adaptation to a progressive illness) was identified as the single most relevant service that enabled carers to continue (McCabe et al. 2008; Aoun et al. 2011).

Bed availability for respite care was generally scarce and it was not necessarily viewed as a specialist palliative care need despite symptom control often being an essential part of the care package (Damiani et al. 2004). In their conceptual mapping exercise on respite care, Wolkowski et al. (2010) discussed the lack of respite inpatient beds which can be due to priority being given to symptom control and terminal care admissions due to the
perceived specialist nature of the care of patients with neurological illness. Paradoxically respite care can be considered to be ‘complex and specialist’ in nature due to the levels of intervention required depending on the illness and its stage (Horsburgh et al. 2002; Owen & Johnson, 2005; Thurgate, 2005; Satterley, 2007; Grande et al. 2009; Russell, 2010).

In neurological diseases researchers have noted that there was a heavy reliance on nursing and residential home provision of respite as there was limited hospice availability for respite care. This was due to the strict limiting criteria for admission which focused on symptom control and terminal care needs (Dawson et al. 2004; Brown et al. 2006; Jones et al. 2007). ‘True’ respite care is considered by some to consist of no intervention, symptom control or changes during their stay (Satterley, 2007). However, for some conditions, (e.g. paediatrics, oncology, elderly care) respite care might mean interventions such as regular review of complex medication regimes and constant supervision (Corkin et al. 2006). These differences demonstrate the lack of understanding and clarity surrounding the meaning of respite. This lack of clarity may potentially lead to poor referrals and inappropriate resource allocation as very little emphasis may be placed on this important area of care and the tailoring of respite care to meet different types of complex need.

Studies reviewed by McNally et al. (1999) demonstrated that respite care could influence the direction regarding permanent residential care for the patient, both in
support of it and also rejecting it as the carer had been able to revitalise themselves and be able to continue in the caring role. A review conducted by Mason et al. (2007) showed there was slightly less likelihood of a patient being institutionalised if the carers accessed regular respite. Equally, Boeije et al. (2003) and Jeon et al. (2007) reported a real fear amongst patients that if they accept residential respite care, it would lead to permanent institutionalisation which created a barrier.

In a study by MacDonald & Callery (2004) and a review by Thurgate (2005), it was evident that the parents’ perceptions of what paediatric respite should be (a residential break) was significantly different from the health care professionals’ perceptions (respite in the home). This was because removing the child from the family home was felt to be detrimental and overnight respite could be arranged by bringing someone into the home. Conversely the parents felt they needed a complete break in order to experience some form of normalcy within the family unit, especially if there were unaffected siblings, albeit for a short period of time.

The respite referral process is often formalised via a health care professional as self-referral is rare (Payne et al. 2004). Patients / carers often have to fight to get access to these scare resources and to find information on what is on offer (Damiani et al. 2004). They are generally patchy and fragmented and frequently unavailable for patients and caregivers which are another example of a postcode lottery when considering availability (McGrother et al. 1996; Wiles et al. 1999; Raynes et al. 2000; Kersten et al.)
2.4.6 The barriers and facilitators of respite

The literature referred to several barriers to accessing respite care. The competency and level of skill of the care providers as well as the quality of care given was a major concern for the informal carers and an important factor in determining where / whether the patient accessed the service (Twigg & Atkin, 1994; Hanson et al. 1999; Horsburgh et al. 2002; Gilmour, 2002; Damiani et al. 2004; MacDonald & Callery, 2004; Thurgate, 2005; Jeon et al. 2007; Russell, 2010; O’Brien et al. 2012a). This could have repercussions relating to caregivers not accessing services at all due to minimal faith in caregiving qualities. Foley et al. (2014) referred to the need for patients to develop trust and a sound relationship with health care professionals in order to be willing to engage in respite. Barrett et al. (2009) in their study demonstrated that carers were more satisfied with the level of caring when qualified staff were utilised, though conversely, unqualified carers used in a separate study demonstrated that care given was of an equally high quality and well accepted by informal caregivers (Green & Wakefield, 2006). It was shown that if caregivers feel uncertain about the quality of care, they will visit frequently to check up on the patient instead of using the time to restore their energy levels (Gilmour, 2002; Takai et al. 2013). In addition, carers felt that the additional work and stress that was entailed in order to organise respite care was not worth it (Williams et al. 2009; Mutch, 2010). They tended to deny the need
for respite to avoid any additional workload and frustration and any perceptions that they are not coping (Brown et al. 2006; Stockwell-Smith et al. 2010). Hughes et al. (2005) looked at the lived experience of the care given to MND patients by interviewing 9 patients, 5 carers and 15 professionals. The carers demonstrated that they felt that there was a general lack of knowledge about the neurological condition by health care professionals which was a major barrier for carers. Similarly, a qualitative study exploring the views of support services for family carers of patients with MND demonstrated that there was concern that respite facilities would not have the required level of expertise to care for these patients but if they did this had a positive impact on the experience (O’Brien et al. 2012b).

Often due to other commitments and having to attend to personal issues, getting a rest was not always an option during planned respite stays (Skilbeck et al. 2005) though the majority of carers did feel able to recommence their caring roles after the admission. Greenwood et al. (2012) also suggest that for some, respite afforded a sense of independence to do what they desired but for others it was the overwhelming guilt that prevented them from enjoying the time away from caring. Furthermore their conclusion was that there remains a lack of clarity around positive outcomes from respite which may be distinctive for each individual and therefore impossible to generalise (Greenwood et al. 2012). More sophisticated planning for respite admissions could enable the carers to make better, more effective use of their time (Hanson et al. 1999). Similarly, in the papers by McNally et al. (1999) and Payne (2006), studies showed that
carers were not making the best use of the respite and were not accessing social activities or support which may be considered advantageous for the future. This may also be because they were unsure what to do in a limited time period and had been out of their social network for some period of time.

Informal carers are usually ‘expert’ in their area of care - they know what the patient likes / requires and professionals being able to replicate this care is vital for the establishment of a trusting relationship between the caregiver and the professional (Thurgate, 2005; Salin et al. 2009). Lack of an appreciation of this and the feeling of not being heard can lead to the caregiver not accessing these services (Hanson et al. 1999; Gilmour, 2002; Jeon et al. 2007). In addition, a ‘clash of cultures’ resulted when formal carers disregarded the informal carers’ knowledge and information regarding the patient (Stockwell-Smith et al. 2010). This led to a general distrust of formal carers. Furthermore, Mast (2013) in a literature review found a recurring theme that carers were more likely to use respite facilities if providers took time and effort to understand the patient and their routine and habits. Learning is required on both sides in order to accept care that may look different from that routinely provided at home (Gilmour, 2002). The End of Life Care Strategy (DH, 2008a) supported this by referring to carers being viewed and treated as ‘co-workers’, a concept initially mentioned by Twigg & Atkin (1994) which refers to agencies viewing carers as working alongside and being ‘interweaved’ with the formal carers work.
Priority for respite care in hospice is generally given to patients nearing the end of life, potentially excluding those with long term conditions who are also in need of respite (e.g. dementia care and neurological conditions) (Green & Wakefield, 2006; Grande et al. 2009). Even when services had been highly rated in studies (Skilbeck et al. 2005) carers still experienced feelings of guilt at leaving their loved ones due to their commitment to their role (Hanson et al. 1999; Russell, 2010; O’Brien et al. 2012b; Mast, 2013), though paradoxically a reason mentioned for respite provision was that patients frequently felt guilty about the caregivers burden of caring for them and wanted to access respite services to allow their carers to take a break (Payne et al. 1999).

Relinquishing care also led to disruptions in the patient’s routine which was often not seen as beneficial by both patients and carers (Ashworth & Baker, 2000; Herz et al. 2006).

Another barrier to accessing respite services is the lack of understanding of what is available (type of service), to whom (type of condition / disease) and when (frequency of respite care) (Hanson et al. 1999; Horsburgh et al. 2002; Jeon et al. 2007; O’Brien et al. 2012a). Patients and carers are woefully ill-equipped to make decisions about support services such as respite and often spend precious time chasing information (O’Brien et al. 2012a & 2012b). More information is required for patients and carers to allow choice and opportunity.
Culturally, there may be obstacles to accessing respite because of the belief that it is the extended family’s role and one’s duty to care for the sick person (McGrath et al. 2006). Finding out what support and respite care people with different religious and cultural beliefs may accept is imperative to meeting the needs of our diverse population (Griffith, 1993; Ashworth & Baker, 2000; Horsburgh et al. 2002; Shaw et al. 2009; McConkey et al. 2011).

2.4.7 Funding for respite care

Direct payments were originally introduced to promote control and choice in service provision for people with learning disabilities (DH, 2005b). In order to extend the choice agenda to older and disabled adults, personal (or independent) budgets (PB’s) were developed which combined resources from all streams of funding and could be used creatively by the service user(s) to establish flexible, individual support plans (Moran et al. 2013). The hope was that they would provide ‘choice and opportunities’ for the carers (Beresford, 2011/12). Research showed that some patients and carers did not want to have the responsibility of their own budget and the consequent auditing, whilst those that were in favour frequently still required input from health care professionals to help guide decisions on care provision (Moran et al. 2013; Gridley et al. 2014).

Allocation of monies from personal budgets for carer’s schemes, including respite care, has been reported as being used with moderate success in order to support carers’ well-being (Sutcliffe et al. 2012). Empowerment of carers to manage resources according to
needs has been seen as a positive move but has also brought uncertainty and constraints alongside which may have added to the burden that carers face within their role (Beresford, 2011/12; Larkin & Milne, 2013). It has also been noted that services may not be available to support demand and choice (Sutcliffe et al. 2014). The funding process for continuing care and personal budgets is illustrated in Appendix 5.

2.5 Methodology used by researchers

Qualitative research is the methodology of choice mostly frequently adopted for respite care research. Interviews, (Vähäsantanen & Saarinen, 2013) sometimes in combination with focus groups or non-participant observation (Charmaz, 2006, p.21), tends to be the methods used for qualitative data collection. This may be due to the research focusing on carers’ experiences and therefore semi-structured interviews and focus groups are ideal methods to obtain the level of information required. Much less common is quantitative research, although there have been a few surveys conducted, especially in relation to carers. Finally mixed methods have had a small but significant part to play in research methodology. This approach has consisted of a mixture of interviews, surveys, assessment tools or outcome scales which have provided rich data on several aspects of respite care (Birks & Mills, 2011).
2.6 Conclusions of the literature review

Several studies have demonstrated similar themes, particularly those relating to:

- Varied availability and access to respite provision (e.g. Jones et al. 2007; McCabe et al. 2008)
- A need for more information regarding respite care and how to access it (e.g. Skilbeck et al. 2005; Arber et al. 2010)
- A need for flexibility and responsiveness to carer needs (e.g. Payne et al. 2010a & 2010b)
- The issues of carer burden and the caring role (e.g. McNally et al. 1999; Harding & Higginson, 2003)
- The numerous barriers to accessing respite care – both from service provision needs and carers reluctance/uncertainty (e.g. Knight et al. 1993; Payne et al. 2004; O’Brien et al. 2012a & 2012b).

The above inform our knowledge and sense of the importance of respite care but there are clearly identified gaps in the literature, which would benefit from further studies. There is minimal research on how the patient living alone could access respite care. Similarly, there is little research focusing on the patient benefit and different programmes of care in respite care provision. Respite is an opportunity for comprehensive assessment and interventions regarding care in a safe environment, but it is unclear what happens during the respite experience and what models of care provision exist and in what circumstances this service is used. Being able to study the
components and ingredients that make up respite care would be beneficial in
developing models of care to suit individual patients. There are varied thoughts about
what respite achieves and what patients and carers expect from a respite experience.

There is a lack of robust studies relating to cost effectiveness of respite care. In these
lean economic times, it is essential to be able to offer a service which is beneficial in
patient and to carers, which also makes financial sense. In a similar vein there is little
research available relating to navigating the complex health care system in order to
ascertain appropriate and timely information about the availability of respite.

The literature related to those with neurodegenerative diseases (NDD) and respite is
varied and sparse. Those with NDDs have divergent needs, which change on a
continuous basis and require extensive support from health care services. Many of those
with NDD are cared for by informal carers who also crave information and assistance.
Finally the literature suggests that planned respite reduces emergency and crisis
admissions (McConkey et al. 2011) but there is no clear guidance or recommendations
on length of time spent in respite, the frequency of access and how access is achieved.
There are inequities of access for many culturally diverse and ethnic groups (Shaw et al.
2009 and McConkey et al. 2011) as well as geographical challenges of accessing services,
for example in rural areas (McGrath et al. 2006).
2.7 A timeline for developing non-malignant palliative care

Palliative care has traditionally focused on patients with cancer although as far back as 1963 Hinton stated that discomfort was not necessarily greatest patients dying from non-malignant diseases ‘were just as likely to have distressing symptoms but less likely to have them relieved’ (Hinton, 1963, p.6). There has been much recognition over the years of the need for palliative care to address non-malignant diseases (Wilkes, 1982; Saunders & Baines, 1983; Hockley et al. 1988). Possibly the most influential driver was the SMAC/SNMAC report (Standing Medical Advisory Committee & Standing Nursing and Midwifery Advisory Committee, 1992) which recognised the much wider scope for palliative care. Two of the report recommendations were:

- All patients needing them should have access to palliative care services
- Although often referred to as equating palliative care with terminal cancer care, it is important to recognise that similar services are appropriate and should be developed for patients dying from other diseases.

Despite this early report there remained reluctance by the NHS to shift resources to a new area of ‘specialist palliative care’ which had no previous record of short, medium and long term outcomes (Dunlop, 2001).

Later research showed that patients with non-malignant illness and their families should have the opportunity to embrace autonomy and choice which was central to the palliative care philosophy (Addington-Hall, Fakhoury & McCarthy, 1998). Similarly
Addington-Hall & Higginson (2001) called for more comprehensive models for caring with patients that had complex long term conditions. A report developed by the National Audit office (DH, 2011) demonstrated a need for expert knowledge and support from neurological diagnosis onwards, support of family and carers and the importance of patient centred care.

2.8 The respite audit

Reflection around the provision of respite brought the realisation that there was no baseline datum available for the researcher to work from. Prior to the development of the research question an audit was conducted to ascertain the use of beds for respite within a large East London Hospice.

The aims were to:

- Determine what type of patients were being referred for a ‘respite’ admission
- The actual reason for admission (determined at initial assessment)
- The length of stay
- What their needs were during admission
- The outcome of the admission

2.8.1 Method:

Details of all patients referred for ‘Respite care’ to the hospice over a 12 month period was obtained from the electronic PalCare data system and clinical notes were accessed.
A proforma was developed to obtain relevant information.

2.8.2 Results:

- 55 patients were referred, 12 sets of notes were missing and out of the remaining 43 patients, only 27 (63%) were admitted for ‘Respite’ over the 12 month period (16 patients (37%) were not admitted due to no bed availability, they were undergoing active treatment with curative intent or their family declined admission)
- The majority had cancer and were referred by the acute hospital doctors or GPs
- 18 (67%) lived with a carer and 9 (33%) lived alone
- Length of stay ranged from 1 - 85 days (mean 19 days)
- 13 patients had a pre-determined date of discharge, 3 died and 10 were discharged
- 14 patients had no pre-determined date of discharge, 8 died and 3 were discharged
- 70% of patients had physical problems on admission
- 40% had a documented recent deterioration

Table 2.1: Pre-determined date of discharge

<table>
<thead>
<tr>
<th></th>
<th>Pre-determined date of discharge? YES</th>
<th>Pre-determined date of discharge? NO</th>
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<tbody>
<tr>
<td>Died</td>
<td>13 (48%)</td>
<td>14 (52%)</td>
</tr>
<tr>
<td>Discharged</td>
<td>3 (23%)</td>
<td>8 (57%)</td>
</tr>
<tr>
<td>Transferred</td>
<td>10 (77%)</td>
<td>3 (21.5%)</td>
</tr>
<tr>
<td>Transferred</td>
<td>0</td>
<td>3 (21.5%)</td>
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Table 2.2: Proposed reason for admission (based on assessment on admission)

<table>
<thead>
<tr>
<th>ACTUAL REASON FOR ADMISSION</th>
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</thead>
<tbody>
<tr>
<td>Respite</td>
<td>12 (44.5%)</td>
</tr>
<tr>
<td>Symptom Control</td>
<td>10 (37.5%)</td>
</tr>
<tr>
<td>Terminal Care</td>
<td>5 (18%)</td>
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</tbody>
</table>

2.8.3 Discussion

The results revealed that few patients were admitted for genuine respite reasons. There were often underlying problems with symptoms and a general deterioration in their condition. This created interest in the reasons patients may seek respite, what they wanted to achieve from it and how, from a professional stance, it might be a missed opportunity to review their condition in order to avoid crisis situations occurring. The findings suggest that those patients who had their admission planned with a pre-determined date of admission and discharge were probably more suitable for a ‘respite’ admission. What was also evident was that patients often lived alone and still desired respite, which was a shift away from original thinking, that respite was solely for the carer.

The limitations to this audit included relying on a data collection system that was not sophisticated enough to record and report accurate details and the written documentation was poor in some cases, leaving interpretation open to debate. This audit was published as part of the Doctorate requirements in a recognised specialised European palliative care journal (Laverty, Faithfull & Arber, 2013).
2.9 Summary of the chapter

An initial literature review was conducted in order to scope the existing literature prior to the final decision regarding the research question and areas of interest. A later literature review was conducted as the theory began to emerge and was constructed. A wide range of articles and books were reviewed; key words and phrases were adopted and all types of respite care were examined to ensure adequate breadth and depth to the literature review. In addition, in order to inform the research questions and depth of problem a local audit was conducted which was subsequently published.

The findings from the audit, the researcher’s existing knowledge and the information from the early literature review combined to create the aim of the study and the research questions.
2.10 The research aim and research questions

Table 2.3 depicts the overall aim of the research study and the associated research questions.

Table 2.3: Research Aim and Research Questions

<table>
<thead>
<tr>
<th>RESEARCH AIM</th>
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<tr>
<td>To determine what residential respite care offers patients with neurodegenerative diseases and their carers.</td>
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</table>

<table>
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<tr>
<th>RESEARCH QUESTIONS</th>
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<tbody>
<tr>
<td>🌟 What is the patient’s experience of a respite admission?</td>
</tr>
<tr>
<td>🌟 What are the issues and concerns for carers in relation to respite?</td>
</tr>
<tr>
<td>🌟 How can respite be used to provide a therapeutic outcome?</td>
</tr>
</tbody>
</table>

The next chapter will explore the methodology and methods employed in order to conduct the research study.
CHAPTER 3: METHODOLOGY AND METHODS

3.1 Introduction

This chapter will provide an overview of the methodology and methods chosen for the study and the rationale to support these choices. Details of the research process undertaken will be explored, including the theoretical framework, data collection stages, analysis, ethical considerations and reflective actions.

3.2 Research design

The research design should be determined in response to the research question (Bryman, 2008; Silverman, 2011). It was proposed that a qualitative exploratory study, which sets out to understand the respite experience of patients and their carers, would be appropriate. The literature provides much information about carers in supporting the concept of respite but there is very little regarding what the patient is able to achieve from a period of respite and any opportunities for improving quality of life and functionality.

Data collection was planned for a period of one year and originally involved patients and carers who are under the care of the National Hospital for Neurology and Neurosurgery (NHNN). However, this did not produce sufficient participants so the geographical area was widened to include a hospice and a community service in south east England.
The researcher was aware that she had some existing knowledge of respite and patients with neurodegenerative diseases and felt it was important not to disconnect that from the process of learning through research. The researcher should acknowledge and embrace what they bring to the research and how they might influence it (Licquirish & Seibold, 2011). It felt inappropriate to attempt to ‘bracket off’ knowledge, thoughts and experience, instead openly acknowledge them in the research process and consider how they enhance what was learnt from the participants. This lends itself well to the grounded theory approach. The researcher’s experience with respite had led to the initial tentative thought that respite can be a beneficial intervention for both the patient and the carer. Inequity of access is a problem and consideration of how this can be remedied is important. In addition, the actual elements of care that are offered during a respite admission were of interest. Therefore a study focusing on respite care from the perspective of those with neurodegenerative diseases and their carers was thought to be an appropriate avenue of exploration.

3.3 Methodology

3.3.1 Quantitative Research

A positivist approach to research is concerned with determining the truth in a systematic manner. It is objective and deductive in nature and is usually generalizable to many situations that share the same characteristics. It tends to focus on numbers and the researcher must remain detached and uninvolved from the study (Welford, Murphy &
Casey, 2012). It is postulated to separate fact from values, is objective in its approach and is governed by rules and regulations that must be adhered to (Dodd, 2008).

Quantitative research is generally considered to be of a higher level of evidence (see Appendix 7) and national guidance documents (e.g. NICE) largely base their decisions on high grade research such as randomised controlled trials. A hypothesis is generated which must be proven or disproven, thus making it deductive reasoning.

**Deductive reasoning:**

Theory $\rightarrow$ Hypothesis $\rightarrow$ Testing $\rightarrow$ Accept / Reject Theory

There were no general hypotheses in existence for this research and in contrast to the approach above, an inductive approach using GT was adopted by the researcher. The aim of this study was to determine aspects of the experience of respite care for patients and carers and therefore did not sit within the domain of quantitative research. Future development of this research could potentially add to the body of knowledge through mixed methods and quantitative research designs in order to answer pertinent specific questions but this was not considered appropriate for early exploratory stages of this study.
3.3.2 Qualitative Research

Conversely, qualitative research invites discovery and new knowledge and a desire to learn about the patient in their own habitat and how illness influences their way of being and ‘recognise diversity as well as regularity’ (Corbin & Strauss, 2008, p. 13). This adopts a subjective stance where there are no absolute truths but multiple interpretations. An interpretative field of inquiry locates the researcher in the world they are exploring (Denzin & Lincoln, 2000) and lends itself well to generating theory, thus following inductive reasoning (Bryman, 2008).

Inductive reasoning:

Observation → Pattern → Tentative/Emerging Theory

Qualitative research has shown to be concerned with service users’ views on health care delivery and services which informs policy at local and national levels (Bryman, 2008). This research study sits within qualitative methodology. It aims to explore and interpret people’s experiences of respite and encourages theory evolution. The researcher was actively involved with the entire research process (i.e. data collection, interpretation and theory generation) and embracing an interactive relationship was crucial in producing a transparent and honest understanding and account of the experience and emerging theory (Carr, 1994).
3.3.3 Paradigm, epistemology and ontology

A paradigm is an enquiry about how the world is viewed. It can be seen as a framework to explain reality and there may be periods of uncertainty which may lead to the accepted reality changing over time (Hall et al. 2013). Sandelowski (2000, p. 247) describes a paradigm as a ‘worldview that signals a distinctive ontological (view of reality), epistemological (view of knowing….), and a methodological (view of mode of inquiry)…. position’.

This study sits within the researcher’s worldview of a naturalistic, constructivist paradigm where research is undertaken in natural settings and human experience is examined and meaning extracted (Mills et al. 2006a & 2006b). A constructivist paradigm assumes that theories grounded in data are interpretative explanations (lived experiences) of the area explored but do not provide a precise and accurate picture (Charmaz, 2006, p.10). Appleton & King (2002) elaborate by explaining that “this mode of inquiry offers researchers an opportunity to examine in detail the labyrinth of human experience as people live and interact within their own social world”. These underlying principles echoed the researcher’s thoughts and feelings and were indicative of what was being asked by the research questions.

The ontological beliefs (the nature of reality) are based on a complex world that is constantly changing and in a state of flux. We all shape the way we are and how we fit into and respond to the world in which we live. Response may be positive or negative
and may resolve or cause problems (Mills et al. 2006a & 2006b) but we are unable to accurately predict what will happen due to uncertainty. Understanding of situations and events may require complex multi-faceted explanations and there is rarely one concrete answer but the aim is to reach a shared understanding. We all play a significant part of the world within which we live which results in interplay between the person experiencing the phenomena and the world (Charmaz, 2009). The world entered by the researcher for the purpose of the study is never uncomplicated and any understanding gleaned is strengthened by the researcher’s tacit understanding (Charmaz, 2009, p. 131) which reinforce the possible numerous realities (Appleton & King, 2002).

This study adopts a qualitative approach. The researcher's ontological stance is constructivist, thus agreeing there can be various interpretations and no one reality, all of which are influenced by context, in this case people experiencing respite care (Mills et al. 2006 & 2006b; Charmaz, 2009). The lived experience of respite is usually undergone during times when the patient and their relative may feel vulnerable due to advancing disease and a multitude of changes. It is imperative that understanding of that episode of care is considered by forging strong links with the data and context and that the honesty of peoples’ opinions and experiences are respected and presumed valid.

Epistemology is the nature of knowledge and what is accepted in a discipline as being true (Bryman, 2008). The researcher holds a subjective, interpretivist stance. Knowledge is not ‘discovered’ but constructed and then interpreted through many lens (Hall et al. 2008).
2013) and the researcher’s active involvement in this process is inevitable and necessary (Mills et al. 2006a & 2006b). All facts determined are ‘value laden’ which are seen as influenced by our personal beliefs and thoughts. Those values come from multiple sources – our own upbringing, the people we connect with and the life we lead. They are deemed crucial in shaping the final theory (Appleton & King, 2002).

3.3.4 The researchers position within the research

The researcher’s role as a nurse was influential in determining the research interest. Her current position and career progression resulted in new ways of working and the exciting challenge of caring for a different cohort of patients, requiring different skill sets. Working in palliative care where the researcher’s passion lies, is dependent on understanding the patients’ and carers’ worlds and how they are coping with chronic, life limiting illness. All existing assumptions and knowledge base were acknowledged and welcomed. The holistic approach to care is fundamental in palliative care and this sits well within a constructivist, relativist approach to the research study.
### Table 3.1 Differences between Quantitative and Qualitative Research

<table>
<thead>
<tr>
<th>QUANTITATIVE</th>
<th>QUALITATIVE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positivism. Rigid rules, logic, explain findings in relation to general law</td>
<td>Paradigm</td>
</tr>
<tr>
<td>and prediction.</td>
<td>Interpretative, constructivist. Understanding of meaning.</td>
</tr>
<tr>
<td>Absolute truth.</td>
<td>Ontology</td>
</tr>
<tr>
<td>Gains objective knowledge from facts and figures.</td>
<td>Epistemology Multiple interpretations of knowledge gained from observing</td>
</tr>
<tr>
<td>Descriptive, experimental</td>
<td>phenomenon.</td>
</tr>
<tr>
<td>Describes and tests cause and effect by hypothesising which is proved /</td>
<td>Aims Describe and explain a certain phenomenon and how it impacts on an</td>
</tr>
<tr>
<td>disproved by scientific means.</td>
<td>individual or society.</td>
</tr>
<tr>
<td>Objective, formal, systematic. Deductive</td>
<td>Approach Subjective, informal. Inductive</td>
</tr>
<tr>
<td>Random selection and assignment of large numbers. Generalisable to larger</td>
<td>Sampling Small, select sample. May only be generalisable to a small</td>
</tr>
<tr>
<td>population / area of care</td>
<td>may only be generalisable to a small population / area of care.</td>
</tr>
<tr>
<td>Numerical (&quot;Hard&quot;) Surveys, questionnaires, tests.</td>
<td>Data collection / Methods Non numerical (&quot;Soft&quot;) Interviews, observations,</td>
</tr>
<tr>
<td>Systematic approach to investigations which is transformed into numerical</td>
<td>focus groups</td>
</tr>
<tr>
<td>data, involving measuring or counting quantities.</td>
<td>Analysis Intense relationship with data Coding to develop common themes</td>
</tr>
<tr>
<td>Relationship between researcher and participant</td>
<td>and constant comparison Interpretation constructed between researcher and</td>
</tr>
<tr>
<td>Detached, objective view Avoid bias / forming relationship</td>
<td>participant Acknowledge researchers previous knowledge and experience</td>
</tr>
</tbody>
</table>


3.4 Justification for study of patients with neurodegenerative diseases

Traditionally cancer patients have received more service choice and development than patients with non-malignant conditions. Recently there has been more interest in who accesses palliative care and a realisation that those with neurodegenerative conditions have a limited prognosis, experience distressing symptoms and have a high carer burden (DH, 2005a; Aoun et al. 2006). The researcher’s background was in oncology but a recent change of role had resulted in the researcher caring for patients with non-malignant conditions. Recognition of the increasing dependence of this population of patients and problems encountered with ongoing caregiving led to a decision to explore respite for neurodegenerative patients and their carers.

3.5 Grounded theory

Grounded theory aims to generate theory from observations of real life (inductive theory) as they are occurring in a given situation. There is no existing hypothesis and it is considered a dynamic process which aims to make sense and attach meanings to human relationships (Charmaz, 2006; Corbin & Strauss, 2008; Hallberg, 2006; Birks & Mills, 2011). These meanings may be through symbolic interaction (interactions which happen between individuals) and is influenced by personal knowledge, experience and external factors (Cowley, 1991). In addition, meaning is constantly developing and changing as we grow as individuals. We encounter problems and we attempt to solve these by using knowledge and action, depending on our relationships with others and their consequent interactions, thus creating interplay between ourselves and others and between
knowledge and action. This can be at different levels – organisational, personal and societal. We use all our skills to interact – language, body, emotions and reflection which create meaning through our personal interpretations (Cowley, 1991). Grounded theory is concerned with the ‘pragmatic application of results’ (of research) as opposed to the absolute ‘truth’ as this may not exist (Annells, 1996). Grounded theory allows the gathering of rich data and permits early analysis which guides further data collection and creates flexibility (Strauss & Corbin, 2008). See Appendix 8 to illustrate the process of grounded theory.

3.5.1 The origins of grounded theory

In 1967 Glaser and Strauss became the original founders of grounded theory when they promoted the concept of qualitative approaches to research. They purported that the systematic collection and analysis of data could lead to robust generation of theory which was ‘grounded’ in the data (Cooney, 2010), thus making it more applicable to reality. Later they parted ways and publications demonstrated their conflicting views of the development of grounded theory (e.g. Glaser, 1992; Strauss & Corbin, 1998). Strauss formed a new allegiance with Corbin, whilst Glaser continued to defend the original grounded theory tenets, stating that Strauss was ‘forcing the data’ and was no longer true to grounded theory. Other versions of grounded theory began to emerge, most prominently Charmaz’ work on a constructivist approach (Charmaz, 1983; Charmaz, 2006). It has been noted that this flexibility in using different approaches to grounded theory is extremely beneficial (Birks & Mills, 2011). This adaptability enabled the
researcher to consider all approaches by exploring underlying principles, processes and analytical methods of grounded theory and led to determining which would be the most appropriate fit for this study.

3.5.2 Constructivist grounded theory

Constructivist grounded theory (CGT) affords the possibility to consider multiple meanings and understandings of reality which is influenced by many contextual factors (Hall et al. 2013) and constantly redefined through interaction with others (Fisher & O’Connor, 2012). It adopts an emic (insider) stance which melds with the researcher’s personal understanding and input, as well as providing an interactive approach to data collection and analysis (Charmaz, 2006). This suggests that the researcher is a ‘co-producer’ of the research which can add depth and meaning to the process (Mills et al. 2006a & 2006b). The researcher needs to be able to enter the participants’ world and discover how they interpret their experiences, thus focusing on their lived experience (Jeon, 2004).

Constructivism asserts that the researcher ‘constructs’ theories from data and analysis as opposed to ‘discovering’ theory (Hall et al. 2013). The researcher aimed to become a part of the participant’s world as much as was possible. She had an existing knowledge base of chronic, life limiting illness and respite care, in conjunction with palliative care which led to a level of understanding of that world. The participants were able to expand and enhance the researcher’s comprehension by describing what their actual
lived experience was from their point of view. The understanding, stemming from data collection, contextual considerations and analysis, led to a co-construction (from both participants and researcher) of further knowledge, resulting in the creation of theory. Acknowledging the participants’ experiences, coupled with the researcher’s background and involvement of respite provided a means to create a model of care that mirrored these findings and co-constructed the theory.

3.5.3 Rationale for choosing constructivist grounded theory

The researcher followed a constructivist approach to grounded theory. This allowed her to be situated within the research and form a part of the understanding from her own experiences which will create meaning between the researcher and the participant. The study is concerned with beginning the journey of identifying ‘constructs’ which make up the meaning, (as opposed to ‘facts’) and building on these as data collection progresses (Charmaz, 2006). The reality of clinical practice, which is where the researcher is situated, coupled with the personal experience of caring for palliative and respite patients and carers, means that CGT and its tenets suits the research question and design and provides an added dimension to the study. This fosters a mutual closeness and permits self-disclosure, contrary to a detachment that may cause the participant to avoid open discussion (Wilde, 1992).
3.5.4 Rationale for rejecting other qualitative approaches

Initially it was felt that an ethnographic approach may suit this research. It would allow the opportunity to immerse the principal investigator into the area of care and observe what happens in everyday contexts. However, as the questions began to develop, and the issues of disability and different models of respite were considered, it was thought appropriate to hone in on a particular area of care, namely those with neurodegenerative diseases and their carers, and access to a specific form of respite. The aims and questions focused on participants reflecting on their experiences which were often beneficial after a period of time. In addition, it would be difficult to observe practice as there were several points of access for residential respite and this would not have been feasible to conduct. In view of the desire to generate theory from observations of real life as they are occurring, grounded theory felt a more realistic approach.

Research which examines experiences often leads to using phenomenology which explores the lived experience of the person(s) and specific phenomenon and describes them (Bryman, 2008, p.15). This study was concerned with being able to explain and interpret the experiences as opposed to merely describing them (Baker et al. 1992). The aim was to develop a deeper understanding of those experiences and then inductively create a theory which could be utilised to plan respite care for patients and relatives with neurodegenerative diseases. This led to grounded theory being the choice for this study.
3.6 Symbolic interactionism

Symbolic interactionism (SI) was developed in the 1960’s by Dewey, Mead & Blumer (Blumer, 1969). Blumer (1969) states that there are three underpinning aspects:

- Human beings act towards things on the basis of the meanings that those things have for them personally
- Meaning is derived from, or arises out of, social interaction
- Meanings are modified through an interpretative process, and therefore meaning is created from each new experience.

Table 3.2 explains the central tenets of symbolic interactionism.

| **PEOPLE** – individually and collectively respond to the meaning they attach to objects that make up their world | **PROCESS** – people are making signs to each other and interpreting each other’s actions |
| **SOCIAL ACTS** – individually or collectively they construct a process in response to a given situation which is confronting them | **COMPLEX INTERLINKAGES** – the constant movement and dynamic nature of organisations, institutions and networks. |

Charmaz (2006) clarifies this further by explaining that people do not automatically react to stimuli but that they respond in a considered manner, indicative of the situation they are faced with. Meanings arise out of, and influence, actions.

The emphasis is on the lived experience of the individual and their interpretation of the world around them (Jeon, 2004). Of equal importance is the language used and this is often constructed through symbols and objects which have significance and meaning,
derived from previous experience. This all contributes to the development of the person’s individual identity (Carlson, 2013). Interaction within the world in which we live would not be possible without a form of language which can be multi-faceted (Corbin, 2003).

Chenitz & Swanson (1986) refer to the hierarchical nature of symbolic interactionism, a useful framework for the purpose of research:

- Micro - understanding individual behaviour and interactions
- Macro – understanding the context, setting and conditions across a full range of variations
- MACRO – shared meaning between groups and societies in order to understand the interpretation of self.

Symbolic interactionism, as a theoretical framework, was considered applicable to this research study because there was an interest in people’s response to respite care, what they achieved and how they differed and developed as individuals. This centred on their (and the researcher’s) interpretation of events and the meaning attached to them which was influenced by their lives and previous experiences. This study was set at a micro level as it could only be generalisable to a specific population although the contextual nature was relevant to this cohort of patients. The researcher’s comprehension of symbolic interactionism and the individual’s meaning of ‘self’ assisted in understanding and analysing the data.
3.7 Plan of the study

3.7.1 Scoping

Initially a brief literature review was performed to establish what research had already been conducted regarding respite care and neurodegenerative diseases. This served to identify gaps in the literature. An audit was also conducted in a large London hospice which determined who was accessing respite and the reasons why. This was supplemented by attending support groups to understand concerns that patients with neurodegenerative diseases and their carers have and how they understand respite. This led to the development of research questions to direct the study.

3.7.2 Collaboration

Discussion with colleagues in a specialist hospital for neurological diseases resulted in scoping of numbers for a study and accessing potential research participants. This collaboration was essential to recruit people. They were also beneficial in introducing the researcher to other professionals working in this area of care who later were instrumental in boosting numbers for recruitment.

3.7.3 Ethical approval

The process of ethical approval was lengthy involving the National Research Ethics Service (NRES), research and development at the University College London and Faculty of Health and Medical Sciences Ethics Committee at the University of Surrey. All
appropriate documentation was prepared. A favourable ethical opinion was received from all establishments.

3.7.4 Data collection and analysis

Interviews and non-participant observation were conducted in different areas of care to ensure rich and comprehensive data (see table 3.3). Analysis was conducted in accordance with grounded theory methodology, including constant comparison of the categories and themes emerging.

3.7.5 Theory development

As a result of the study findings, a model of the relationship between caring and respite began to emerge. This, alongside the writing up of the research, can be referred to as a ‘crystallisation’ of the research process by bringing everything together (Annells, 1997). This process is illustrated in figure 3.7.
<table>
<thead>
<tr>
<th>Data collection</th>
<th>Location (urban / suburban)</th>
<th>Participants</th>
<th>Referrer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews 1-5</td>
<td>London (U) Home Hertfordshire (SU) Home</td>
<td>Patients Carers</td>
<td>CNS MND CNS community neuro diseases</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>ANALYSIS</td>
</tr>
<tr>
<td>Interviews 6-10 (3 joint)</td>
<td>Surrey (SU) Home Sussex (SU) Home London (U) Home</td>
<td>Patients Carers</td>
<td>CNS community neuro diseases CNS Discharge planning/respite</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>ANALYSIS</td>
</tr>
<tr>
<td>Non-participant observation</td>
<td>Sussex (SU) Hospice</td>
<td>Patient Staff</td>
<td>CNS Discharge planning / respite</td>
</tr>
<tr>
<td>Interviews 1-4</td>
<td>Sussex (SU) Hospice</td>
<td>Staff</td>
<td>Researcher</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>ANALYSIS</td>
</tr>
<tr>
<td>Interviews 11-17 (1 joint)</td>
<td>Hertfordshire (SU) Home Surrey (SU) Home</td>
<td>Patients Carers</td>
<td>CNS community neuro diseases CNS Discharge planning/respite</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>ANALYSIS</td>
</tr>
</tbody>
</table>
Figure 3.7 PLAN OF THE STUDY

Audit (Scoping)

MNDA support group  Interview guide  Purposive sampling (Data Collection) 
Develop Research Questions

Interviews (n=5)

ANALYSIS
Initial Coding
Review interview guide
Attend HD clinics

Theoretical Sampling (iterative with interviewing)

Interviews (n=8)
Non-participant observation

ANALYSIS
Initial Coding
Interviews (n=4)

ANALYSIS
Focused Coding
Refinement of sub / categories

ANALYSIS
Focused Coding
Theoretical saturation

ANALYSIS
Theoretical Coding
Emerging core categories (THEMES)

DEVELOPING AND REFINING THEORY
3.8 Methods

3.8.1 Accessing Support groups

An informal means of increasing knowledge base and acclimatising the researcher to the issues and concerns that face patients with neurodegenerative diseases and their carers was by attending some informal support groups. This served to ascertain the scale of disability and problems encountered by those with neurodegenerative illness. The informality lent well to introducing the research to potential participants and allowing an opportunity for questions which were useful for initial scoping purposes. In addition, it was advantageous to gather opinions and thoughts regarding respite care which, in turn, guided the interview topics.

3.8.2 Theoretical Sampling

Purposive, selective sampling was initially adopted which is usually deployed for qualitative research (Coyne, 1997). Participants were chosen who fit the criteria for inclusion (Table 3.3) and had been diagnosed or cared for someone, with a neurodegenerative condition (Coyne & Cowley, 2007).

A shift to theoretical sampling occurred as concepts and codes began to emerge which provided direction for the researcher. This involved an iterative, continuous data analysis and identification / refinement of emerging categories / themes which directed the researcher to identify other suitable research participants or questions in order to gather more specific data (Coyne, 1997). This made the sampling more responsive to the data and not pre-determined before the project begins.
Saturation can be considered a subjective conclusion (Hallberg, 2006; Rintala et al. 2014) as there are always different directions that the data may take you but research is usually time and / or cost limited and a decision regarding the research aim and questions must be determined. As this research was part of a doctorate programme there was a temporal element which resulted in a targeted area of sampling relating to a specific patient cohort (neurodegenerative diseases), people involved in informal caring (carers of the patients with neurodegenerative diseases) and who accessed an area of care (residential respite). As these patients and carers were interviewed and patients observed receiving respite, elements emerged which demonstrated challenges in accessing this service, the planning around an admission and how the carers managed their responsibility of caring.

Theoretical sampling was difficult because of the small number of people accessing respite. As themes emerged and the desire was to focus on these areas, the researcher discussed them with the recruiters (specialist CNS’) who were alert for any people accessing respite that might be able to explore these areas. This process continued until saturation when all elements had been thoroughly explored with further participants and no new or further categories were identified or emerging (Charmaz, 2006), illustrated in Figure 3.7.

As the categories began to develop, the researcher needed to further understand the experience of respite by witnessing its delivery. Consent was obtained from hospice
staff and patients to observe care and interview the staff who provided the interventions during a respite admission.

Table 3.4: Inclusion and Exclusion criteria

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 years and above (to give valid consent)</td>
<td>Self-choice – if patients / carers prefer not to be included</td>
</tr>
<tr>
<td>A diagnosis of Huntington’s Disease (HD), Motor Neurone Disease (MND) or Multiple System Atrophy (MSA). Later extended to all neurodegenerative diseases.</td>
<td>Patients should be of a performance status suitable to be interviewed. Those considered to be in the last few weeks of life, too weak or unwell will be excluded.</td>
</tr>
<tr>
<td>Carers of patients with a diagnosis of HD, MND or MSA Later extended to carers of patients with a diagnosis of any neurodegenerative disease.</td>
<td>Patients and carers who do not have a good command of the English language, if there are no adequate translation services available.</td>
</tr>
<tr>
<td>Ability to understand and write English (unless have translator facilities - including family - available)</td>
<td></td>
</tr>
<tr>
<td>Patients who have received respite within the last six months</td>
<td></td>
</tr>
<tr>
<td>The patient is able to communicate – either by speaking or by using simple letter/word boards, symbols or pictures or by a form of electronic communication aid.</td>
<td></td>
</tr>
</tbody>
</table>

3.9 Data collection

3.9.1 Approach to interviews

Interviews in qualitative research are a ‘conversation with a defined purpose for collecting information’ (Wilde, 1992) which can provide rich data and be directed by the participant. Semi structured interviews utilise topic guides which provide frameworks to loosely direct conversation and ensure no important points are missed, which can be especially beneficial when the researcher is a novice. Charmaz (1990) refers to framing questions according to emerging data. Initially there are
broad topic areas which were then honed to determine salient topics and categories (Wimpenny & Gass, 2000).

Interviews can provide long episodes of discourse which may be irrelevant and time consuming, although may be recognised as therapeutic and cathartic for the participant. It is the researcher’s role to know when to move the participant forward in their narrative and begin to hone from the general to the specific area of interest (Bryant & Charmaz, 2007) which becomes easier with experience over time. Interviews, as one data collection method, suited this research study well as it enabled the researcher to engage in a personal, relaxed manner with the participant(s) and explore their thoughts and experiences in a familiar environment using their own narrative (McCann & Clark, 2003b).

3.9.2 Interviews

The interviews took place in the participant’s home (see appendix 13 for topic guides for patients and carers), to promote comfort and ease for them as it would have been difficult for the carer to be relieved of their duties. The staff interviews were situated in the hospice where they worked but in a quiet room away from the clinical area. All interviews were loosely based on a topic/prompt guide (Appendix 13) which encouraged flexibility and free discussion between the interviewer and participant(s) (Bryman, 2008). Having the interview process as unstructured as possible allows trust to develop and can be potentially therapeutic (Corbin & Morse, 2003). The prompts were continually reviewed and influenced by the collected data and ongoing analysis.
The initial tentative target was 7-10 patients, 7-10 carers (linked if possible) and hospice staff (covering grade ranges health care assistants to senior clinical nurse), but was also dependent on emerging categories and when saturation might be reached.

Recruitment of patients and carers took place over one year. At times this proved challenging as many of the patients referred had far advanced disease and communication was difficult. This resulted in some interviews being conducted jointly with assistance from their informal carer to facilitate understanding. A final number of 17 patient and carer interviews (4 of which were joint, comprising of the patient and carer to provide support and translation for the patient) and 4 staff interviews were conducted. The staff interviews were during non-participant observation and were pre-arranged via e-mail, depending on clinical pressures.

All interviews lasted between 20 minutes and one and a half hours. All patient / carer participants were spouses and had a long history of togetherness and familiarity. Being able to share their story telling and reflections was advantageous at times and often served to remind each other of pertinent facts and memories relevant to the research (Sakellariou, Boniface & Brown, 2013). It provided a transparency and illustrated how the couple melded together (Bjornholt & Farstad, 2014). Conversely, there were occasions where there were tensions between the patient and carer and a reluctance to share information (Sakellariou, Boniface & Brown, 2013). The carers used the opportunity when the researcher was leaving to have their say ‘off tape’ which was particularly concerned with the burden of caring and how the patient no
longer had an understanding of how difficult this was. The respite they were offered was their saviour and they continued to relish their personal time when they could retrieve some of their old life. The researcher found that many of the interviews created a deep connection with the participants and often resulted in feeling ‘caught up’ in the emotion of the narrative (Corbin & Morse, 2003). This served to quickly forge a comfortable relationship with the patient and carers.

Staff interview data was analysed and used in the context of building the theory. These were key staff members who delivered respite care in a supportive, specialised environment. It was useful to discuss their approaches to respite and consider their thoughts on the development of this area of care.

3.9.3 Non-participant observation

Non-participant observation is a method of data collection where the researcher observes activities and interventions to gain an understanding of the phenomenon being researched (Bryman, 2008). They do not participate in the activity being observed and notes are taken of interesting interactions, behaviours or occurrences (Corbin & Strauss, 2008). The participants understand the researcher is present and their role, as well as giving consent to be observed.

This method was adopted as the researcher was influenced by emerging data and a keenness to explore the actual respite experience and observe the people who delivered that care. It also permitted the researcher to compare what had been said
in the interviews and what actually happened in practice as well as further refine topic questions (McCann & Clark, 2003b). Some of the participants interviewed accessed respite in a local hospice where they had one dedicated respite bed. The researcher observed three shifts of care given to participants, previously interviewed, over a period of 20 hours. Data collected included field notes, which were based on ‘in the moment’ thoughts and feelings. They covered personal reflections on care administered and the experience of the researcher observing in the clinical setting context. These notes were used in conjunction with personal memos to question thoughts and feelings experienced by the researcher, for example probing whether urban versus suburban care context differed and how important or relevant the environment was to the patient and staff. Using this approach, coupled with interviews gave additional depth and verification to the data collected.

3.9.4 Memoing, reflexivity and the reflective diary

During the study it is essential that the researcher maintains an open and transparent position. Reflexivity, the ‘capacity to reflect upon one’s actions and values’ (Arber, 2006), ensures confidence, scrutiny and credibility in the researcher. It is an opportunity to systematically reflect on the researcher’s part in the process and the events that are occurring, alongside how they might fit into the bigger picture. It is seen as developing insight into the researcher’s work and applying a critically analytical approach (Birks & Mills, 2011).
The researcher found the divide between being a clinician and a researcher challenging initially. As participants posed questions in their interviews regarding access to information and support it was difficult to separate herself from the professional role of offering advice and signposting. Being reflexive allows an opportunity for translucency.

**REFLEXION**

Thinking about an issue

Continuing and subjective self-awareness

(Adapted from Colbourne & Sque, 2004)

Memo writing (field notes) can assist in the formulation, revision and refining of theory generation. This is writing short, precise notes which serve as a means to capture thoughts, feelings and ideas as they occur (Birks & Mills, 2011). They will also aid reflection and make any assumptions explicit and stimulate the researcher to challenge the interpretation of the data. This will provide a balanced view and assist in making meaningful linkages between the data and any theories emerging (Hunter et al. 2011a), making memos ‘the vehicles that transport the researcher from the concrete to the conceptual’ (Birks et al. 2008, p. 71).

Memo writing and keeping a diary enabled the researcher to be reflexive. These were utilised from the beginning of the study, before and after each interview and during data collection and analysis. One example was the unforeseen difficulties experienced with recruitment. Returning to the diary demonstrated how the researcher had performed a scoping exercise to consider the potential participants.
The time in between the scoping and the recruitment beginning had seen ongoing health care cost cuts and therefore this had resulted in respite being viewed as a Cinderella service and significant cuts being made in its availability. The diary served to remind and reassure the researcher of the process followed and how health care continued to evolve.

The diary was particularly useful for recording the theory generation process which felt arduous at times. Returning to the data and memo recordings to verify if the model demonstrated a true reflection of the findings was valuable, as well as providing a clear audit trail (Birks et al. 2008). This was undertaken repeatedly, enabling the researcher to question whether the model truly mirrored the data collected and analysed.

3.10 Data analysis

The aim of grounded theory is to understand and interpret the data which gives us the information required to construct new theory. The data is all encompassing, returning to it at all given opportunities. Data collection and analysis in a grounded theory study happen concurrently (Corbin & Strauss, 2008). The researcher needs to question whether emerging theory truly represents what the data says. The aim is to ‘describe and interpret the social world with such vividness that you can imagine yourself there...’ (Wimpenny & Gass, 2000, p. 1491).
The intention is not to discover the theory, but a theory that leads to the understanding of an area under investigation (Heath & Cowley, 2004). Analysis began after 2-5 interviews and can lead to changing of the topic guide to reflect new thoughts and emerging themes. It is an iterative process which swings backwards and forwards through the data.

In order to collate the vast amount of data, the NVivo programme was utilised. Electronic software packages safely and efficiently store and organize the data to allow for ‘human analytic reflection’ (Saldaña, 2009). Unfortunately, after loading and coding the data, a fault was found with the system and the coding was not visible. Due to time limitations this was abandoned and manual coding was adopted which was time consuming and unwieldy at times.

3.10.1 Coding

Coding is the embryonic stage in interpreting the data that has been collected. It begins the story and encourages the researcher to get close to the data and analyse from multiple viewpoints to ensure a wide understanding (Charmaz, 2006). In constructivist grounded theory there are three stages; open, focused and theoretical coding.

Analysis began with transcribing the interviews, followed by repeated listening to the recordings and re-reading of the transcriptions to ensure total immersion in the data. Returning to the data whilst coding was essential to verify emerging codes and
categories. In addition, the field notes were typed up as soon as possible after the observation period in order to retain the nuances of the experience and capture detail.

3.10.2 Open Coding

Open coding, or the ‘bones of theory’ (Charmaz, 2006) refers to the first stage of the process where data was broken up or ‘fractured’, in order to make small chunks to work with (Saldaña, 2009). Initially the coding was conducted through line by line analysis of data. This began the process of creating concepts which are the basic units of analysis. Events in the data were compared and contrasted in order to identify common concepts that are emerging and each concept was rechallenged with new data and events (Corbin & Strauss, 1990). This was an intense approach but it allowed the data to be examined in minute detail and the researcher became very familiar with the nuances of each interview (Birks & Mills, 2011). There were no overarching conclusions reached at this stage but a questioning technique was adopted; for example considering what the participant was trying to convey and how many alternative ways could it be interpreted (Charmaz, 2006; Birks & Mills, 2011). Each code was named as it was identified and this included ‘in vivo’ codes; i.e. those that were direct participant quotes, which enabled the researcher to stay close to the data and reflect the language used by the participants (Charmaz, 2006). This process produced a large number of codes which then needed to be further sorted. Appendix 14 demonstrates the open coding process.
3.10.3 Focused Coding

Focused coding then occurred which involved the collapsing of codes (see table 3.5) to create subcategories/categories which described a segment of datum (Saldaña, 2009). Categories are felt to be the ‘cornerstone of developing theory’ (Corbin & Strauss, 1990). They are created by grouping larger segments of data together which have similar meaning, significance or commonalities (Allan, 2003) and offers deeper understanding (Charmaz, 2006). This served to ‘recombine the data’ which helped establish links between subcategories and categories (Rintala et al. 2014). This was an iterative process involving pendulum like swinging between data sections, adopting a constant comparative process which served to ensure that the subcategories and categories surfacing truly reflected the data collected (Birks & Mills, 2011). The result was the refinement of concepts into higher level categories, through decisions regarding appropriateness and relevancy (Engward, 2013).

Table 3.5: An example of a collapsed code

<table>
<thead>
<tr>
<th>FOCUSED CODING (Collapsing of initial codes to form a category)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ACCESSING RESPITE CARE</strong></td>
</tr>
<tr>
<td><strong>OPEN CODING</strong></td>
</tr>
<tr>
<td>Access to information</td>
</tr>
<tr>
<td>Barriers to accessing respite</td>
</tr>
<tr>
<td>Appropriateness of respite</td>
</tr>
<tr>
<td>Personal research to investigate how to access respite</td>
</tr>
<tr>
<td>Lack of choices - dates / places</td>
</tr>
<tr>
<td>Funding issues</td>
</tr>
</tbody>
</table>
3.10.4 Theoretical Coding

The aim is to identify a core category which is most representative of the theory and appears most frequently during analysis (Allen, 2010). Core categories or themes are the ‘outcome’ of coding and is created from higher level conceptual thinking and interpretation (Saldaña, 2009). The constant comparison of data allowed the emergence of categories which encouraged collaborative engagement with participants and the active involvement of the researcher (Hunter et al. 2011b). This is analysing to an abstract level which is indicative of interpreting the data.

The core categories / themes emerged as the researcher grouped the categories and rechecked the data to ascertain the match of these to the data (see table 3.6). This involved revisiting the interviews and transcripts in order to ensure applicability.

Table 3.6: An example of the development of a theme.

<table>
<thead>
<tr>
<th>THEORETICAL CODING (The production of a theme from categories)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>THE COMMODITY OF RESPITE</strong></td>
</tr>
<tr>
<td><strong>FOCUSED CODING</strong></td>
</tr>
<tr>
<td>Accessing respite care</td>
</tr>
<tr>
<td>Respite as restoration for patient</td>
</tr>
<tr>
<td>Knowledge &amp; understanding of respite</td>
</tr>
</tbody>
</table>

Data saturation occurred when no new themes or variations were identified as emerging.
During this process the use of diagrams was abundant, which attempted to explore the tenets of the relationship between respite and caring and how outcomes could be determined. Diagrams are visual displays of linkages which assist the researcher to develop their analytical approach (Rintala et al. 2014) and allow a creative license. The data was constantly referred to in order to verify the diagrams and thus develop the theoretical models. The iterative process continued until the models accurately reflected the data. This was an important and stimulating part of the research process.

3.10.5 Constant Comparative Analysis

The constant comparative method is an integral part of the grounded theory analysis which involves constantly comparing data with all other data in order to “explore variations, similarities and differences” (Hallberg, 2006). It was a continuous movement, back and forwards between the emerging codes and the process of making comparisons with the data (Charmaz, 2006). This provided further verification that the developing categories were truly grounded in the data (Bryant & Charmaz, 2007), which allowed the researcher to make sense of, and analyse the new ideas (Charmaz, 2006). The iterative process revealed the full complexity of the data and was not considered complete until all themes had been determined and the final theory made explicit.
3.11 Theory development

Theory development should be grounded in data, be traceable back to data and resonate with the context in which it was derived (Bryant, 2009). Theory development involved collating data analysis, emerging theory and memos, alongside relevant supporting literature in order to provide a working theory (Engward, 2013). There are two types of theory development: substantive theory which is produced for a specific area of enquiry with clear definition and grounded in the data (Charmaz, 2006) and formal theory which is a substantive theory developed to a higher conceptual level (Birks & Mills, 2011). It is substantive theory that is usually generated by this approach which is classified as a middle range theory, involving specific phenomena and a small number of concepts, leading to a limited applicability (Reeves et al. 2008). The substantive theory is generalisable to a similar context and in order to widen its applicability it requires further explorations and refinement. Its true verification will be by testing against real world situations (Engward, 2013). Allan (2003) states that the theory needs no further justification as it emerges from ‘live data’.

3.12 Theoretical sensitivity

An important part of the process throughout was for the researcher to be able to enter the participant’s world and be sensitive to what was being said and understood. The researcher gained insight into the subtleties of the data (McCann & Clark, 2003a) and recognised and reflected on her previous knowledge of respite care in a palliative care setting, which served to offer reflexivity and transparency
within the study. The researcher was mindful of any personal irrelevant beliefs or values that may be infiltrating the data (Birk & Mills, 2011), which might be brought to the study from any literature or personal and/or professional experience; for example, her past and present knowledge of respite resulting in a fixed way of viewing the criteria for need and the process required (Hoare et al. 2012; Rintala et al. 2014). In addition, attention was given to ensuring that the existing knowledge did not compromise the developing theory by distinguishing the new from the routine (Strauss & Corbin, 1998).

The researcher was aware of her personal and professional experience relating to respite care. Informal conversation with patients and carers (via support groups) and staff (who cared for these patients) regarding their thoughts about respite care also served to provide ‘sensitising cues’ (McCann & Clark, 2003b). Constant questioning, accompanied by memoing and reflection enabled the researcher to demonstrate theoretical sensitivity by engaging an inquiring, curious approach and questioning what was happening with the data. The researcher’s diary assisted this by the constant revisiting and examining of key points in the research process and the researcher’s current thinking and how this has been developed. For example, after one productive interview (perception of researcher) it became clear that the carer (who had agreed to a joint interview) had been put in an awkward position by her husband (the patient) because he had not wanted her to speak alone with the researcher which had been the carer’s preference. The conversation ‘off tape’ was full of emotion and rawness as she tried to explain how difficult and fraught with
anxiety her life was and the only thing that kept her motivated to continue caring was the opportunity for respite care. This felt extremely powerful and served to remind the researcher that the consent process was merely a formality that could potentially hide untold guilt and pressure from internal sources. Consequent consent to interviews was explored more fully and the researcher was more sensitive to relations between patient and carer when a joint interview was scheduled, instead of automatically presuming that agreement was mutually acceptable to all parties (see memo 2, p. 140).

3.13 Ethical Considerations

Approval was sought and obtained from the local Research Ethics Committee, the Research and Development Committee and the University Ethics Committee. Recruitment was poor and further discussion determined that only one site might be limiting. An application for an extension to other sites (who were in agreement) was applied for and agreed (see Appendices 9 and 10).

Potential participants were approached by the clinical nurse specialist within that area of care. They were offered a comprehensive information leaflet about the study (Appendix 11) and consent was obtained for the researcher to contact them via telephone or letter, depending on their wishes, to discuss further. The researcher then contacted interested participant(s) and discussed the study, allowing adequate time for reading and understanding of the information and to raise any concerns, either then or at a further pre-arranged time. Each potential participant was
informed of the aims, methods and anticipated benefits and any potential disadvantages of the research, as well as additional emotional support if required.

Research in a palliative care population can be fraught with challenges. Participation can be hindered by fatigue and a sense of using up of their precious time (Reeve et al. 2010) although many patients wish to share their experiences (Terry et al. 2006) and may view this as their legacy. The participants were all eager to be a part of the study and be questioned about their experiences. They seemed pleased to be afforded the opportunity to tell their stories and appeared grateful that someone was genuinely interested in what they had to say. They were keen to receive feedback at the end of the study because they perceived this would be the culmination of their input which may benefit themselves and others.

During the interviews the researcher observed for fatigue and distress. Participants did not demonstrate any anxiety which would have been followed up with previously arranged telephone pastoral support. They did tire easily and were always encouraged to take a break or terminate the interview sooner than desired if required. This occurred with three participants who experienced overwhelming fatigue and needed to rest, consequently their interviews were shorter.

3.13.1 Consent

Consent was taken in writing (Appendix 12). For those participants unable to write they were required to clearly acknowledge their understanding and their informal carers signed on their behalf. All participants were assessed for mental capacity. All
records of consent were maintained and available for checking. Participants were informed that they are free to withdraw at any time without affecting their care or treatment plan.

Confidentiality and anonymity were assured at all times (Richards & Schwartz, 2002). Any reference to identification of the participant was not available for general use and any publications have ascribed pseudonyms for both person names and places of care. The participant’s dignity and privacy was respected at all stages of the research project by ensuring they had ample and sufficient opportunity to communicate and the interview was paused (with reassurance) if they required medical or nursing intervention.

3.14 Criteria for rigour

The emphasis should be on how the research was conducted (process) and how the data was interpreted and conclusions drawn and the return to data (product). Rigour should be supported by constant comparison by basing each next step on the last one (Hunter et al. 2011b) and it should stay faithful to the reality of the subject being studied (Cooney, 2011).

Using Charmaz’s criteria (2006) rigour may be demonstrated by:

- **Credibility** – can strong links be recognised between the data and analysis as well as sufficient robust evidence to support claims?
This was demonstrated by constant review and supervision of developing codes, categories and theories from the academic team which included an experienced grounded theorist. Protracted reading and persistent engagement with the data coupled with memoing after every interview and as themes emerged, added to the reliability. The use of participant’s direct quotes served to further illustrate the credibility of the coding analysis process (Chiovitti & Piran, 2003).

**Originality** – does the theories and arguments offer fresh insight into an area of care?

The development of a unique model showing the relationship between caring and respite and potential outcomes provides a new vision for the provision of respite care which can also be used for training purposes.

**Resonance** – does the theories and analysis make sense to the people who share these circumstances? Does it provide a good ‘fit’ to everyday reality?

The coding process was discussed with peers to determine applicability to everyday situations. Presentation of the models at an international conference invited critical comments and sharing of information. In addition, the demographic details afforded opportunity for visualising the context of the study (Chiovitti & Piran, 2003).

**Usefulness** – can the interpretations be used in an everyday practical world?

The researcher discussed the findings and emerging thinking with patients and carers accessing respite in order to determine relevance, appropriateness and verification. In addition, to exclude bias, the researcher did not have a clinical role / connection with the specialist, community and voluntary establishments where the data was collected.
3.15 Summary of the chapter

The study was conducted using constructivist grounded theory (CGT) methodology. CGT assumes a relativist approach where the belief is that there is no absolute truth or reality (Charmaz, 2006). This allows the researcher to be interactive with the data. The study participants were selected from hospital, hospice and community services by professionals who had a specialist input into their care. They all had, or were accessing, different forms of residential respite and were able to be interviewed, either separately or jointly, to talk about their experiences. The study was undertaken via appropriate ethical / research and development committees and supervision techniques to ensure a robust approach to research. In addition non-participant observation was undertaken in a unit offering a dedicated respite bed.
CHAPTER 4: PRESENTATION OF FINDINGS

4.1 Introduction.

The purpose of this chapter is to introduce the findings of the study. The findings are presented in an order that portrays the journey that patients’ with neurodegenerative diseases and their carers travel in order to receive respite. There are three themes which consist of:

- Procuring the commodity of respite;
- The order and chaos of respite and
- Respite as restoration and biographical reconstruction for the carer.

Each of these themes has been derived from the evolving subcategories and categories. These will be explored individually and excerpts from the interviews will demonstrate the relationship between the data and the emerging categories through inductive analysis.

A brief literature review was conducted in order to explore the developing themes but, in accordance with grounded theory, the main literature review was conducted for the discussion. The participants’ identities and respite establishments are protected by the use of pseudonyms.

4.1.1 The study participants and non-participant observation.

There were seventeen interviews conducted: seven patients and ten carers. There were six matched pairs (spousal relationship) and four joint interviews with patients whose contribution was severely limited by their disease stage. There was a variety
of neurodegenerative diseases. A description of each patient’s disease can be seen in Appendix 1 and table 4.1 illustrates the participants’ demographics.

### Table 4.1  Demographic details of the study participants.

<table>
<thead>
<tr>
<th>Pt ID</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Diagnosis</th>
<th>Occupation</th>
<th>^PS</th>
<th>-SES</th>
<th>Place of respite</th>
<th>Time since last respite</th>
<th>Length of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1 Chris</td>
<td>85</td>
<td>Male</td>
<td>WB</td>
<td>MND</td>
<td>Retired advertising</td>
<td>3</td>
<td>A</td>
<td>NH</td>
<td>3 months</td>
<td>24 mins</td>
</tr>
<tr>
<td>C2 Pat</td>
<td>72</td>
<td>Female</td>
<td>WB</td>
<td>(MND)</td>
<td>Retired advertising</td>
<td>0</td>
<td>A</td>
<td>(NH)</td>
<td>3 months</td>
<td>57 mins</td>
</tr>
<tr>
<td>P3 Sean</td>
<td>67</td>
<td>Male</td>
<td>WB</td>
<td>MSA</td>
<td>Retired insurance broker</td>
<td>3</td>
<td>A</td>
<td>NH</td>
<td>4 months</td>
<td>20 mins</td>
</tr>
<tr>
<td>C4 Sam</td>
<td>63</td>
<td>Female</td>
<td>WB</td>
<td>(MSA)</td>
<td>Financial work</td>
<td>0</td>
<td>A</td>
<td>(NH)</td>
<td>4 months</td>
<td>43 mins</td>
</tr>
<tr>
<td>*C5/P5 Gary / Mary (Pt present: limited speech)</td>
<td>64/66</td>
<td>Male / Female</td>
<td>WB</td>
<td>(HD)</td>
<td>Export management / Housewife</td>
<td>0/4</td>
<td>C2 D</td>
<td>Hospice</td>
<td>6 months</td>
<td>1.20 hrs</td>
</tr>
<tr>
<td>*C6/P6 Sally / Paul (Pt present: limited speech)</td>
<td>64/66</td>
<td>Female / Male</td>
<td>WB</td>
<td>(MND)</td>
<td>Housewife / Sales Engineer</td>
<td>0/4</td>
<td>D C1</td>
<td>Hospice</td>
<td>5 weeks</td>
<td>1.28 hrs</td>
</tr>
<tr>
<td>*C7/P7 Elsa / Isaac (Pt present: limited speech)</td>
<td>57/56</td>
<td>Female / Male</td>
<td>WB</td>
<td>(MSA)</td>
<td>Practice manager in solicitors / Fireman</td>
<td>0/4</td>
<td>C1 B</td>
<td>Hospice</td>
<td>2 months</td>
<td>1.13hrs</td>
</tr>
<tr>
<td>C8 Sylvia</td>
<td>57</td>
<td>Female</td>
<td>WB</td>
<td>(MS)</td>
<td>HCA</td>
<td>0</td>
<td>C2</td>
<td>Hospice &amp; neuro specialist home</td>
<td>3 months &amp; 6 weeks</td>
<td>1.04 hrs</td>
</tr>
<tr>
<td>P8 Philip</td>
<td>55</td>
<td>Male</td>
<td>WB</td>
<td>MS</td>
<td>Carpenter</td>
<td>4</td>
<td>C2</td>
<td>Hospice &amp; neuro specialist home</td>
<td>3 months &amp; 6 weeks</td>
<td>48 mins</td>
</tr>
<tr>
<td>*C9/P9 Deirdre / Daniel (Pt present: limited speech)</td>
<td>56/64</td>
<td>Female / Male</td>
<td>WB</td>
<td>(MND)</td>
<td>Administrator NHS / Outreach worker for</td>
<td>0/4</td>
<td>C1 C1</td>
<td>NH &amp; Hospice</td>
<td>4 months &amp; 1 month</td>
<td>1.06 hrs</td>
</tr>
</tbody>
</table>
Table 4.2 identifies interviews with staff working in respite services

<table>
<thead>
<tr>
<th>Grade of Staff</th>
<th>Place of Care</th>
<th>Length of interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>CNS</td>
<td>Hospice / Community</td>
<td>50 mins</td>
</tr>
<tr>
<td>Ward Manager</td>
<td>Hospice</td>
<td>25 mins</td>
</tr>
<tr>
<td>Staff Nurse</td>
<td>Hospice</td>
<td>20 mins</td>
</tr>
<tr>
<td>Health Care Assistant</td>
<td>Hospice</td>
<td>20 mins</td>
</tr>
</tbody>
</table>

4.2 Theme one: Procuring the Commodity of Respite

The commodity of respite refers to a service which there is a demand for, in order to support carers to maintain patients in their own home for as long as possible (Evans, 2013b). Procuring the commodity of respite signifies the beginning of the journey of...
acquiring respite for carers and patients with neurodegenerative diseases and what they hoped to achieve, such as outcomes that are beneficial to both the carer and the patient. It illustrates the initial hurdles that need to be negotiated in order to consider and make a decision to access respite as a care option. *Procuring the Commodity of Respite* includes the categories of: accessing respite care; knowledge and understanding of respite and respite as restoration for the patient (Table 4.3).

**Table 4.3: Categories and subcategories of the theme ‘Procuring the Commodity of Respite’**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
<th>Subcategory</th>
</tr>
</thead>
<tbody>
<tr>
<td>PROCURING THE COMMODITY OF RESPIE</td>
<td>Accessing respite care</td>
<td>Access to information about respite and personal research.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Barriers to access, choices and appropriateness of respite.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Funding.</td>
</tr>
<tr>
<td></td>
<td>Knowledge &amp; understanding of respite</td>
<td>Expectations of stay.</td>
</tr>
<tr>
<td></td>
<td>Respite as restoration for the patient</td>
<td>Access to specialist disciplines.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Facilities, care and activities available.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Desire to address mind and body.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Trying out new equipment in a safe environment.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Building relationships with health professionals and future plans.</td>
</tr>
</tbody>
</table>
4.2.1 Accessing respite care

There were several subcategories around accessing respite care. By far the most universal issue that was reported was that patients and carers had no real means of knowing about respite, or how to identify respite services that are available to them or where to seek information about services. Many of them understood the notion of respite care but all thought it focused on a break for the carer and were unclear about any other advantages of respite. The category of accessing respite care includes the sub-categories of: access to information about respite and personal research; barriers to accessing respite, choice and appropriateness and funding.

4.2.1.1 Access to information and personal research about respite

Carers report having to chase up referrals that were made by health care professionals to respite care and to find ways to become knowledgeable and informed about what was on offer. Carers found themselves in a situation where they had to constantly connect services and access possibilities in order to make any sense of this commodity. They felt very frustrated by the lack of information available to them and the level of probing and personal research they needed to do themselves. What was equally concerning for them was that in their view professionals had minimal knowledge of respite services, or how to refer for respite, and its availability in their locality of care. A male carer, Gary (C5), describes how he went about finding out more information. He needed to be sure his wife Mary (P5), who had Huntington’s disease (these patients experience sporadic and unpredictable spasms and loss of ability to walk, talk and think), would be cared for in accordance
with her complex needs related to issues such as positioning, symptom control and management of her dementia. In doing the ‘research’ himself meant he could check the information and feel confident in the decision to have respite for his wife:

‘R: Yes ok, so you recognised that you needed a break. Did you have a choice of places you could go?
P: Ummmm,. I’m not really sure but I was quite ...um.. through doing a bit of research myself I became aware of Stanley Ranner and the fact that Sawbridge specialized in Mary’s type of illness. Umm, so that was really where I wanted Mary to go to reassure me she would get the proper care and attention........
R: Yes. And they covered that area.
P: At that time, yes’. (Gary, C5)

He had not been supplied with literature about options for respite and wanted to make sure he had a head start. He looked at local care options and what they offered in the way of facilities and specialist knowledge regarding Huntington’s disease. He felt this was part of what he needed to do in order to rest easy about the respite admission and ensure his wife received the appropriate level of care for her needs. He wanted Mary (C5) to have respite in a facility which specialised in neurological conditions (i.e. had knowledge and understanding of her disease and was able to provide adequate and appropriate care to meet her needs).

In a similar vein, carer Sally (C6) was frustrated about the lack of communication equipment (i.e. electronic devices that could be experimented with whilst he was in the hospice) available for her husband Paul (P6) who had MND. He had rapidly lost his ability to speak which was devastating for him. They were a close family and they

**FOOTNOTE:** R = Researcher; P = Participant; C = Carer
all wished to continue to involve Paul (P6) in decision making and discussion despite
his loss of speech. Sally was very concerned about the communication equipment
available in the hospice and the speech and language therapist’s seemingly lack of
knowledge of the patient’s special communication needs.

P: I think she’s a temporary stand in for somebody who’s on maternity care
and when Paul went into hospital he couldn’t use his light writer so we were
saying to her, what other things have we got? What else can we do? And she
didn’t really know an awful lot, did she? (asks husband). And wasn’t really
very helpful. So we had a few words and she has actually now managed to get
hold of this from the motor neurone, (points to a box on the floor) but it’s
taken time so it’s left Paul really for over a month without any communication
at all.
R: And is there a speech and language therapist at the hospice? Do you see
anybody there?
P: No, we haven’t seen anyone there but they came up with a board, I don’t
know what it is called but it’s a plastic board and it had 4 different coloured
corners and you use your eyes so you look at the red and then you look for the
red letters and you communicate like that. So I was saying to the therapist
‘well, what about one of these boards’ and she said ‘well can’t you get one
from the hospice’ so I said no I can’t because that one’s there’s and they use
it. I said we’ve actually made, we’ve laminated an ABC alphabet board with
‘please’ and ‘thank you’ and ‘wee’ and ‘sit up’ and ‘window’ and all that on it
ourselves. But I really felt that she should be doing that’. (Sally, C6)

Caregivers may expect professionals to provide the necessary information /
equipment to assist them. Having to chase the professional and prompt them
regarding information can be frustrating and tiring. There is understandably an
expectation that a professional who was ‘expert’ within their field would have the
necessary knowledge to assist the patient and carer to consider immediate and
future needs in an unpredictable situation such as a neurodegenerative disease. This
coupled with an evident lack of interest, was disturbing and problematic when they
really needed the continuity.
Memo 1:
One interview (Gary, C5) made me feel very awkward. The carer was clearly aggrieved about caring for his wife and the constant battle to obtain adequate respite resources. I was a member of the health service and was therefore ‘one of them’. He completed the interview and appeared to relish telling his story but I felt generally unwelcome and he was keen for me to leave. These people must feel so alone and frustrated by the lack of interest from many professionals and services. How can the process of respite be made slicker and easier for vulnerable people to navigate through?

Carer Deirdre (C9) had problems finding information about respite.

‘P: Well that was what started me thinking about it and then I started to make inquiries. The biggest problem I came up against with Daniel’s illness is finding out what services are available to us. Umm...and also how do I get referred to these services? And the GP...I presumed the GP would know but in fact the GP didn’t even know about the hospice. I had to have a telephone conversation with my GP to say please could you refer me to the NL (hospice)?’ (Deirdre, C9)

It may be reasonable to think that the GP should have knowledge of hospice services but, though this GP was considered to be effectual, she did not have the essential information to signpost the carer, whose mother did the background research. However once the respite facility was identified, the GP quickly expedited the referral.

One carer Sylvia (C8) was working in the health service so she had prior knowledge and understanding of respite but it was her mother who had made enquiries to find local respite provision.

‘P: I spoke to the doctor, the GP, and I said to her that my mum had just found out that St C’s did respite – St C’s has an enormous reputation locally, really, really good reputation so I spoke to the GP and said to her if that was possible and you have to refer, would you refer and she said yes, so I rang them and
they said yes, it has to be a GP referral so that’s how we went about it’.
(Sylvia, C8)

Access to quality information in a timely manner is essential (Arber et al. 2010) and barriers to meeting information requirements is usually due to carers not knowing where or who to go to and what they actually need to know (Sinfield et al. 2012). It is clear that often, in order to obtain the information required about respite, carers have to be proactive in requesting or seeking it out themselves (Bee et al, 2009) which may be haphazard, time consuming or later than would have been useful (Sinfield et al. 2012). This is an added burden to an already toiling person. When professionals are unsure of the respite services available this can also augment the carers anxiety and distress (Evans, 2013b).

4.2.1.2 Barriers to access, choices and appropriateness of respite

When patients and carers get to know about respite they then need to circumnavigate different options for care placements which can be limited. In addition, the selection process may be difficult to comprehend and the flexibility around the stay may be limited. Carer Sam (C4) theoretically had a choice of two places but one was too far away.

‘P: We had a choice of two from the PCT. Dansford or somewhere else miles away so we had no option. I knew Dansford was wrong when we went to look round but as I said we didn’t really have choice - my hands was tied behind my back at the time’ (Sam, C4)
Sam’s (C4) circumstances were that she required access to respite quickly as she needed to go away for a couple of nights to help her daughter. She therefore felt she had little choice as there was only one facility (Dansford) near enough to her home which was convenient. In relating this story she was visibly upset about the nursing home, namely the environment (no comfortable chair, no en-suite), attitude of staff (‘quick check over’ on admission due to being short of staff, no demonstration of dignity) and an apparent lack of attention to her husband’s needs, especially in relation to identifying when he became unwell from sepsis.

Carer Gary (C5) refers to the business of accessing respite as a ‘struggle’

‘P: Oh, we are actually having a period of respite coming up at the end of this month, ummm, although it was a struggle
R: In what way?
P: The county council said originally that they couldn’t fund Mary going into Sawbridge again because it was too expensive but I was quite adamant that there was nowhere else that provided the level of care to meet Mary’s needs which are fairly complex and very demanding
R: So what happened?
P: I have now got an agreement, at least for another visit and hopefully another go
R: They haven’t offered you regular respite?
P: Not the moment, no. That’s something I am keen on’. (Gary, C5)

Gary (C5) had managed to negotiate an agreement for another visit despite initial opposition. He had been made aware of Sawbridge hospice which had the added benefit of specialising in neurodegenerative diseases and had dedicated respite beds. He had the resilience to stand up to the authorities and demand that his wife received adequate quality care which he felt Sawbridge provided. The future remains
uncertain about continued access to this place of care and the struggle will continue. Gary (C5) had a strong personality and likened caring for his wife Mary to work which was unpaid. He recognised his need for respite in order to continue caring and he had the skill to negotiate with the county council. Many carers had to use their negotiating skills in order to achieve their desired place for respite. Many participants in the research were of a higher socio-economic class and therefore they may have been more articulate and able to argue their position and get the services they wanted.

Philip (P8) had accessed both a hospice and a specialist care home for respite so he was able to compare and contrast the advantages and disadvantages of each place of care.

*P: ‘The hospice is palliative care and most of the stuff is round the quality of dying. Cobra is all about the quality of living – which I am still doing’ (Philip, P8)*

Philip (P8) (and his caregiver Sylvia, C8) were well aware that he had a life limiting illness but wished to live life as long as possible. They looked for respite that reinforced the passion for making the most of what he was able to do and how that enriched his life. Cobra represented what was more meaningful for him as he wanted to focus on living rather than dying. This addresses how patients and carers consider the appropriateness of what they are being offered, regarding both the facilities and the care provided. In studies by Gardner & Kramer (2009) and McWilliam et al. (2008) concerns around care preferences towards the end of life for older people
and their family caregivers were examined, revealing themes related to ‘living your life while dying’. This illustrated the importance of attempting to maintain some semblance of normality for as long as possible and continue to enjoy living. Philip (P8) preferred to focus on the ‘quality of living’ rather than the ‘quality of dying’.

Issues around choice have featured in government policies over recent years (e.g. the Calman-Hine report (Calman & Hine, 1995), the National Cancer plan (DH, 2000) and the End of Life Care strategy (DH, 2008a)) but implementation has been influenced by local measures and allocation of monies (Slater, 2010). The NHS end of life care programme (DH, 2004) focused on choice using its specific end of life care tools, whose uptake countrywide has been variable. Of particular note was the ‘Preferred Place of Care’ plan (now known as ‘Preferred Priorities for Care’) which was designed to be a patient held record of preferences and choices which follow the patients into a variety of settings. Documenting patient’s preferences infers that choice is freely available but this has not always been seen to be true, depending largely on resources available (Storey et al. 2003; Wilson et al. 2011) which have been diverse and inequitable (Commons Health Committee, 2004).

4.2.1.3 Funding

Caregivers had little knowledge of the process around funding for respite and often came across it by accident, which does not seem to be noted in the literature. There was minimal knowledge available and families often had to do their own fact finding to ascertain the potential impact funding might have on the provision and accessibility of respite. When continuing care was applied for and agreed, the
process often became much easier and smoother. This participant Sylvia (C8), who was caring for her husband who had MS (Philip P8), was pleasantly surprised about the flexibility and speed of access to respite.

‘P: From the beginning of October till the end of December – 3 months.... but having said that we had a really good social worker who came and did all the paperwork with us and said you know I can help with the forms. I know what to tick. And it went through really quickly. She was great, really good. ....... and now because I need more respite and continuing health care recommended that we should have respite every 6 weeks but they weren’t offering the sort of money that would pay for the sort of respite we needed, but actually I was quite impressed because instead of saying that’s it, take it or leave it...because you do hear things don’t you?.. they did actually say ok we’ll have a chat about it and ring you back and they compromised and gave me half as many weeks at double the money so I’m now getting 4 weeks respite with them, provided by continuing health care, paid for by them and I get 2 weeks at St C’s, not requiring funding so that allows us a week every 2 months. And last year I was only getting a week every 6 months so....’ (Sylvia, C8)

The navigation through the process was beneficial for this family as they had a social worker to help them with the paperwork and to facilitate the process. Having a professional who knew ‘what to tick’ was a great asset and they were able to access respite through continuing care and also freely through the hospice. Sylvia (C8) became quite adept at determining how to negotiate more respite services by bargaining monetary value for the paid establishments (i.e. getting a higher cost centre for fewer weeks) and then supplementing that with access to the hospice which was free of charge and allowed her a set number of weeks a year. Her work in health care and her determination to sort things out enabled her to be more proficient with the system and navigation through it. She divided the time up to ensure she had regular breaks. Fundamentally her concern was the quality of care
her husband Philip (P8) received and she worked hard to safeguard that reassurance. It might be questioned how equitable this is when others receive extremely limited options.

Deirdre (C9) was a caregiver who worked in health care as a bed manager but was surprisingly unaware of what services were available. She heard about the ‘pot of money’ for respite / carer break quite by chance when she visited the local carer support branch.

‘P: I think it was the guy I met down in Banford carers who said to me that the government will provide funding to allow me to have respite care. So my understanding of that is that there is a pot of money allowed that is available for carers so that their patient / loved one can go away somewhere be it a care home or other type of care place while we have a break and it was actually that then I thought if that money is available I might as well make use of it and go actually and have a break. In fact it was interesting because once I linked up with NL Hospice it was Anne who assessed Daniel’s needs and it was she who approached continuing care and said we are eligible for this much but at first it was quite limited…’(Deirdre, C9)

Deirdre (C9) was unsure of where the ‘pot of money’ came from until she spoke to the community clinical nurse specialist who began the continuing care process by assessing Daniel’s (P9) appropriateness for this level of funding (see Appendix 5).

Similarly to Sylvia (C8), she had a professional who was able to assist with the necessary form completion in order to expedite this process which was a great help. Deirdre (C9) focused on her need for a break and most of the information she had received about respite had been carer focused although she appreciated and
acknowledged that Daniel (P9) was able to have his needs assessed and eligibility for continuing care ascertained.

Many placement choices are dependent on money and how the costs are being met. Generally nursing homes require payment from continuing care funding, whereas hospices are usually charitable institutes but have very few beds available and need to give priority to patients who require symptom control or end of life care. Some hospices may have continuing care funded beds (e.g. Sawbridge). The local authorities will always endeavour to place people in the least expensive options (e.g. care homes with minimal trained staff). Hospices tend to be more sought after than nursing homes because they incur no charge, have a higher number of qualified nurses and often good access to multi-disciplinary teams.

4.2.2 Knowledge and understanding of respite

The category of knowledge and understanding of respite included the subcategory of: the expectations of the stay. Some participants had some understanding of what respite was and had heard of it previously, often due to other family members accessing it.

\[P: \text{Yes, I’d heard of it, not necessarily to do with a hospice, but I’ve heard of other people having a relative go into, perhaps a nursing home to give the carer a break.........” (Patsy, C11)}\]

Frequently the issue was that they were not sure or had a vague understanding of their entitlement and how the process worked.
Gary (C5) was unsure who to discuss respite with. He was already receiving a sitting service one evening a week and on a Saturday (both occasions to watch his local football team play) but he did not recognise this as a type of respite.

On one occasion a caregiver Deirdre (C9) had heard the researcher speak of this study (although she had not connected that meeting with the request to be a participant with this research) and it had provided the trigger to consider respite as something she might be able to access.

It helped Deirdre (C9) start to make enquiries and she went on to seek advice from the local carers group and discussed it with the hospice community palliative care clinical nurse specialist and her GP. It was a good source of information and other participants noted their use of charity organisations for seeking out information and advice. Specialist associations are often organised by people who have been carers of loved ones who had that condition so their personal experience is invaluable. In general, people are more aware of the internet and how to access information, and these study participants were adept at this once they were able to ascertain what to
look for. This is possibly more indicative of a higher socio-economic group who possess the intelligence to pursue this avenue.

This participant, Sam, (C4) had a bad experience and was questioning her ideas around respite and what this should mean.

P: Well before you came I actually went onto the internet and looked up respite care, uummm to see if what I felt was respite care was wrong because I have been made to feel that what I feel respite care is about is wrong. And interestingly enough one sentence flew off the page which is this one here which is ‘respite also provides a positive experience for the person receiving care’ and to my mind that actually sums it all up so Simon should be able to go somewhere he has the facilities of Green Acre during the day where he can chat to other people, ummm where he can have art therapy, he can have massage, he can have reflexology – all the things that are there that he loves and have a nice lunch and the rest umm, and not in a hospital situation - in a home from home situation.... (Sam, C4)

Sam (C4) had expectations of respite because her husband Sean (P3) already accessed weekly day services at the local hospice which he greatly enjoyed. She had also looked up a definition of ‘respite care’ on the internet and this reinforced what her expectations were – as well as carer break it should also be a good experience for the patient. The carers had differing priorities and notions regarding who the respite was primarily for, but each of them always wanted to secure the best possible care for their loved one, thus ensuring a good experience for the patient.

It might be considered unreasonable to expect a nursing home to be able to achieve what a hospice can in terms of care and review of the patient–carer situation.

Nursing homes are established to provide basic nursing care for activities of daily
living. This will normally be provided by unqualified carers with support from a very small number of registered nurses. GP’s will only visit on a pre-arranged (usually weekly) basis to provide general medical care, contrasted with hospices where full time specialist palliative medical input and other disciplines are available. If patient’s needs are purely care needs (i.e. assistance with personal hygiene and mobilisation) then a nursing home would be considered a better option, as opposed to a hospice where high level and specialist care is available to those who need it (e.g. patients with neurodegenerative diseases).

4.2.2.1 Expectations of stay

The perceptions of the purpose of respite for the patient were mixed. Many thought that a review of the patient’s overall situation would be beneficial. Carer Sally (C6) was preparing for a respite stay in a hospice where they have medical and nursing cover. She had been experiencing restless nights with her husband Paul (P6) so looking at his sleeping patterns, as well as a general review of his medication, was reported as being important.

‘P: I hoped they would sort out his sleeping problems which they did do, they sorted that out and what else did they do? They put him on the right medication… to sort that too’ (Sally, C6)

There was also an element of advice, information and signposting for relevant help and support which the caregiver or patient may not even be aware of. They acknowledged that their understanding of the disease and its manifestation may be unknown territory and any assistance was gratefully received.
P: I thought, well you know that they may come up with ideas of doing things I don’t know about having had patients with Motor Neurone Disease. For me, I’ve never known anybody with it and we’re just learning as we are going. And we’re.. we are sort of dependent on people telling us: well you can do this, you can do that without, you know, our knowledge that there is such a thing. You know what I mean? I thought if he was in there somebody in there may say oh well what you want to do is...is this. (Patsy, C11)

This caregiver Patsy (C11) was actively seeking some advice and guidance about caring for her husband Jim (P11) who had MND. She was very open to new ideas and ways of performing care. She acknowledged she was learning by experience, just picking things up as she went along and relying on professionals to tell her what she could and couldn’t do. Patsy (C11) felt a distinct lack of preparation and knowledge in the caring role that she felt the respite experience could help with.

One question that arose was if those admitted to the hospice for respite had different needs to those who were admitted for terminal care or symptom control.

During non-participant observation at a hospice that had a dedicated respite bed, an interview with a ward sister and a health care assistant reported that they felt those patients who were there for respite, terminal care or symptom control had the same specialist needs, although they should be generally more medically stable:

R: When you have a respite patient in, do you see them as having different needs to the other symptom control / terminal care patients?
WS: ‘Used to, but not so much anymore. Because our respite patients... a lot of our patients are very complex and have a high level of need, ummm.... So I think there is a sub-conscious assumption that they might be easier but that is no longer the case. Ummm... years ago maybe when they all had performance status 1 but now most of them are performance status 4 and have a lot of need and, although they might be better symptom controlled and don’t need lots of stats (medication) like lots of the other patients, they clearly have
needs in a different way. So I think they should be viewed........ I think they are viewed differently but I think they should be viewed similarly to the patients we’ve got because they’re here for a reason; they’re here because they’ve got palliative care needs. If they could be in a NH, they’d be in a NH. So I think they should be viewed as holistically as any other patient.’ (Ward Sister, hospice).

HCA: Well I think they’ve all got their own needs and you treat them accordingly whether in for respite, or they’re dying or............whatever. You see what their needs are at the time. (Health Care Assistant, hospice)

The staff members above focused on the importance of assessing needs and patient centred care. Life limiting illness will always require ongoing assessment as things change regularly and that mirrors the philosophy of palliative care. Conversely a patient who had MND, Penny (P12), who had also previously been a health care professional, thought that a respite patient had contrasting needs. At pre-assessment (completed at home) she had been asked what she would like to achieve and she had specified three things but unfortunately these had not been addressed during her stay. She felt let down and disappointed by this, although generally she had remained positive about the respite experience.

‘P: I felt that when I had asked twice to see the chaplain, I actually felt well...I feel now I had asked twice, I had told Pete (discharge planner) before I went in, we talked about that, that actually that should have been something that should have been followed through on the staff’s part. I think my expectations were a bit higher than the reality. I would recommend it but I would really recommend they (others accessing respite) clarify everything they want to get from respite. And also, I think the needs of people going for respite are very different from the needs of those that are going in there uh, you know for end of life care or symptom control. (Penny, P12)
Penny (P12) felt that patients nearing the end of their life required different care – i.e. they might require specialist input and medication. She wished to distance herself from end of life care as she felt she still had some living to do. She was looking for a different set of skills – somewhere they could safely meet her care needs and medication administration but also focus on her quality of living such as stimulation of her mind via activities and to experience some pampering.

4.2.3 Respite as restoration for the patient

The category of respite as restoration for the patient includes the subcategories of: access to specialist disciplines; facilities, care and activities available; the desire to address mind and body, trying out new equipment in a safe environment and building relationships with health professionals and future plans.

4.2.3.1 Access to specialist disciplines

A positive aspect of respite care for the patient was access to members of the multi-disciplinary team, (mostly physiotherapists, occupational therapists and speech and language therapists) and an opportunity to receive individualised care on a regular basis during the respite admission which could target specific issues that cannot be met at home.

R: Did he see any therapists? Any kind of, anybody like physiotherapists, OT’s anyone like that?
P: Yes they all came to see him. The OT came to see him and a physiotherapist came to see him, didn’t they? (asks husband) And asked us what equipment we had at home. And they were the ones that got us the hospital bed...... it wasn’t in place when he came home but it was few days later wasn’t it? (asks
husband). And they gave us a turntable, and a slide sheet, umm, I already had a handling bout. I think that was about it, wasn’t it (looks to husband for confirmation). Yes. (Sally, C6)

Sally (C6) was delighted that her husband had access to all disciplines in the hospice. His needs were constantly changing due to his deterioration in mobility and therefore he required ongoing review of equipment needs and care which the respite afforded him. He was able to be reassessed regarding his equipment needs and ensure this was delivered before, or soon after, discharge.

Similarly this carer Patsy (C11) felt that the respite had been conducive for her husband.

‘P2: Um, he definitely saw the physio and the OT on more than one occasion and they tried to use the...uh they did some massage and stuff and they were looking to see if they could use another neck support and that’s why we came back with one of these, with a different type of neck support. And they also tried the eye gaze technology, communication.....’ (Patsy, C11)

Jim (P11) had accessed respite in a hospice. He had advanced MND and was progressing. His muscle tone was deteriorating; therefore he needed more neck support as this was beginning to make sitting out in the wheelchair uncomfortable. In addition, his communication was being affected as he was unable to use his electronic devices due to loss of muscle power and fine movement in his upper limbs. His respite stay allowed an opportunity for many disciplines to assess him in order to ascertain if there were any further aids or supports he could be offered. He
was able to successfully try a full hoist as his ability to move had greatly deteriorated. A hoist was then ordered and arranged for discharge.

4.2.3.2 Facilities, care and activities available

For some patients and carers the social activities and nursing care that was available were important. Gary (C5) was delighted his wife Mary, who has Huntington’s disease, was able to participate in social activities as her condition left her physically disabled.

‘P: Yes, they involved her in a few activities, ummm, she did a little bit in the garden, umm she also got involved with some painting’. (Gary, C5)

Penny (P12) was looking forward to the holiday aspect of respite as her usual life was quite humdrum and routine. She was a young woman who used to enjoy beauty pampering.

‘P: I didn’t really have any expectations apart from what Pete had told me about there being a massage therapist and things going on there that... R: Did that appeal to you, or were you not worried either way? P: Oh no, it appealed to me greatly, I thought it would be fantastic to go in and have a bit of pampering’ (Penny, P12)

Penny (P12) was pleased about the prospect of complementary therapies which are usually readily available at hospices, normally provided by volunteers. Patients can access these different therapies via day and inpatient services / respite. Penny’s (P12) focus was on the social activities which were a real treat for her as usually she spent her day at home with minimal external social stimulation.
Similarly carer Sally (C6) was impressed with the total care given to her husband and how his day was filled with activities.

*P:* They gave him a lovely bath in there. They had a deep bubble bath, like a spa bath. And they gave him one of those. During the day, what else did he do during the day? They took him for walks, they have beautiful gardens there so we used to go out in the gardens didn’t we? And when I wasn’t there and it was a nice afternoon, they’d take him out in the garden’. (Sally, C6)

Paul (P6) accessed respite in a rural hospice and Sally (C6) describes the ‘lovely’ experience of her husband Paul’s respite with many different aspects including a relaxing spa bath, beautiful gardens and a thoroughly nice environment to savor and relax in. They were both able to share the aesthetic surroundings which added to their overall pleasure.

4.2.3.3 Desire to address mind and body

Patients and carers were both keen to emphasize that although they were living life via a diseased body, their hearts and minds remained alert and active. Patient Sean (P3) spoke longingly of what he wanted from a respite stay. He felt frustrated that he wasn’t being seen as a whole person because of his neurodegenerative condition.

‘P: ’Well yes, physiotherapy and other activities. Ummm, stimulation of mind and body. Exercises, walking which is a major problem. Ummmm, mental activities like, silly things, like quizzes and things. That sort of thing........’

(Sean, P3)

Carers worried about particular environments for accessing respite as they felt this would be of little benefit and would not provide what their loved one required.
Patsy (C11) wanted respite in the hospice and is critical of what an ‘old people’s’ home could offer.

‘P: I would feel less happy Jim going in to, say, an old people’s nursing home; uh I feel that that just wouldn’t be the right place for him. He has absolutely nothing wrong with his mind, you know, there’s nothing...he doesn’t want to be...you know he needs, I think with the hospice, things are going on all the time and therefore it is a very different environment to an old people’s home.’ (Patsy, C11)

In addition to Sylvia (C8), Patsy (C11) also had friends with neurodegenerative conditions who had accessed care in nursing homes with negative results. She had been put off from this option by what she had heard from friends and felt it wouldn’t meet her husband Jim’s (P11) specialist care needs.

Carer Joy (C10) felt that an important part of her husband Bert’s (P10) respite experience was the social interests on offer. Friends and family visited regularly but unfortunately Bert (P10) went into a nursing home for respite where the experience was not good on many levels. His mobility had been deteriorating but he was still able to do some things for himself, albeit extremely slowly. He required assistance but also time to complete movements and care. The social activities available were few and far between and often his personal care delayed him attending those that were offered as he had to wait for assistance when staff were available.

P1: Well, Bert’s mind is still very active and he likes to be with other people, he doesn’t like being isolated ummmmmm....and he likes taking part in the activities that he can participate in, he can’t do anything where you are
playing any games or anything like that as his manipulation is almost non-existent’ (Joy, C10)

4.2.3.4 Trying out equipment in a safe environment

Having a neurodegenerative disease means that care needs change constantly and there are very few periods of lengthy stability. The carers become proficient with a piece of equipment and then the patient’s condition dictates a necessary change to an alternative. This is also daunting for the patient and being able to try out new equipment in a safe environment can be reassuring for both patient and carer.

‘P: I had hoped, well, I had hoped they would find better ways of doing some things. That, and in some ways one thing that has come out in that he was happier to have the bottle, whereas we were always putting him on the commode and that is quite, you know moving Jim with slings and you know, having to have extra help whereas he came out and seemed quite happy that a couple of times a day at least he would just have the bottle, you know, I can sit with the bottle and the chair and that’s a whole lot less hassle, uh than he did when he went in. So I was quite pleased about that. I was hoping that they would find more ways of helping with his head, but we haven’t really come to that conclusion. And the other thing was that they had something called eye gaze, which I was hoping he would have a go on that to see if it would work. I think they did try. It is a problem with Jim’s head, so we haven’t really established if that will never work, or if it just needs more, you know’ (Patsy, C11)

This hospice admission resulted in several adjustments for the patient. It was a time where they could experiment with different pieces of equipment, particularly related to moving and handling. Jim (P11) could explore this apparatus safely and with confidence and he felt more contented to use the urine bottle which reduced the amount of moving and handling for his wife Patsy (C11).
Carer Pat (C2) found her husband’s attitude to equipment frustrating as he tended to ‘make a fuss’ about changes. She felt respite would give him an opportunity to see other people utilise different equipment and become naturalised to them.

‘P: The ability to use implements (for feeding) and not make such a fuss about wheelchairs. Familiarise himself’. (Pat, C2)

Pat (C2) was keen to get equipment and aids sorted and felt her husband Chris (P1) was being obstructive in moving this forward. Many patients find it difficult to accept their failing health but carers are more readily able to do so as they are the ones providing the practical care and appeared to be more realistic about managing daily care.

4.2.3.5 Building relationships with professionals and future plans

Future plans when there is an uncertain outlook meant that patients and carers wished to begin to familiarise themselves with people who would play a large part in their future care. It was likely that they would need the hospice’s input in time to come, especially for community symptom control and possible end of life care. For those that received respite from the hospice, this gave them an opportunity to meet professionals in a non-threatening manner. This patient felt so confident that he began to plan for future residency.

P: It takes about a week for them to get to know you and you to get to know them. So the second week was very much easier.......I made overtures to them about becoming a permanent resident and they said they would be happy to have me (Cliff, P13)
Cliff (P13) had not previously considered long term care at the hospice. He had been a resident in a nursing home for a short period of time but this had not worked out so a care package had been arranged to support his ongoing care at home. His hospice respite experience had been so good and felt right that he then began to think of long term arrangements (this hospice had a very limited amount of continuing care funded beds – this is unique for a hospice but it is due to it being a specialist neurological unit). He had met a gentleman during his respite admission who stayed there long term and he had realised that by residing there he would be able to access so much more than he was able to at home.

Respite, as a commodity, is limited due to pressures on valuable resources. There is some availability in different places of care, the majority of which is offered in nursing homes, some of which offer ‘specialist’ care (see Appendix 6 for the availability of respite care in the UK).

Respite in the right environment with appropriate resources (e.g. a multi-disciplinary team), can have many functions such as carer relief and stimulation (participants C4, 5, 6, 7, 8, 9, 11 and 13), patient review of care needs (participants P6, 7, 8, 11 and 13), patient socialisation (participants P1, 5, 6, 7, 8, 11, 12 and 13), advance care planning for preferred place of ongoing care (participant P9, 13) and the ability to continue living at home (participant C4, 5, 6, 7, 8, 9, 10 and 11), particularly if that is the preferred place of care (Evans, 2013b), which may benefit patients and carers in
their journey towards death with a neurodegenerative disease. An opportunity to engage and trust professionals is also important for the future (Foley et al. 2014).

However, not every respite experience is good and the data reveals that it can be an onerous task in chasing information to access respite, and that funding is key to achieving the appropriate specialist care that patients with neurodegenerative diseases require and carers need, in order to entrust their loved ones to respite. They are also able to mix and match different forms of respite, according to needs. If funding and care is adequate and timely, the respite experience can add value to the patient by exposing them to facilities, equipment and social interests which focus on them as an individual, providing additional support and an infrastructure fit for their future care.

### 4.3 Theme two: The Order and Chaos of Respite.

The second phase in the journey is that of the order and chaos of respite. Once respite had been identified as an option, the admission is planned. If this is the first time respite has been offered, the patient and carer can both encounter a level of uncertainty about the forthcoming experience (Gilmour, 2002; Russell, 2010). The patient may feel vulnerable about accepting care from unknown people and the carer may find it difficult to hand over that responsibility to others (Gilmour, 2002). This theme is part of the journey towards accessing respite and evaluating the worthiness of it as an intervention and as an experience. The order and chaos of respite is formed from the categories of control, checking up and surveillance and maintaining normality (Table 4.4).
Table 4.4: Categories and subcategories of the theme ‘The Order and Chaos of Respite’.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
<th>Subcategory</th>
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<tbody>
<tr>
<td>THE ORDER AND CHAOS OF RESPITE</td>
<td>Control</td>
<td>Preparation, Handover and Communication</td>
</tr>
<tr>
<td></td>
<td>Checking up and Surveillance</td>
<td>Expert Carer, Quality of Care</td>
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<tr>
<td></td>
<td>Maintaining Normality</td>
<td>Routine, Compromising</td>
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4.3.1 Control

The category of control includes the subcategories of: preparation and handover and communication. A feeling of being in control was important for many of the carers with some feeling more strongly than others about it. This carer Sylvia (C8) was concerned about things being done well and properly and staff knowing her husband and his care needs.

‘C: Ummm.. practicalities are fine, that’s not a huge problem, ummm......yeh, just not quite knowing quite what to expect........... ummm....wanting to not to have control or have to have control of everything but actually being quite nervous of losing control of everything....if that makes sense? I’m a bit of a control freak, being worried that things wouldn’t be done properly, ummm.... You know, knowing that if he doesn’t have the cream on his face his skin falls off... ummm you know, just worrying that things would be worse when he came out than when he went in’. (Sylvia, C8)

Sylvia, (C8) was very concerned and nervous about losing control of everything. She works as a health care assistant in a mental health institution and describes herself
as a ‘control freak’. Her main concern was care not being carried out thoroughly. These concerns have been found in other research; for example, Kaarbo (2011) looked at the family perceptions of good end of life care in nursing homes and found that attention to detail and individualized high quality care was considered to be of ‘great importance’.

Sylvia (C8) describes her husband Philip’s (P8) specific needs related to skin care and she is concerned that he will come out of the respite care in a worse state than he went in. This stemmed from the experience of her friend who also supported her husband who had a neurodegenerative disease and who had been admitted to a nursing home recently. He had come out with serious pressure ulcers due to poor care. She was understandably concerned about this, as the period of respite ended with more care needs and the serious situation of a pressure ulcer that had not existed previously. A need for carers to maintain a level of control and to feel confident that their loved one will be well cared for is a key aspect to coping with uncertainty. Strang, Koop & Peden (2002) also found that a carers coping strategy was to endeavour to maintain some level of control but this could be well managed if health care providers listened to the caregivers and took time to understand their needs and concerns (Sandberg, Nolan & Lundh, 2002).
4.3.1.1 Preparation

Preparation for going in for respite could be seen as hard work and similar to a military procedure. This carer Deirdre (C9) of her husband Daniel (P9) who has MND reports:

‘C: Ummm...yes, that in a way, now that I’ve done it a couple of times I’ve got it all on the computer but actually it’s not as easy as you think because there’s an awful lot of meds, there’s an awful lot of time medication – there’s the clexane injection, the feeds overnight umm and also I had to take it all in the car because they wouldn’t send an ambulance and my sister came along with her car because I also had to take all my equipment... and I had to make sure we had the right bed, that we had the right chair, ummm and that they had the pressure cushion. They had the chair, they had the bed but they didn’t have the pressure cushion for the chair, they didn’t have the feeding pump they didn’t have the suction pump, they didn’t have the rotating stand’.
(Deirdre, C9)

Deirdre (C9) uses her computer to store information about the needs of her husband, particularly relating to his medication and injections. The carer’s responsibility regarding managing medications has been found in other research. McNamara & Rosenwax (2010) reported that carers identified, amongst other things, a need for help with medication management from health services. This carer also had a lot of equipment to cope with such as feeding pumps and pressure cushions which did not seem to be available in the respite facility, according to Deirdre (C9).

Similarly Sylvia (C8) found herself doing much running around to prepare her husband Philip (P8) from all angles for the respite stay. A great deal of planning by the carer goes in to the respite stay including considerations regarding medical cover:
‘C: I had to ask our GP if she would be prepared to go from here – she’s just up the road, to Cobra and they said no, they wouldn’t do that. He would have to be registered with the local GP, temporary registration, and I had to get written permission for them to crush his medication to put it through his PEG, from my GP to say that was OK, which obviously I don’t for St C’s. So more sort of medication issues, more things to make sure I’d done in that respect but now I’ve done it I’ve got a copy of the letter on file and that’s fine.

R: Did that feel like a burden at the time?
C: Umm, it is an extra job isn’t it? Everything’s an extra job, ummmm but now I’ve done it.... (Sylvia, C8)

Completion of these tasks was seen as jobs well done and useful for next time. This carer commented about everything feeling like extra work but necessary.

Carer Pat (C2) likened the volume of packing and overall preparation to having a toddler and taking them out of the house.

‘C: You certainly had to deal with it, you make lists and that, he’s got his medicines which are quite complicated. I had to make certain he had all his clothes and he knew where everything was and he wanted to take the computer with him and all sorts of stuff like that I mean it was like taking a toddler, everything. (Pat, C2)

Pat (C2) describes how you need to be organized, make lists and plan for the respite admission. This is to enable the loved one to have everything they need to make their respite stay as comfortable as possible.

4.3.1.2 Handover and Communication

The handing over of care can be poignant for the carer who understands that the patient may feel very vulnerable and unsafe. Carers can sense they are relinquishing their duties (de la Cuesta-Benjumea, 2010) and they need to ensure that they relay
all relevant information (e.g. specific care needs) in a thorough and timely manner. They need to feel reassured and trust the carers who are taking over this responsibility (Soltysiak et al. 2008).

Sylvia (C8) is particularly adamant that her handover to the respite staff is acknowledged by them. Her way of ensuring her voice was heard was to complete a personal care plan. This reassured her she had done all that she could to ensure a safe and pleasant respite stay.

‘C: Ummm, there usually has been, it’s progressive so there’s usually something (to handover). Yes, I do and I just feel more comfortable seeing him settled. I don’t think I could cope so well with him being collected and taken. And he can’t speak for himself very well, and his voice has always fluctuated so if I say the things I know they’ve been said and I have admitted to being a control freak already (laughs). Yeh, ummmm.. I still don’t like it. I don’t like the walking away bit… .... I did a 7 page care plan (laughter) they were really good about it and they said that’s great and actually they kept it and then gave it back to me and said........I did a page on bowels, a page on skin viability, I did medication, I did everything, ‘cos in that way I knew it was all there. (Sylvia, C8)

Once again Sylvia (C8) laughs about her ‘control freak’ nature and recognises that the professionals understood her anxiety but welcomed her expertise and organisation. She explains that once the care plan had been written she felt a positive sense of achievement as it was something she can keep and refer to. Sylvia (C8) was particular in writing down the care whereas others felt a verbal handover which was listened to and recorded by the professionals was sufficient.
The lack of ability to communicate makes the patient extremely vulnerable and was mentioned by several participants (C5, 6, 7, 8, 9, 11). This made the carers even more adamant about making sure handover was clear and understood by those taking on the caring responsibilities.

Sylvia (C8) and Philip (P8) were receiving respite care in two organisations – a hospice which was able to offer a comprehensive review of his physical and nursing needs and access to equipment and advice and a neurological home that offered excellent nursing care and stimulation of his mind. Both institutions provided different aspects of care for Philip (P8) and addressed both his physical and social needs.

This carer, Deirdre (C9), had experienced unwillingness for formal carers to get to know her husband Daniel (P9) and how he communicated. She tries to justify her dissatisfaction by being forgiving about their lack of knowledge initially.

‘C: I don’t mind people who haven’t met Daniel before for the first time – I don’t expect them to realise they have to ask a yes / no question because we aren’t naturally good at that and I don’t expect them to know straight away how to communicate with Daniel……but I do expect that after a while’.  
(Deirdre, C9)

Daniel (P9) had lost the ability to speak but had limited movement in his fingers so he used a light writer. It was laborious work as he was very slow but it did allow Daniel (P9) to communicate exactly what he wanted to say. Deirdre (C9) has expectations about the way paid carers should communicate with her husband Daniel. She expected professionals to explore ways to communicate with him ‘after a while’ and
attempt to understand his problems. This is pertaining to having the skills to communicate with people who have lost the ability to speak and who are unable or need time to use electronic equipment due to muscle loss and wastage caused by their neurological condition. Finding a way to communicate effectively with the person is fundamental to the success of respite stays for vulnerable people with speech disabilities.

Carer Joy (C10) talks about her experience of respite in a nursing home when her husband Bert (P10) had to go there whilst she was having essential adaptive work done to their home.

‘C: From the assessment, I thought the person, the Care Manager, was a very approachable person. We were quite impressed with her, weren’t we Bert? And it did give me confidence but we were so upset by the end of the time that he was there that we did write an official complaint. We looked at it within the areas of: hygiene, dignity, nutrition, mobility and skincare. Bert likes being shaved every morning and this wasn’t happening, for one thing. My daughter and I went to see the Care Manager and raised all our concerns and she said she would see that this would happen, that he is shaved and have his teeth cleaned. In fact she put....the next time I went in there were large notices on his bathroom door saying ‘Mr Snow must have his teeth cleaned every morning’, and I thought that’s such a basic......who needs to be told that somebody needs to have their teeth cleaned? So, ummm....Yes, she fixed notices to say that he should be shaved daily and have his teeth cleaned both morning and evening. But despite these prominent notices, we felt shouldn’t have been necessary in the first case, later that same week a carer told Bert he didn’t need a shave once a day, and Bert said he did, as he always had a shave daily...’. (Joy, C10)

Initial thoughts were positive about this care home but ended in a complaint about the level of care being delivered. Bert (P10) had some dexterity but needed support and assistance to perform his activities of daily living. He was also able to mobilise
small distances and transfer with assistance. All his movements were slow and required patience and understanding. Joy’s (C10) absolute horror of the situation regarding formal carers being briefed about basic care needs (and then ignored), demonstrates how distressing it is for carers to witness such poor care. This fits well with the overall negative attitude to nursing homes that the public tends to have which is often due to the employment of unqualified carers who are given minimal training and are paid a basic wage. They may have little experience, training and passion for caring for this group of patients with MND (Castle & Anderson, 2011).

Control and acceptance of the ever changing situation by carers was sometimes more evident. The carers endeavoured to accurately report the needs of their loved ones to the professionals, thus demonstrating their expertise, proficiency and understanding of the care required. The assessment and evaluation of the care being delivered during respite links with the category of checking up and surveillance as this further explores the concept of the expert carer.

4.3.2 Checking up and surveillance

Throughout the study, carers referred to frequent visiting during the respite admission as they felt a need to constantly monitor the quality of care. This was to ensure their loved one was not being neglected or compromised in any way. Quality of care given and received can be of great concern and the caregivers may see regular monitoring of care during respite as one of their key roles (Davies & Nolan, 2006; Hertzberg & Ekman, 2000).
The category of checking up and surveillance includes the subcategories of expert carer and quality of care.

4.3.2.1 Expert carer

This carer, Sam (C4), felt uneasy about placing her husband Sean (P3) in the respite facility. She gives examples of information she has handed over with regard to his routine and essential nursing care which were not carried out.

‘C: ..................... and when I was there I said to the person, one thing Sean needs is an upright chair like he has upstairs. She said no problem; we can get one because there wasn’t any in the rooms. So the first day we arrived no chair, just an ordinary little round, social chair I call it – certainly not suitable for anyone who has got any problems so I had a word with them about that and they said yes, yes we’ll look for a chair, etc, and I also pointed out to them that because of his bowel cancer he goes at certain times during the day – he’s sort of trained himself and umm, if possible get him to walk to the toilet to keep him mobile. Well they didn’t do any of that. The times went out of the door; he came home chronically constipated which took us 3 weeks to get sorted. He came home with a urine infection. When I went to pick him up on the Sunday and I took one look at him and called the nurse and said he’s ill there is no way I can take him home, you know I am sure he’s got a UTI, had anyone checked it? No. ..................... So he was so weak.... he also suffers from postural hypotension so I could see he was almost gone, so I actually said to the nurse we need to get him on the bed and raise his legs up and bring him back. But if I hadn’t turned up then I don’t know what would have happened – he would have been left sitting in a chair and he may not be here now because the sepsis takes over so quickly...’ (Sam, C4)

The acquisition of resources such as chairs and other basic equipment was a recurring issue. Sam C4 had to fight hard to ensure the provision of this equipment in their home and then was denied it in a care institution offering respite, which led to her frustration. There was no follow through of her instructions regarding his bowel
care which had been carefully orchestrated to achieve a satisfactory outcome. The consequences of fundamental care not being given were far reaching and could have been more serious. She was aware of how quickly things change and acted accordingly but there seemed no sense of urgency from the care home staff when he became unwell. It was left to the carer to take charge of the situation.

This carer, Elsa (C7), can instinctively tell if her husband Isaac (P7) is not comfortable even if he appears to be.

‘C: Yes, I mean sometimes if I go there I can see immediately looking at him that he’s not particularly comfortable in bed because he has a particular way…. I mean I know whether he’s comfortable or not but they probably think that he’s comfortable; with his cushions around him…a lot of people would be but I know he isn’t….‘ (Elsa, C7)

The refreshing and common sense nature of this carer lends itself to understanding that professionals will not possess that tacit knowledge about the patient as well as she does but that is to be expected and acceptable.

Informal carers have often explored several options for care delivery in order to find the most convenient, efficient and effective method. Professionals should acknowledge this and regard them as equal partners in care (DH, 2008b & 2010a). Davies & Nolan (2006) looked at older people in care homes and found that the caregiver would spend time ‘keeping an eye’ on the quality of care being given to their loved one and would feedback comments to staff which satisfied their control.
element and also ensured ongoing monitoring and engaging with staff. They were able to say what routines, likes and dislikes the person had so that care could be delivered with these in mind (Hertzberg & Ekman, 2000).

4.3.2.2 Quality of care

This patient, Penny (P12), felt that having to repeatedly explain her care to professionals was extremely wearing.

‘P: No I wasn’t worried about that (referring to the quality of care), I was worried about having to explain everything, explain how I am cared for, how I need to be cared for, because it’s exhausting you know’ (Penny, P12)

Penny (P12), who was an ex-healthcare professional, felt that it was unnecessary and avoidable because care could and should be handed over, both verbally and by care plans, between professionals. She was concerned about explaining care because she used non-invasive ventilation* all day (due to her weak chest muscles affecting her ability to breathe) and this meant that talking was exhausting. She had already had an assessment at home, prior to admission, where she had explained her care routine and needs. Her concern was about having different carers on each shift that might not consult the care plan and expect her to explain her care.

*FOOTNOTE: Non-invasive ventilation (NIV) is a form of ventilatory support that does not require endotracheal intubation (Woodward & Waterhouse, 2009, p 374). It reduces the work of breathing when respiratory muscle weakness, resulting in respiratory impairment, is a problem which is common in motor neurone disease. Many patients have to eventually use NIV for ever increasing periods of the day and night as their muscles continue to deteriorate. It was used by two of the study participants and makes speaking extremely difficult, laborious and exhausting.
This carer, Rose (C13), was passionate about care environments meeting the needs of patients. She compares and contrasts the ‘state’ of her husband Cliff (P13) after experiencing a nursing home respite stay and then a hospice respite stay.

‘C: I think if they found something suitable for whatever illnesses they have got, instead of just any old place, they’ve got to really check what the person needs. And where the best possible place for the care that person needs, because it makes a lot of difference. Because when he came out of the…nursing home……he was in a terrible state, it took quite a while to get him back to normalisation. But when he came out of Sawbridge (hospice) he was a different...different man’ (Rose, C13)

The work involved in returning the patient to ‘normalisation’ (what he was like at home prior to admission) totally negates any benefits of respite that the carer may gain.

Carer Sally (C6) speaks of her visiting regimen to make sure ‘everything was alright’ as it was the first time for her husband Paul (P6) accessing respite.

‘R: Did you go down every day to see Paul? C: Yes, every afternoon and then I came back (home) for a little while then I went back in the evening and stayed with him for a few hours. I know perhaps I shouldn’t have done but as it was the first time I wanted to make sure everything was alright’. (Sally, C6)

It was her expectation that she would need to do this. She recognised her husband Paul’s (P6) vulnerability in a strange place and strove to ensure he was well cared for, although she (and Paul) did know and trust the hospice and staff as they were already known to them.
Redfern (1993, p. 141) says that quality is such “an esoteric and personal a concept that it is difficult for any two people to agree on what it is”. It is usually a product of interaction between the patient and the health care professional, taking into account particular beliefs and values of the individual.

4.3.3 Maintaining normality

Maintaining normality and continuing a normal life for participants primarily centred on the importance of a routine. The desire to create a semblance of normalcy within the chaos of caring resounded with both patients and carers. Both the person with the illness and their carer strived to continue their life but they both had to make certain adaptations. Curtin et al. (2005) looked at patients with chronic renal illness and discussed the concept of self-management in everyday life and how personal ‘normality’ consisted of having to change in response to a chronic illness with the patient focusing on a differing ideal and having to realign what is going to be their norm.

The category of maintaining normality was made up of the subcategories of routine (which involved positive and negative aspects of the patients and carers experience) and compromising, (which entailed both patient and carer understanding that care in respite might not mirror care at home).
4.3.3.1 Routine.

The patients reported that the routine of basic care was of paramount importance and was crucial to how their day was organised. If the patient’s or carer’s perception was that their routine wasn’t acknowledged and followed, (as much as was reasonably possible) during respite, it could potentially have devastating effects.

One patient, Sean (P3), received respite in a nursing home. His wife Sam (C4) was extremely distressed at the level of care she and the family witnessed given to Sean.

‘C: He never had a chair - they never gave him a proper chair. They got him up in the morning and he sat in that chair (wheelchair) until lunchtime when they took him in to have some lunch brought him back to his room and he sat there, had his supper there, got him out of there and put him to bed. I think the routine over there is almost inhumane. For 10 days he was strapped in his wheelchair’. (Sam, C4)

Sean (P3) was bed to chair dependent but continued to engage meaningfully in activities, if given the opportunity. A proper arm chair resembled to them a level of conventionality and independence. To be left in a wheelchair felt undignified especially as he was ‘strapped in,’ and after numerous requests for a proper chair had been made by the family. Sam (C4) uses strong language in describing the routine as ‘inhumane’ and felt passionately that the level of care in this nursing home fell far below what is acceptable. This experience had been seven months previously but still felt distressing and raw for Sam (C4).
Routine provided a much needed structure and often ensured an element of control for the patient and the carer. The timing element of the routine was fundamental. This provided order to the patient’s day and was instrumental in ensuring efficiency. Home life centred on a good routine and the success of a respite admission could be heavily weighted on the ability to adhere to that same routine (Davies & Nolan, 2006).

Daniel (P9) felt that one of the very few things he had left available to him was the ability to bring order to his care by directing his routine. At home he received a one-to-one care package that afforded him this opportunity but an institution would find it hard to match that level of input.

‘C: Do you want to answer these questions sweetie? Were you given choice? Did they ask you what your day was like so you could answer in a yes or no way? (NB: patient unable to speak – uses hand signals and light writer). 
Pt puts thumb up. Wife asked him if they also came in and did things to him without asking and he put thumb up. Wife said to husband that when he returned from home he said on light writer that he felt nurses were bullies – husband said yes – laughter about the language he had used to express this’. (Daniel P9) & Deirdre (C9)

‘C: He wanted to be out almost the 2nd day he was there. I think to Daniel it is very important as he does like things done by a certain time but obviously we had to explain that you do have to fit in with the routine here’ (Deirdre, C9)

Daniel (P9) felt strongly that the nurses had been ‘bullies’ as they had come in and ‘done things to him’. He felt that the nursing home was more suited to patients with dementia and not people with neurodegenerative conditions who had specialist care needs such as communication. He had tried to communicate what he had wanted but the detail and desire to get it right was missing. He liked things done at a ‘certain
time’ and this was individualised to his needs. Unfortunately when accessing respite care he had to fit into the timetable of the care facility.

From the carers perspective, the routine being followed during the respite stay could be so reassuring that they didn’t feel they had to visit during the admission, although they did acknowledge (to a significantly greater degree than the patients) that institutions are unlikely to be able to exactly follow a personalised routine because of competing demands.

‘R: And did they stick to the routine that you had, kind of going at home? C: Yes they did.
R: Did they talk to you about what that looked like? Did they ask you about it? C: Yes they did. They said did it work for me. I said yes, he likes this routine and these times are fine, all the medications... and they just followed the same pattern all the way through, they followed it and they were good................ ’ (Sally, C6)

The concept of ‘routine’ could be considered to have an association with ‘rituals’ which can be thought of as symbolic in many ways (Philpin, 2002). Often ritualistic behaviour can be viewed in a negative fashion but it can also contribute to a sense of normality for patients (Freshwater & Biley, 1998). Routine can also be seen as order which has been identified as a pre-requisite of structure and adds to the positive nature of caring (Greenwood et al. 2009) as well as feeling an element of control over care (Foley et al. 2014). The need for certainty and structure was evident for many patients (participants P3, 5, 6, 7, 8, 9, 11, and 13) because it provided a level of security and a safe perspective for them.
Philpin (2002) discusses the underpinning focus of alleviating and ameliorating anxiety when routine and rituals are developed and sustained and explains that security in their given situation is often a by-product. The security lies in the knowledge of knowing what happens next, thus removing uncertainty. The element of control the neurological patient may have for this process may be the only means of command they now possess. Neurodegenerative diseases result in a significant amount of physical decline and dependence so the patient's loss of authority and personal power over their lives is likely to be significant.

Many participants declined the opportunity to be involved with services such as day hospice because this would affect their routine and be counterproductive in striving for good care. A change might also be detrimental (e.g. no regular mobilising) which might result in them not returning to their pre-respite condition which meant more adaptation.

‘C: Before he went into, for the respite care, he was able to walk using a frame and I would go just behind him ready to do any steadying that was necessary. But within a couple of days or so in the respite care, he had never stood or taken a step. The carers there just transferred him very, very quickly without giving him any time to straighten up, they were taking him from the easy chair that he was sitting on over to the commode chair, or the wheelchair. Bert has a wheelchair to take him down to the dining room and things like that. So he was never straightening his body, so my daughter-in-law said he had become chair shaped because he had never straightened up’. (Joy, C10)

This gentleman was already less mobile and requiring more assistance before his respite admission. His ability to mobilise quickly diminished when routine was abandoned in the nursing home and he became ‘chair shaped’. He was not able to
regain that mobility after discharge and was only able to transfer from bed to chair.

Earlier studies of patients with dementia (Seltzer et al. 1988; Adler et al. 1993) demonstrated that often their functionality or ability to be independent of their activities of daily living declined during an episode of nursing home respite.

Any changes to the patient’s routines were viewed both positively and negatively. Sometimes, due to deterioration, the routine and care delivery might need to be adapted and the respite offered a safe environment for different methods to be explored and tried. If there was a need identified by the patient / carer, this was construed as a welcome change but any change was often unnerving and carers might find it difficult to resume their duties because they felt unsure and out of sync.

‘R: So when you came back from holiday, how did you feel about the respite admission and him coming home?
C: A bit apprehensive, because I knew the regime was changing. They had tried a new hoist during respite, I knew we couldn’t use the standing hoist anymore which I had got into a habit, we knew how that worked, he was going to be hoisted...uh people I was using weren’t used to hoisting very much, so we were going into a whole new regime, so I did feel a little bit worried about how this is going to work...............’ (Patsy, C11)

This carer, Patsy, (C11), had asked the hospice staff to review her husband Jim (P11) as he had shown signs of decline. A manual handling assessment had revealed he was no longer safe with the current (standing) hoist and they had trialled the full hoist. She had recognised the need for the assessment and that changes were required but felt very worried about how that would work at home, especially when she took back the reins of care. The community occupational therapist spent time
explaining the hoist when it was delivered but Patsy (C11) felt a change in routine always had an impact until she was able to embed an amended routine.

Another participant, Sally (C6), discussed how difficult it was to re-establish routine at home after respite care. Her husband Paul (P6) had adjusted to the hospice who had tried to adhere to his usual routine.

‘R: And when Paul was ready to come home, how did you feel? 
C: Alright, but quite nervous, you know. It was getting back into the routine again but I was glad to get him home. 
R: Why were you nervous? 
C: I don’t know. I suppose it was because I had had 2 weeks away and he was settled there (in the hospice) and we’ve got to get used to it (routine) all over again’ (Sally, C6)

Similarly, Sally (C6) had readjusted her own personal routine during her break from caring and now needed to return to the usual/normal routine again, which was daunting for the carer and another adjustment she had to make to get her husband settled back home.

Finally, creating and maintaining routines offered an opportunity for both patient and carer to construct a new form of relationship which was special to them and could be adapted as required (Furlong & Wuest, 2008). This replaced the lost intimate spousal relationship with a practical relationship that served a purpose and achieved good quality care.
4.3.3.2 Compromising.

Compromising relates to understanding, and more importantly, accepting, that the quality of care and adhering to a rigid routine may not be the same as what they were at home. This concept tended to be adopted more by carers. Patients were much less willing to compromise and carers were often the buttress, visiting frequently to fill in the gaps in care and putting things right (e.g. correct positioning). Carers understood that institutions were unlikely to be able to adhere to the routine established at home and there was a hope that the patient would settle and accept these changes, which were temporary, when they were admitted for respite. This is demonstrated by this carer Elsa (C7), who readily acknowledged the need for institutional order and a routine of their own.

‘R: Do you feel that the things he does….when you first took him in there and described his day, do you feel they listened to you?
C: Ummmm.............I don’t know because they’ve got to do things that fit in with them as well haven’t they? I mean sometimes... in February.... I mean even though he’s in respite I still obviously go into see him cos I’m around, local and he might be still be in bed at half past 10, 11 but they’ve got a lot of people to look after haven’t they, so as far as I’m aware they do try to, don’t they Isaac? (asks husband who nods affirmatively)
R: So he gets things like the medicines on time?
C: Oh yes, sure’. (Elsa, C7)

Elsa (C7) was really dependent on this respite provision in order to continue caring and was grateful for the ongoing support and therefore very reluctant to criticise. All institutions, even hospices that focus on holistic, patient centric care have to follow some form of structure depending on factors such as their staffing and activities
professionals available. She recognised how vital the success of these admissions was on the consequences and her long term plans for having her regular breaks.

Compromising can refer to negotiating the quality of care given to the patient and, if considered of a high enough standard, was sufficient to reassure this carer.

‘C: I obviously expect him to be physically well looked after, clean, skin viability checked on, you know, medication given and I expect him to be well hydrated and use his PEG as….as they normally would. I don’t want him coming out with a pressure sore.
R: Do you expect them to follow your routine? Is that important to you?
C: I don’t mind if they don’t follow my routine as long as they achieve good care. No that’s.......... I just want the end result to be good. No, they don’t have to follow my routine as long as they don’t neglect him’. (Sylvia, C8)

In von Kutzleben et al. (2012) their work on people with dementia showed the maintenance of normality was a recurring theme and the need to continue life in a meaningful manner to sustain the individual’s identity. Little attention being given to usual routine often meant bad care in the patients and carers opinions. This was supported by Hogstel et al. (2005), who talked about the complexities of caring and how energy to face issues, creativity to deal with crises and resulting personal strength can be gained by some carers from the chaos and unpredictability of the caring process.
4.4 Theme three: Respite as Restoration and Biographical Reconstruction for the Carer

The final phase in the journey is reminiscing about the life lost, the caring relationship and the emerging revitalisation of the carer in preparation for their onward caring journey. Biographical disruption which is the deviation from the normal state of health and assumptions held about oneself and the future (Bury, 1982) creates a need to readapt to a different life brought about by chronic illness. This is referred to as biographical reconstruction – a coping mechanism to integrate the illness into the person’s life and identity (Bury, 1982; Williams, 2000) when there is a deviation from the state of normality (Reeve et al. 2010). The caring role comprises many facets which involve a level of readjustment to a constantly changing life due to the deteriorating health of the person being cared for. This theme is termed Respite as Restoration and Biographical Reconstruction for the Carer which consists of the category of: magnitude, tensions and responsibilities of the caring role (Table 4.5).

4.4.1 Magnitude, tensions and responsibilities of the caring role

There is little doubt that the caring role holds much duty and responsibility and can be seen as onerous, a struggle as well as rewarding. The carers were able to express their feelings, thoughts and anxieties about this duty that they undertook. This category includes the subcategories of: restrictions, burden and frustrations imposed by caring; the loss of a previous life, reminiscing and changes in relationships; carers
own health needs; and gratitude for the facility of respite and consequent restoration for the carer.

Table 4.5: Categories and subcategories of the theme ‘Respite as Restoration and Biographical Reconstruction for the Carer’

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
<th>Subcategory</th>
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| RESPITE AS RESTORATION AND BIOGRAPHICAL RECONSTRUCTION FOR THE CARER | Magnitude, tensions and responsibilities of the caring role | Restrictions, burden and frustrations imposed by caring.  
Loss of previous life, reminiscing and changes in relationships.  
Carers own health needs. Gratitude for facility of respite & restoration. |

4.4.1.1 Restrictions, burden and frustrations imposed by caring

Many carers found the issues around caring were very limiting and took over their entire life. This carer, Pat (C2), spoke of how her husband Chris (P1) was ‘quite nice to nurse’ but she felt torn between leaving him and any issues that may occur.

‘P: He is quite nice to nurse. I mean I don’t mind nursing, it doesn’t put me out, the only thing that I find is restricting is that I can’t really leave him for more than about an hour and I don’t want him wandering about when I’m not here, you know’ (Pat, C2)

Her concern arose because he was unsteady mobilising but was reluctant to use aids all of the time. She was cautious about leaving him for periods of time due to the uncertainty around his safety. Her constant vigilance was necessary which was
wearing for her. Pat (C2) described herself as a ‘nurse’ as opposed to a spouse. There have been studies looking at the multiple roles of the caregiver and how rapid the caregiving role can be thrust upon them without any prior knowledge or preparation. The nature of the illness can mean these roles change constantly over time and are likely to compete with each other in relation to the carers’ psychological resources and ability to adapt and cope (Kim et al. 2006). Being a ‘nurse’ can mean a shift in the quality and substance of their relationship.

Similarly Sam (C4) was mindful of the different aspects of caring. The scale of organisation of care and the relative lack of freedom to be an individual was troublesome.

‘P: It’s not really the physical work as I have the carers four times a day. It’s the organisation, making sure he got his meds, and not being able to walk out the door and doing something I want to do.’ (Sam, C4)

This lady was very tearful about the constraints put upon her. She was experiencing a disruption to her identity as she couldn’t have a life of her own. She had given up her life to initially care for the children whilst her husband worked away and then when it was ‘payback time’ he became ill and she was left to care for him. Carers often experience a loss of social interaction and identity which has an impact on their psychological well-being (Ray & Street, 2006). There were many low times for the carers where they found it hard to remain decisive and confident in their abilities to continue. It is not unusual for people to map out their life course and expectations and then when illness occurs it results in complete and catastrophic disruption to
immediate and future plans. Having to rebuild lives in view of these changes culminates in a new ‘normal’ emerging and this is assimilated as part of their life.

This biographical restructuring can apply to patient and carer (Bury, 2001), as many lives are potentially affected in neurological illness.

Sam (C4) and her husband Sean (P3) had experienced a traumatic episode of respite in a nursing home which has left them, particularly carer Sam (C4), reluctant to consider respite again. However she realises that, in order to sustain her ability to deliver care, she needed to rethink this option.

‘P: Yes, because I realise that if ummm, I want to keep him at home.... and keep going I am going to have to accept this (respite). But so many people say to you.. oh you should take time out for yourself, you should look after yourself, well put yourself in my position and try and do that.’ (Sam, C4).

Sam (C4) feels annoyed that people think the caring role is something you can let go of for a period of time and pick up again whenever it felt right to do so. The extent of her caring meant she had little opportunity for time to herself and she regretted this deeply.

Some participants were able to see how burdensome the caring role could be. Chris (P1) referred to the fact that it would be good for his wife Pat (C2) to forget everything and have some time out and know he was well cared for.

‘P: ....that I recognised that my wife needed a break because it is very continuous stuff, you know. There is no relief really and umm, so she could, so
Chris (P1) was aware of the monotony and routine of the caring role and wished that his wife Pat (C2) was able to ‘clear her mind completely’ and consequently instigated the idea of respite. He had early stage MND and showed insight into the burden of caring.

Some carers merely coped by taking one day at a time.

‘P: So I just take one day at a time. Never look to the future, try not to look back.’ (Sam, C4)

Sam (C4) felt her only means of survival was to remain in the present time and not look back or forward. Her hopes and dreams of their retirement had been shattered so she coped by being in the moment. A previous study by Ray & Street (2007) demonstrated that this is a coping strategy for carers – it is too painful to consider what has been and the focus is set on the day to day caring work. They define this as the ‘non-finite loss’ which captures the reality of the multi-faceted and constant losses which are felt by carers as the disease progresses. There have been other studies that found maintaining an element of control was possible if the caregiver focused on the present and took one day at a time (Hull, 1992; Langer, 1993).
Likewise Gary (C5) acknowledged the magnitude of the role and commented on his ‘weary’ state.

‘P: Well I felt that if I was going to carry on looking after Mary that it was something I needed to do (accept respite) because I was starting to feel quite weary.
R: Yes
P: Sort of..... locked in if you like’
R: What do you mean ‘locked in’?
P: Nowhere to run to or go to. Just here.....carrying on caring... (Gary, C5)

His description of feeling ‘locked in’ speaks volumes about the isolation of caring and the mindset of keeping going. He described the routine and weary nature of caring and recognised that he needed to access respite in order to bolster his reserves.

Similarly, Strang, Koop & Peden (2002) conducted a study looking at home based care and found that carers described their experiences as ‘insular’ because their life rotated solely around the illness and the consequences of it. In her study, Olson (2011) portrays the carers of patients with cancer as having lost their direction and sense of control due to the disease and trying to learn to live with it. She describes this as ‘temporal anomie’ which originated from the work of Durkheim who defined ‘anomie’ as a state of ‘normlessness’ when behaviour does not follow normal guidance and rules set out, usually by society (Collins & Makowsky, 1998).

Elsa (C7) becomes tearful as she describes the dread of returning to the carer role.

‘P: What when I’m driving back? (asked about how she feels returning). I don’t want to come back (becomes tearful)
R: You don’t want to? Tell me about that. What are you feeling inside?
P: Well you have to go back to reality don’t you (looking at husband). That’s it really.
R: And does that feel like a big mountain for you to climb?
P: Yes, I often get a bit tearful on the way back.’
R: OK. And how do you get over that? What happens?
P: Mind over matter isn’t it? (Elsa, C7)

Elsa (C7) uses strong language (‘dread’) to illustrate the emotional cost of caring, the terrible reality of her husband Isaac’s (P7) situation and her escape from it. She then has to face it again but adopts a fatalistic attitude to returning to the role, describing another coping mechanism of ‘mind over matter’, although her journey back to caring is accompanied by strong emotion and tears. After the interview was over Elsa (C7) followed the researcher out to her car and talked about how awkward she had felt being honest in front of her husband but it was also cathartic for her to be able to express how she felt in front of him.

Memo 2:
One carer Elsa (C7) struggled significantly with telling her story. Her husband Isaac (P7) had insisted he was present for the interview and this slightly curtailed her ability to say things. When I was leaving she had a quiet word then and was able to cry. I wondered if it was truly cathartic to relive those memories and analyse them or is it soul destroying?

The burden of caring is well documented in many areas of chronic illness. Respite has been shown to promote carer well-being and quality of life, thus reducing overall burden (McNally et al. 1999; Corkin et al. 2006; Shaw et al. 2009; Evans 2013a). The role and responsibilities of caring have been described as a relentless burden and respite can provide a means to divert attention to the carers own interests and requirements (de la Cuesta-Benjumea, 2011). The study’s findings illustrate the
ability of the carers to pick up the reins and continue in their caring role after a period of respite, although resilience and sustainability remain a challenge (Ward-Griffin et al. 2012).

4.4.1.2 Loss of previous life, reminiscing and changes in relationships

The literature has discussed the significant changes in relationships that patients and carers experience. This was noticeable in the interviews with participants and was quite poignant at times. Some participants found it refreshing to reflect on past life and enjoyed reciting memories.

Pat (C2) brings to the forefront their previous shared relationship as husband and wife and the flamboyant life they once shared.

‘R: How has, has this illness curtailed your activity? I mean were you having a great retirement?
P: Oh god yes, I mean we were sailing and all sorts of things
R: OK
P: We were roaring about all over the world
R: Right so now you’re not getting out at all?
P: No
R: Not too much at all?
P: Not really no. I suppose I could easily organise a sort of babysitter and go out but quite honestly it does depress him you know he is very, very dependent on me psychologically as well as for his dinner’ (Pat, C2)

She is able to discuss how vast the difference and the reality of what they had before, compared to now. She refers to ‘organising a babysitter’ as if he is a child who cannot be left. Pat (C2) was quite bitter about the limitations imposed by her husband’s illness and emphasized his psychological dependence on her which was
restrictive. Frequently relationships have to be constantly redefined due to chronic illness and carers may detach themselves from the person that the patient used to be in order to cope (Ray & Street, 2006).

Sam (C4) relates the plans that they had to be grandparents and how that has all changed. Her only way of seeing her daughter and granddaughter now is to pay a private carer which holds a hint of desperation about it.

‘P: Both. I mean my daughter’s actually about to have another baby so…. I mean a year ago, my granddaughter is coming up 2 now but when she first had Alice, Sean was ok he had just been diagnosed with Parkinson’s I went over there 2 days a week and helped look after her and gave my daughter a break, etc. And then when Sean became so ill I knew the only way I could see my daughter and granddaughter would be to pay for someone to come in because I, you know, she works as well, she’s a clinical psychologist and puts 4 days into 3 and Alice goes to the child minder but again the idea was that we would split the care between the 3 of us, her husband, me and her so she wouldn’t have to go to a child minder but everything’s just gone out of the window.’ (Sam, C4)

She was very distressed about the change to plans and had not easily adapted to this adjustment in intentions or her multiple caring roles. She felt that arranging for her grandchild to come to her would then mean she had ‘two children’ to look after which was not possible. She acknowledged that she could not sustain this level of caring and something had to give.

Memo 3:
I attended an interview where the carer Sam (C4) felt cheated out of her life. She was extremely tearful and made me consider how many of these people really do want to take on this role. There was so much resentment and loss of everything she held dear. The respite provided them with ‘time
off for good behaviour’ and was a god send for many of them. They could afford to dream for a while and be ‘normal’.

Elsa (C7) talks about her holiday feeling soon evaporating on return to the usual routine. The magnitude of the caring role means there is little time to ease back into it. It is hard physical work as well as being psychologically draining.

‘P: It’s a bit like you haven’t been out of here really (laughs ironically) A bit like when you go on holiday and then you come back and you think...was I ever away 2 days ago?’ (Elsa, C7)

Elsa (C7) misses her past life. Her holidays are very precious but never long enough and the returning is painful. She is a relatively young woman who gave up a good job to care for her husband and felt strongly this was something she was obliged to do because ‘that’s what you do if you are married’. In their study looking at the caregiving experience of family and friends who care for people living with MND, Ray & Street (2006) refer to the increase in emotional labour because caregiving is quite often undertaken in the context of a sense of duty. There is a dichotomy between the roles of caregiver and spouse and trying to sustain an intimate relationship. They also describe how difficult it is for spouses to consider the body in a different way. It used to be an object of sexual desire and the only approach made in the past would be for personal and intimate reasons whereas now it had to re-evaluate and redefine the body they had spent years getting to know with a consequent loss of intimacy (Ray & Street, 2006). Furthermore, Brown & Stetz (1999) speak of an expectation of
Many caregivers have commented on feeling losses during the process of caregiving for a loved one. The loss of the ‘unique person’ is often significant and irretrievable (Davis et al. 2011) along with the waning of intimate, personal conversations and sharing of special, private moments which can be difficult to come to terms with (Ducharme et al. 2006). Furlong & Wuest (2008) referred to the stage of ‘mourning change’ which was ‘what used to be’ versus ‘what is’ in a relationship. They were fundamentally grieving for a past life that was now gone.

4.4.1.3 Carers own health needs

Many of the carers had their own health needs which were as a result of caring or, more generally, age related conditions.

Elsa (C7) had been started on anti-depressants to help cope with the altered life she was living and finding difficult to adapt to. Her dose had been increased and she felt that this had been beneficial.

‘P: I feel that I need to know... that I am going to get a break.
R: And do you begin to feel tired? A bit more weary? Anything else happen at that time? Do you get more tearful? Do you feel more stressed?
P: Yes, I get a bit crotchety, don’t I Isaac? (asks husband who laughs). I try not to but.... the doctors have...umm.. upped my anti-depressants.. yeh... I feel like.....and I feel a bit better’ (Elsa, C7)
She is mindful that she gets ‘crotchety’ and her husband Isaac (P7) agrees with this but she finds it hard to find a way out of the perpetual cycle she lives, which holds little value to her at the present time. The emotional upset is always present.

The carer Joy (C10) was an elderly lady who had begun to experience wear and tear to her body. She worries about the stress she is putting on her body but can’t see an alternative.

‘P: Well, because of my back and I have also got Carpal Tunnel Syndrome now and I also had an operation on this shoulder last July, so I just I really shouldn’t be putting that amount of stress on my body [laughs]. But when you, you do it don’t you? You just have to....’ (Joy, C10)

Her husband Bert (P10) has cortico-basal degeneration (CBD) which is now advanced and he requires assistance with moving, handling and personal care. Joy (C10) is elderly and has her own health needs but is still trying to help Bert (P10) onto the toilet and move if he is uncomfortable in between the formal carers’ visits. She feels she has little choice in the matter and therefore adopts a positive attitude towards the caring role. Her husband is still able to do some things for himself and they cope as best they can. Their GP is aware of the situation but had minimal contact which Joy (C10) and Bert (P10) feel is due to the GP’s lack of knowledge about CBD. Their specialist community nurse is a great resource and has been instrumental in getting them a good care package and seeking alternative respite.
Memo 4:
One interview was with a gentleman Cliff (P13) who was extremely disabled and his wife Rose (C13) who had her own care needs. I found it very difficult to keep the interview focused on the patient as Rose (C13) felt she needed to tell me her health worries. At times she sounded bitter about the situation. Conversely I felt so humbled by Cliff (P13) and his gentlemanly poise and dignity and how he tried to see the positivity in everything. He was on the cusp of accepting full time residential care and it felt almost part of the journey as this had led from a respite admission which has provided good rehabilitation and a rejuvenating experience for his carer.

In one study it was shown that physical health problems were more likely to trigger the carer to begin to think about self-care than any type of psychological or emotional distress or anxiety. Self-care referred to the carers looking after themselves and seeking health care advice and support when they became unwell or frailer. They were then also more likely to accept help in the form of respite (Furlong & Wuest, 2008).

4.4.1.4 Gratitude for facility of respite and restoration
For the vast majority of participants there was an acknowledgement that the respite break had been a positive experience.

Chris (P1) was able to weigh up the benefits relating to the length of time of a break and could identify pitfalls that could potentially cause more problems for his carer.

‘R: ...did you, do you think your expectations of respite were completely met?
P: Umm, not in practical terms, no it was all fine. I think in emotional terms it, (SOB, air blowing) it was perhaps harder for Pat to break free, ummm, in a fortnight, than would have been ideal. Perhaps a fortnight isn’t long enough. On the other hand, to do it for longer than that is very, very complicated indeed so. I think the expectation of the break for Pat was good’. (Chris, P1)
Chris (P1) feels that his wife did get what she needed from her respite break. He went to a nursing home but it was unusual in that his ex-wife lived around the corner from the home so he spent each day in her company. They also paid privately for this break and careful consideration and research went into creating the ideal situation for him in order to meet his needs which, at that time, were primarily for social interaction and company.

Sally (C6) was grateful for the extended respite stay in the hospice. It afforded her the opportunity to ‘stabilise herself’. This related to her tearfulness and overwhelming tiredness prior to the break.

‘P:.....and they actually kept him in for a fortnight for me to stabilize him and stabilize me really....and now this staying overnight with him too.....I’ll just take it whenever you can offer it to me, any night I’ll take a night sit. (Sally, C6)

Here Sally (C6) depicts how equilibrium is required in order to continue caring, derived from a symbiotic relationship between the carer and the patient which demonstrates how respite can benefit both patient and carer. Sally (C6) recently had been offered some night sitters which she was very thankful for. Her husband Paul (P6), who had MND, was going through a period of rapid decline (muscle weakness, swallowing and speech deterioration) which resulted in the need for more assistance. She was happy to accept whatever and whenever they could offer it. She had realised since the hospice admission how beneficial different forms of respite could be. This boosted her ability to continue caring and provided some stability and structure to help both her and Paul, thus demonstrating biographical continuity.
Finally Sylvia (C8) tearfully refers to Philip’s (P8) view on respite for her. She likens it to the man he used to be and the jobs he used to do which she now has had to take over. He used to be in control and now there is nothing that he can physically manage, but psychologically he can encourage her to accept respite.

‘P: …….and something that Philip hasn’t said because we haven’t given him the opportunity is he actually says that (starts crying………………, finds it difficult to control herself, Pt also starts crying) that respite is something he can do for me because he’s the sort of person who would be doing everything, you know the garden, mending the car, decorating, all the stuff that I have to do, ummm, so it is something he can actually do…he sees it as contributing to me being ok. (Sylvia, C8)

This was very emotional and powerful. Sylvia (C8) says that Philip (P8) sees it ‘as contributing to me being ok’, indicating that his small sense of jurisdiction ensures his wife can remain well and can continue to keep him at home and care for him – another example of biographical continuity for both patient and carer.

Respites are an intervention that offers much more than caregiving relief (Evans, 2013a), for example it can mean a way to integrate back into a social (and normal) life for the carer (Victor, 2009) and an opportunity for the patient to access therapeutic interventions which enable them to maximise their functionality and quality of life (Holm & Zigauras, 2003).

Evans (2013a) explored the concept of respite and noted that it often had an impact on the patient and the caregiver in positive ways. He commented that respite could not be seen as a standardised service but should be individualised to meet needs in
order that both care recipient and caregiver achieved the maximum outcome. From the study findings the outcomes for patient and carer vary greatly depending on original aspirations and expectations. Penny (P12) emphasised the need to clarify what is expected prior to admission in order to be realistic about outcomes and what can be achieved. Clearly different venues offer varied facilities and specialist input of care and this should be explored before a decision is made regarding place of respite.

### 4.5 Summary of chapter

This chapter has presented the findings of the research. There have been three themes identified: The commodity of respite; The order and chaos of respite; and Respite as restoration and biographical reconstruction for the carer. Extracts from the narratives have illustrated how the analysis is grounded in the data and the subsequent emerging themes.

The three themes present a journey commencing at accessing, understanding and attaining respite, moving on to the actual experience of respite and concluding with the carer reflecting on past lives, personal memories and the successive restoration of the carer. Sustainability and resilience are key components to facilitate the ongoing caring role.
**Research Aim**
What do patients with neurodegenerative diseases and their carers understand by the term Respite?

**Research Questions**
- What do patients experience from a respite admission?
- What do carers gain from a respite admission?
- How can respite be used as a therapeutic outcome?

**Findings**

### Themes

#### Procuring the Commodity of Respite
- Accessing respite care
- Knowledge and understanding

#### The Order and Chaos of Respite
- Control
- Checking up and surveillance
- Maintain normality

#### Respite as Restoration and Biographical Reconstruction for the Carer
- Magnitude, tensions and responsibilities of caring role

### Categories

- Accessing respite care
- Knowledge and understanding
- Respite as restoration for the patient

### Subcategories
- Access to information
- Barriers to access, choices and how appropriate
- Funding
- Expectations
- Access to the MDT
- Facilities, care and activities
- Desire to address mind & body
- New equipment
- New relationships
- Preparation, hand over and communication
- Expert Carer
- Quality
- Routine
- Compromising
- Restrictions, burdens and frustrations
- Loss of previous life, reminiscing and changes
- Carers own health needs
- Gratitude and restoration
CHAPTER 5: DISCUSSION AND EMERGING THEORY

5.1 Introduction

This chapter presents a discussion of the emerging theory from the data. This is constructed within the interpretative paradigm of constructivist grounded theory. This methodology was conducive to staying closer to the data and understanding its meaning through an interpretative lens. In addition, these patients have significant disability and the methodology allowed the understanding from a more personal perspective. The use of memos and a reflective journal aided the analysis by adding substance and authenticity to the emerging theory.

The original research enquiry was to explore what residential respite care could offer patients with neurodegenerative diseases and their carers, which led to the research questions of what do patients and their carers experience and gain from it and how can it be used to provide a therapeutic outcome? The grounded theory emerged as the data revealed the journey travelled to access respite for these patients and carers and what components were required to make that respite meaningful for both parties. The participants repeatedly referred to the confusion they experienced around knowledge of respite, how that could be procured and what they could expect to achieve.

5.1.1 Contextualising: Neurodegenerative diseases and respite care

Although neurodegenerative diseases are life shortening and therefore palliative from diagnosis, the patient may live for a number of years, gradually deteriorating
and requiring increasing amounts of care (DH, 2005a; Clarkson, 2008). Patients with these conditions have constantly changing needs due to their gradual, steady (with episodes of rapid) deterioration, (Aoun et al. 2006; Brown & Addington-Hall, 2008).

Appendix 1 provides details of neurodegenerative conditions. Patients experience either short or longer periods of dependency, a vast range of (often complex) needs and a desire to sustain quality of life which all culminates in a necessity to adapt to an altered routine and environment (e.g. use and access to equipment, different living arrangements) in line with their decline (Dawson & Kristjanson, 2003).

Respite care as a commodity is not offered frequently in the UK although with the political pressure to keep carers healthy and able to continue in this role, there has been more interest in this area of care (Personal communication, 2014). Appendix 6 details some respite facilities operating in the UK but this is not an exhaustive list. Appendix 17 depicts some personal thoughts from the researcher regarding respite and its overall aims.

The study demonstrated the perpetual need for patient and carer readaptation to an amended and disrupted life which resulted in a steep learning curve for the patient and carer, thus a level of ongoing support was paramount. Carers and patients with neurodegenerative conditions commonly aim to normalise the challenging and ever-changing situation of these life limiting diseases in order to find ways of coping and enabling biographical continuity. Charmaz (1991) refers to adapting to a different routine as the condition progresses, allowing familiarity to be adopted as
normalisation which can be a sound indicator of people’s ability to cope (Deatrick et al. 1999). The desire to retain a degree of normality was evident in the findings from both patients and carers. Respite was found to be an important intervention in assisting families to adjust to changes when living with a progressive neurodegenerative disease. The findings of the study indicate that respite allows an opportunity for patients and carers to adjust to constant change due to disease progression and subsequent deterioration. The next section offers a deeper analysis of the findings and explores the developing emerging theory.

5.2. The Relationship of Caring and Respite

5.2.1 The caring relationship

The study participants discussed the strain of caring and how their lives had changed due to this new and often unwanted caring role (participants C2, C4, C5 and C7). There were a variety of feelings towards acquiring this role which were often unexpected with little or no time for preparation or consideration of the implications. Some participants felt that caring was a natural course of events and would have been reciprocal had the circumstances been different (participants C6, C8 and C10).

The many concerns of taking on the role of carer and the subsequent burden of caregiving features in the literature and there are studies which suggest there may be significant reluctance to assume this role and it can be heavily resisted (Hughes et al. 2013). In two studies of carers of people with multiple sclerosis and dementia
both reported feeling obliged to carry out the role from a sense of duty but resented this (Hughes et al. 2013; Strang & Haughey, 1998). Carers in these studies felt that being a carer and giving care was part of being married and therefore carried out their caring role from a moral and ethical stance. Caron & Bowers (2003) also felt that the marital history was relevant – a good marriage usually foretold satisfaction with the caring relationship and the spouse was keener to undertake this role, whereas a previous difficult relationship might result in emotional distress for the carer having to undertake this role. This was coupled with people frequently feeling they did not have a choice regarding caring and there was a natural expectation from the patient, close family and society that they would take this on (Arksey & Glendinning, 2007). The findings in the literature echoed in this study as all the carers either demonstrated a desire to take on these duties (participants C6, 8, 9, 10 and 11) or felt an obligation to do so due to their marital status and out of a sense of duty (participants C2, 4, 5, 7 and 13), which is the starting point for ongoing caring and another aspect of the need for respite.

5.2.2 The need for respite, information gathering and how to access it.

The initial respite journey begins with determining whether respite is actually required at that time during the illness experience for the patient and/or the carer, and if so, where and how to access respite. The overwhelming message emerging from the data was the distinct lack of guidance to help the carer (and patient) gain knowledge and information of respite within the healthcare system that they were trying to navigate. Access to, and understanding of, respite was essential for carers
making decisions about embarking on the respite journey to ensure the timing was right for both of them. The level of information available to carers was found to be sparse and inconsistent and carers (and patients where possible) were having to chase intelligence by their own volition, often with minimal support or guidance from others; e.g. health and social care professionals (e.g. participants C4, C5, C8, C9 and C13). This lack of information about respite was particularly pertaining to where respite was available, how and who could access it, what it offered, when it could be accessed and how it would be funded as also noted by Hughes et al. 2005 and Jeon et al. 2007. Patients and carers were endeavouring to make decisions with a dearth of information which was difficult and frustrating for them. They required support and a clear trail though the process.

If a decision was made to accept respite it often followed that the referral process was extremely blurred with some health care professionals reported to not understand where and how to negotiate respite. Some of the study participants described the active pursuit of paperwork, transferring it personally from one professional to another in order to attain completion and returning it back to the respite facility (participants C8 and C9) to be exhausting and all-consuming for the carers. There is very little mention of this application process within the literature but it was a real concern for carers who already carry a heavy burden. The lack of a clear referral pathway between professionals was significant and deemed by carers as tiresome and undesirable. This was also noted by Turner-Stokes et al. (2007) who conducted a survey looking at the interface between the three specialities of
neurology, rehabilitation and palliative care. The results identify a paucity of coordination and referral and a significant shortfall in rehabilitation services to promote maximising quality of life and functionality. The Australian community support association website (MNDcare, 2011) developed a patient rehabilitation pathway which clearly demonstrates the interplay between disciplines and how this can be advantageous for patients with MND and their carers (Ng et al. 2011).

5.2.3 Reasons to access respite.

The literature partially supports some of the reasons identified in the study for respite, namely carer break (McNally et al. 1999; Lysne, 2005; Green & Wakefield, 2006), carer holiday (Yeandle & Wigfield, 2011), patient assessment (Pomeroy et al. 1999) and patient socialisation (Bamford et al. 2009; Russell, 2010). The degree of need for respite generally relates to the level of patient dependence which frequently increases as time moves on. This is typical of neurodegenerative diseases, where a marked decline can sometimes occur rapidly. This is also indicated in the literature, along with carers recognising, in hindsight, the value and need for respite (Kristjanson et al. 2005; Herz et al. 2006; McLaughlin et al. 2010).

There were different reasons described, both relating to patients and carers, for accessing respite. The main study findings described the reasons for respite as: carer break/holiday/own health needs/restoration; alterations to home in relation to increased patient care needs; carer needing to attend to normal life concerns; patient socialisation and patient assessment during deterioration/progressive...
disease and supporting changes/revisions relating to equipment, routine and care needs. In addition, patients and carers were keen to start becoming familiar with the health professionals who would be taking an increasing role in their future care. Exploring the level of support available during respite and those staff who will be delivering it was a key element which Yeandle & Wigfield (2011) identified as being crucial to early consideration of multiple ways of providing care in the future.

The beginnings of the respite process involves determining initially what each person requires from respite in order to provide a level of clarity, resulting in offering guidance around what can be reasonably arranged and/or provided. This can also inform the decision regarding the most appropriate place of respite care to meet the patient’s needs. Penny (P12) was keen to experience respite whilst her family went away on holiday and felt her initial assessment (conducted at home) had provided an overview of her care needs and what she wished to achieve. The assessment was carried out by a clinical nurse specialist who was experienced in palliative care and the purpose was for the hospice to be prepared for her admission, including her particular needs and desires. Unfortunately her admission fell short of expectations and interventions promised were not forthcoming (although they were available), thus she did not experience the full benefit of what respite could offer.

### 5.2.4 The resources available and how to access them

One concern that arose from the study findings was the limited facilities available that offered respite care. Patient choice is high on the policy agenda and several
initiatives such as self-care and self-management are designed to promote independence (Independent Commission on Whole Person Care, 2014) and keep patients safely at home for as long as possible if that is their wish (DH, 2008a). Furthermore, in their report on all services for people with neurological conditions, the National Audit office stressed the need for individualised care plans and the integration of health and social services, including information and contact details, to ensure access was available to all, including a priority of keeping patients out of hospital and in their own home and supporting carers (DH, 2011). Similarly, it is acknowledged that there are many informal carers in the UK who save the NHS a considerable amount of money and who should be regularly offered an independent assessment of their own needs, including the requirement of a break from the caregiving role (DH, 2012; DH, 2014a). Despite these influential reports and papers, there remains a scarcity of provision and availability of good quality respite services that are able to offer a high standard of needs assessment for patients to allow them to maintain their maximal functionality and address their social interests (Ingleton et al. 2003; Owen & Johnson, 2005) and, in addition, to release the carer from their responsibilities in a safe and confident manner which may go some way to sustain them in their ongoing role.

The preparation for the respite admission was mentioned negatively by some carers (e.g. participants C2, C9 and C13). It felt an additional burden to pack everything (e.g. medication, feeds, equipment); this was especially noticeable if the respite occurred in a nursing home where they were ill equipped for managing neurological patients
Other carers mentioned it as an expected chore (e.g. participants C2 and C9) prior to a respite admission and quite enjoyed the element of organisation involved. There is scant mention of this preparation for respite in the literature. In their review of respite use by carers of patients with dementia, Neville et al. (2014) refer to the additional burden for carers due to work ‘generated from preparing the person for respite’ but are not specific about what that entails.

The study participants had a mixed experience of respite, which demonstrated the unequal and diverse distribution and access to respite services. The vast majority of these participants were of a higher social class and demonstrated a logical approach to articulating what they required and logically seeking appropriate information and resources. This finding was significant because patients and carers from lower social classes may not have access to, or insight into how relevant or available respite care may be in their journey. Broadly speaking it was reported that respite offered in a nursing home did not provide sufficient specialist care and expertise for neurological patients and didn’t live up to the expectations of carers (e.g. participants P3, P9, P10 and P13). Patients with neurological diseases have highly specialised needs related to communication, feeding and breathing function and require specific care that needs to be delivered via trained professionals (Hicks & Corcoran, 1993; Aoun et al. 2006). Nursing homes are unlikely to employ staff that fit these criteria and therefore it is doubtful that this would be the correct environment for them to receive respite care. The study findings revealed that the environment of care, staffing and access to
social interests were generally poor in the nursing home setting (e.g. Sean (P3) where even basic care needs were not met), although one man chose a nursing home to be near his ex-wife and used the nursing home as a hotel. He was vaguely aware that he could access some social activities but preferred to choose his own interests and company outside of the nursing home. Conversely, if the participants were able to access a hospice or neurological specialist home for respite these offered access to a multi-disciplinary team who provided an assessment and overview of the patient’s illness and condition and supported the patient and carer to manage any deterioration particularly in physical functioning. There was an exception to this, namely one participant (Sally, C6), who felt aggrieved by the lack of interest and knowledge of the speech and language therapist. Sally (C6) felt she had to provide the necessary communication equipment and direct the therapist to find out more. This was intensely annoying for the carer who felt she was coping with enough without having to prompt professionals to do their job, especially when communication loss is a major challenge in neurodegenerative diseases.

Communication impairment has enormous significance for carer support. During respite, professionals need to adapt rapidly to an altered method of communication (word / picture boards, electronic or eye gaze technology) in order to address the needs of the individual. This can be a frustrating time for both patients and professionals, adding to the vulnerability of the patients and concern of the carers that their loved ones will not be understood. The National Service Framework for
long term conditions (DH, 2005a) has a quality standard for providing equipment in a timely fashion to support people to live independently.

Where patients were also able to access different social and recreational activities in the hospice or specialist home settings (e.g. art therapy, gardening, quizzes, games), these opportunities were highly regarded as they enabled patients to escape their routine and a sometimes ordered existence. These findings were supported in the literature, for example, Hicks and Corcoran (1993); Jeon et al. (2006); Jones et al. (2007) and Evans (2013b) referred to the need to promote independence during respite care, and the provision of socialisation interests.

5.2.5 Funding

In the brave new world of primary care trusts leading into GP commissioning, confusion existed between professionals and the resources available to access. Continuing care could be easily accessed by some carers, especially when a professional was able to assist with the milieu of form filling (participants C8 and C9), but for those who struggled with the system it felt unwieldy and complex, in the midst of their ongoing battle for adaptation to a progressive illness (participants C11 and C13).

In order to answer the policy thrust and to support carers, respite resources ideally should be provided and be transparent enough for everyone to requisition. Having this long term outlook could have significant cost savings and may keep patients in
the community for long periods of time, thus avoiding hospital admissions (e.g. for carer breakdown) or placement in residential care (DH, 2008a; DH, 2010a; DH 2012; DH 2014a). Of some concern is the Palliative Care Funding Review (Hughes-Hallett et al. 2011) which places the responsibility for respite services with either ‘the state or society’ if the purpose of respite is to give the carer a short break. If, however, it represents planned inpatient care to ‘monitor the clinical needs of the patient and to make any necessary adjustments to their care’ (Hughes-Hallett et al. 2011, p. 57) this will be funded through the palliative care tariff. This kind of distinction offers hope for patients with neurodegenerative diseases who need review of their constantly changing needs. The discussion around short breaks for carers implies that the recommendation for the procurement of carer respite services from NHS funding may no longer be possible which could be significant for voluntary organisations that already struggle to provide these additional services. More information relating to availability of respite in the UK is in Appendix 6.

On the reverse side of the availability of resources is consideration of the development of personal budgets for carers to fund their own requirements and take an active role in choosing facilities that provide the best care for their loved one. This is seen to be empowering for the service users (Beresford, 2011/12), although there is meagre information available at present relating to its effectiveness. In order for people to take on these challenges they need to be appropriately equipped with sufficient information to make informed decisions (Larkin & Milne, 2013). There is a need for professionals to support patients and carers to make full use of the monies
allocated by providing unbiased advice and assistance regarding services and resources available (Beresford, 2011/12; Glendinning et al. 2013; Larkin & Milne, 2013).

The study participants accessed different facilities which varied in cost consequences. The hospice was free of charge but beds were at a premium and therefore it was more difficult to procure a bed, whereas admission to a nursing home or specialist neurological centre was simpler but came with a cost which had to be ascertained prior to entry.

5.2.6 The patients’ perspectives of respite care

Many of the study participants found that respite care enabled them to have time away from their usual and mundane home routine, which afforded them an opportunity to consider and reflect on their overall situation and make plans for the immediate and short term future whilst in a supportive environment. This was particularly so for those who accessed specialist neurological respite facilities and hospice care because they were able to discuss their deterioration and what the future might look like with expert professionals; for example, Cliff (P13) was able to explore future care options, including residential care and Paul (P6) was able to discuss advance care planning and end of life care.

Respite could also be instrumental in helping patients plan for their physical deterioration, an increased level of dependence (resulting in the need for more
support) and adaptation to the changes associated with their progressive illness. Many of the patients and carers described respite as a catalyst for self-transformation (a process of ‘redefining the self within the context of the illness’) by having time to consider how the illness was affecting them and their loved ones (Carpenter et al. 1999). This echoes the concept of biographical restoration and reconstruction (see figure 5.1). It facilitated the use of different types of equipment such as communication aides and moving and handling equipment (e.g. participants P6 and P11) or the adoption of an alternative routine such as trying a different toileting programme or method for moving and handling (e.g. participants P9 and C10) which were beneficial in adapting to the practical, social and emotional constraints and demands of the illness. However this process was only evident when there was access to a highly specialised, comprehensive multi-disciplinary team such as in the hospice or specialist neurological facility.

It was also apparent that occasionally a change in patient attitude to respite occurred, especially if their routine and patterns of need could be addressed – a reaction which might not have been previously imagined prior to the respite experience. A ‘positive shift’, that is accommodating to their illness which requires adapting to an altered outlook and creating a new purpose of life, (Sprangers & Schwartz, 1999) – a form of biographical reconstruction (see figure 5.1) - was experienced by both participants P11 and P13 who were not initially keen to experience respite and only did so due to pressure from their spousal carer who needed a break and was concerned about the care being given at home (i.e. they
considered the formal carers who came each day were not providing the appropriate level of care) in line with the patients’ recent deterioration.

There were many participants who experienced tensions due to the dichotomy of the carer requiring a break and the patient denying that need and wanting to remain at home (e.g. participants P1/C2; P5/C5; P7/C7 and P9/C9). With some neurodegenerative conditions (e.g. HD, MSA, PSP), lacking insight into loved ones feelings and needs is a feature of the disease, nevertheless this was difficult for the carer to sensitively reconcile and negotiate with the person they married; however after experiencing a good respite experience in a hospice, where they described having their physical concerns and social needs and interests addressed, they had a different view of respite. In contrast, one patient adopted a ‘head in the sand’ stance to the respite experience (Isaac, P7) which meant that he fought against any positive shift or restoration, wanting to keep doing the same things in the same ways, and was unable to consider new ways of doing the things that might now be considered more important. Instead he insisted on maintaining normality through his usual routine which gave him a sense of control over his care regime (Foley et al. 2014) and found any level of compromise in the respite care facility difficult to adjust to. He actually did say that he enjoyed the respite experience but did not achieve what might have been possible with access to a multi-disciplinary team and social opportunities, due to his reluctance to engage fully in the experience. The respite was primarily for carer break, which was achieved but opportunities were missed for the patient due to his attitude towards respite. During the admission he tended to
spend his time watching television although he was offered the chance to participate in social activities (e.g. games & quizzes) and complementary therapies.

5.2.7 A transitional process involving restoration for patient and carer

Major and continuing disruption/s from a long term condition such as neurodegenerative illness leads to a fundamental re-evaluation of a person’s life as well as the lives of their carers and family. In an attempt to make sense of what is happening, people engage in biographical work, such as reconstructing the story of their life and illness (Tower et al. 2012). Biographical reconstruction is a method of building a new story of oneself that incorporates the illness and, by doing so, helps them to do certain things such as normalise the situation, adjust to the sense of loss associated with the illness and establish a new sense of self (Bury, 1982). This sense of restoration that some participants experienced from the respite experience went some way to renewing their sense of identity and gave a purpose to life and something to look forward to (Charmaz, 1983). Similarly, Frank (1998 and 2013) refers to the importance through narrative of accepting the illness and ‘reclaiming and reconstructing’ a new life which, during health, would not have been envisaged as acceptable. Part of biographical reconstruction for participants in this study was the mobilisation of internal and external resources (Bury, 1982) by accepting and benefitting from respite care; for example, participants described how they stayed motivated by the experience and felt more willing to accept support from professionals following the respite experience.
Achieving a beneficial outcome for the patient and a level of reconstruction for the carer was important in relation to the respite experience in the study findings. Selder’s transition theory (1989) describes a disrupted reality through the experience of illness which results in initiating the need for a life transition. This refers to the process of creating a new life and finding meaning by initially experiencing uncertainty and a lack of logic or reason which then leads onto restructuring some other (different) form of reality. Many patients and carers were clear that respite was an intervention they had not requested, or identified needing, in the early stages of their illness. As the illness worsened, both carer and patient began to realise they required an additional avenue of support, which respite might offer: a concept commonly supported in the literature (Kristjanson et al. 2005; Herz et al. 2006; McLaughlin et al. 2010). Studies conducted in other areas (e.g. wound care, altered body image), however show that if the body cannot be healed by medical intervention the restructuring of life is difficult to achieve and a true transition is questionable (Neil & Barrell, 1998; Wilkes et al. 2003). Conversely, the work around biographical disruption and reconstruction centres on an acknowledgement of a new and different reality (Bury, 1982; Williams, 2000).

Many studies refer to the ‘labour of caregiving’, indicating that it was hard manual work, alongside the emotional and mental work involved in giving care (Strang et al. 2002; Brown & Stetz, 1999). Carers had to constantly adapt to change and reconstruct their own lives in accordance with the patient. They had little or no personal control as the patient’s rate of deterioration set the pace for altered lives.
Strang & Haughey (1998) describe this as two spheres of existence – a very large sphere which is their caregiving world and a much smaller sphere which is their non-caregiving life. Furlong & Wuest (2008) developed a theory of finding normalcy for self and described this as a dynamic continuum where the carer learns to manage ongoing change and, amongst the chaos, endeavours to care for themselves as well as the patient. Similarly Deatrick et al. (1999) refers to the cancer model of normalisation during family transition where the fracturing of reality occurs, followed by a period of limbo, then a reconstructing of a different (but similar) family life that is considered to the ‘new normal’, including an ongoing level of uncertainty.

![Carer biographical disruption, restoration and reconstruction](image)

The element of control featured strongly, particularly for carers who rightly considered themselves expert carers and knowledgeable in organising their loved one’s care. Lowson et al. (2012) likened this to a conductor and an orchestra where,
in their own environment the carer holds the role of conductor, orchestrating the care services and systems necessary for the patient to receive care. When a respite admission occurs the health care professional(s) takes over and the carer adopts the role of second fiddle within the orchestra (care services) which can be demeaning and frustrating. Respite should be seen as a sharing experience so that mutual respect and learning can take place. Being able to share caregiving responsibilities could be seen as advantageous to the carer as they would feel less isolated and part of a team. These findings support the importance of having people that carers could trust to help with caregiving (Soltysiak et al. 2008) and the relief experienced which enabled them to feel ‘refreshed and renewed’ to carry on (Strang et al. 2002).

Charmaz (1991) explored the concept of control and found a link between the level of ‘intrusiveness’ of illness and the amount of choice and control carers possess. Uncertainty was significant if control was felt to be low and the approach of ‘living one day at a time’ thereby ‘concentrating on the here and now and relinquishing other goals, pursuits and obligations’ was adopted as protection against feeling a sense of loss (Charmaz, 1991, p. 185). In earlier work she had suggested that a loss of control led to a loss of self which was often inevitable and stemmed from the carer being unable to control one’s life in the way previously assumed (Charmaz, 1983). The study findings did not completely suggest a concern with losing control. Indeed, some patients and carers welcomed advice and support in order to cope with changes due to deterioration (e.g. participants P6/C6 and P9/C9). Davies & Nolan (2006, p. 290) found in their study of the changing roles of carers and professionals
that a joint review of the patient’s care needs could ‘provide a vehicle for education and informing relatives about the changing health needs’ of their loved ones. Mast’s literature review (2013) and Lysne (2005) also showed that patients and carers are much more likely to embrace the concept of respite if the service providers show interest and concern regarding the patients likes, dislikes and routines by working with, and recognising carers as partners. The ‘subtleties’ of the individual patient are best known by the expert informal carer who should be acknowledged as such (Arksey & Glendinning, 2007). The partnership of handing over care and handing it back after respite was not always obvious. Carers felt passionate about ensuring professionals were aware of care needs (Sylvia, (C8) devised an 7 page care plan) but returning that courtesy was not often overt when, in fact, carers needed to be reassured of quality care but were also willing to learn from the professionals (Lindsay, 1996). Lindsay (1996) refers to the service providers having to possess ‘chameleon-like qualities’ in order to conform to what the patient and carers require which is considered essential if respite is to meet the individual needs of patients and carers with neurodegenerative diseases. The practicalities of this may be prohibitive for providing such a service within the means of the voluntary sector, which provides some specialist respite care and certainly within the domain of nursing homes who only provide basic nursing care.

5.2.8 The concept of mutuality

A reciprocal element that emerged from the data was how the carer described looking for evidence to indicate whether the patient had benefitted from the respite
admission. This was manifested by carers scrutinising the overall picture of care in the respite facility and examining the activities given or offered to their loved ones and ascertaining if they met expectations and coincided with the interests and needs of their loved one. Being able to achieve anticipated and desired outcomes (e.g. review of care needs, assessment for communication aides) from the respite for both patient and carer could be beneficial, ensuring the patient remained at home with maximal, albeit limited, functionality and support as well as planning for future care options. For example, during respite Jim (P11) was able to have his swallowing reviewed by a speech and language therapist which resulted in a referral for a feeding tube. There was occasions where the communication was of great concern within the nursing home setting, with no apparent interest or skills on behalf of the staff to discover how best to manage the patient (e.g. Daniel, P9). For neurological patients, who frequently lose their ability to communicate but still have full cognition, this can be frustrating and frightening. The surveillance of the patients by the carers was similar to the ‘cues’ referred to in Neufeld and Harrison’s study (1995). They described a ‘constructed reciprocity’ where caregivers of older dependent people would gain benefit from caregiving if they felt that the patient had benefitted from the care input.

Generally any negative focus on respite was not mirrored in carers who required a break from caring but whom equally desired positive outcomes from the admission and encouraged the patient to seek these out. For example, Elsa (C7) suggested that her husband (Isaac, P7) thought of respite as a social experience as he attended day
hospice every second week where he appeared to appreciate the community spirit. The carer felt reassured and less guilty, not only if the physical care and support offered was of a good standard, but also if the patient enjoyed the stay in a social way, which permitted the carer to have her own personal time away from caring and a feeling of satisfaction. This was congruent with the findings of a Swedish study which looked at carers of people with neurological disorders who accessed residential respite. Mutual benefit could be achieved if the patient was well cared for and the carers were listened to and felt safe about handing over the care (Berglund et al. 2012). Table 5.1 demonstrates the benefits and achievements each participant gained from respite and how this contributes to biographical continuity and restoration.

Carers experienced a sense of biographical restoration through relief of caregiving duties and having an opportunity to live a normal life, albeit for a defined period of time. Being able to revisit their old life and have a holiday was extremely welcome and greatly appreciated. Carers could recognise the physical and emotional profits. Many patients were physically disabled and there was little or no chance for improvement in their functionality. This shifted the emphasis to addressing and stimulating their psychological being. Being able to participate in social activities was extremely meaningful for the participants.
Table 5.1: Benefits and achievements for study participants from respite

<table>
<thead>
<tr>
<th>Study Participants</th>
<th>BENEFITS AND ACHIEVEMENTS</th>
<th>Carer relief &amp; stimulation</th>
<th>Patient review</th>
<th>Patient socialisation</th>
<th>Advance care planning</th>
<th>Continue caring</th>
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5.2.9 Life for carers before and after illness – the present and reminiscing

Carers talked about reconciling the differences between life prior to the illness and life thereafter (Drew, 2003). A respite stay considered satisfactory for both the carer and the patient provided a form of reconstruction and valued ‘time out’ for the carer and was instrumental in carers being able to continue in the caring role. The temporal nature of caring was also addressed in Hanson et al. study (1999) using focus groups (n=3) to establish that carers needed preparation to consider how they would spend their time whilst their loved one was in respite, whilst Ashworth and
Baker (2000) and de la Cuesta-Benjumea (2011) found that having time to ‘escape’ and keeping busy with outside interests was an active coping measure for many carers. There was reference to this in the study, for example, Sylvia (C8) discussed how she concentrated on home refurbishments and decorating to keep busy and make the best use of her time away from caring. In Escandon’s work on caregiving (2013) time was given a different context through consideration of time frames (past, present and future) which introduced the merging of the old and new, thereby retaining some of the past but creating a dynamic, progressive future. This mirrors the concept of biographical restoration where reviewing the past and adapting to the future is indicative of the reconstruction necessary (see figure 5.1). In a similar vein Olson (2011) spoke of ‘temporal anomie’ where people initially lost direction during a state of ‘normlessness’ which then transformed into reorientation and focus. The provision of respite could be seen as being instrumental in encouraging this temporal shift by enabling carers to re-orientate themselves to a different life plan / future, thus achieving biographical restoration and reconstruction. In addition, knowing that future respite was available (even without a firm date being set) was sufficient to psychologically prepare carers for the future care journey due to their existing knowledge of pending deterioration, coupled with rest and recuperation. This was a prominent aspect of the findings and having the secure knowledge that respite was available ensured the carer could endure the time in between respite admissions. If the respite had gone well the carers would eagerly anticipate the next admission. Being able to have regular respite was important and provided motivation for the
care to continue caring, especially when they had trust in that institution (Mullan et al. 2011; Neville et al. 2014).

Constant negotiation and communication by the carers appeared crucial for ensuring respite was offered on a regular basis which, for some, involved informing the key provider when the carer was beginning to struggle (e.g. participants C7 and C9), whereas Sylvia (C8) arranged for her husband Philip (P8) to have access to both hospice respite (no cost incurred) and a specialist neurological home (paid for by continuing care funding). Sylvia (C8) had worked hard to secure regular respite by searching for different options and considering funding possibilities of having reduced length of stay but in a specialist establishment offering higher quality care. She also had the advantage of knowing the health care system which meant she had prior information to direct her enquiries (she was a health care assistant who was responsible for respite provision in a mental health institute). Navigating the health care system requires skill and tenacity. Insider knowledge (those working the system and aware of potential shortfalls and short cuts) is extremely valuable. A recent publication goes some way to addressing the issues surrounding choice and how to access information (DH, 2014b).

There were a few carers who were fortunate enough to be able to book a respite admission in advance because the institution where they accessed respite was able to offer this (e.g. specialist neurological home). Most nursing homes will also have booking systems because they are funded by the local health authority, although few
preferred to access these places due to the quality of care and interventions provided. Pre-booked respite was frequently mentioned by the carers as a preferred option, however this was not available in all settings (e.g. from a hospice offering one dedicated respite bed).

As time goes on, reciprocity and mutuality within the relationship is lost as the patient is unable to contribute much, if anything, to the partnership and may also, as part of the illness progression, not have an awareness of the carer burden. Caron & Bower (2003) considered the dual dimensions of the carer’s role. They described in their study two procedures: the ‘interrelational’ process which is ‘preserving’ the patient-carer relationship and all interactions are orchestrated by the carer to reflect the way things used to be, although there may be minimal return from the carer and the ‘pragmatic’ caregiving process which was more focused on surveillance of the care given to ensure the patient was comfortable. As time goes on, the move from ‘interrelational’ to ‘pragmatic’ inevitably happens. This shift from patient needs to carer needs was evident in the study findings where, over time, carers describe beginning to slightly detach themselves from the familiar, spousal relationship in order to develop hardiness and adopt a more appropriate, pragmatic, needs based approach to care (e.g. participants C4, C9 and C11). Ray & Street (2007) describe the enormous sense of loss of being previously loved and looked after that carer’s experience which threatens the relationship bonds that originally held them together. Furlong & Wuest (2008, p. 1667) poignantly refer to this as surrendering the ‘mind-set of couplehood’.
Reminiscing about lost dreams and planned futures was an integral part of the study findings (e.g. participants C4, C5, C7 and C13). The carers often found it cathartic to reflect on the past, contemplate the present and speculate on the future. Reminiscence is richly described in the literature as a therapeutic process in relation to patient care in dementia (e.g. Harmer & Orrell, 2008; Stueber & Hassiotis, 2012) but does not pertain to carers and lost relationships through caring.

5.2.10 Acquiring resilience, reconstruction and building sustainability

As medicine continues to improve, it is inevitable that people will find themselves in caring roles for much longer periods of time, often many years. The role may include managing complex personal budgets and health care systems, fighting for what should be readily available and supervising care arrangements (Larkin & Milne, 2013).

In the study, the onward journey of caring was dependent on a good respite experience which was instrumental in moving towards biographical reconstructing of their reality and feeling able to sustain their resilience. Resilience has been described as ‘the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and ‘bouncing back’ in the face of adversity’ (Windle, 2010, p.12). This is essential for the carer to continue in their role. Resilience has been studied mainly in relation to children and mental health (Atkinson et al. 2009; Cherry et al. 2013) but many of the tenets are translatable to
carers. Formal support (e.g. respite) is perceived as a ‘positive influence’ in providing psychological and physical support to continue caring (Strang & Haughey, 1998) as well as a previous loving relationship with fond memories and cultural influences (Cherry et al. 2013). Carers who possess certain personality traits are also envisaged to be more resilient. For example a sense of coherence, which was particularly important in coping with additional stress, was seen to be made up of understanding that life was organised and rational, manageable in terms of the individual being able to control it with internal and external resources and finally worthy of their personal investment of time and effort (Antonovsky, 1987). Coherence might be demonstrated by the distress associated with significant communication deterioration and loss as a result of the neurodegenerative disease. This was a particular challenge for many of the carers but adapted to by seeking alternative means of communication and ensuring others knew how to successfully interact with them.

Throughout this study there were elements of fortitude and courage from carers who referred to chasing information in order to make the best decisions about place of respite, monitoring the care administered to ensure it was satisfactory and being able to carry on after their planned respite break, thus indicating their reconstruction, restoration and ability to continue caring. Wilson et al. (2014) developed this concept with the response shift theory – a period of adjustment and transition to a situation which would not have seen possible (or desirable) in the
past. This is derived from the need to adapt after a review of ‘expectations and choices’ available.

Time and being ‘time poor’ was a recurring theme particularly for carers (most patients did not focus on time apart from the set structure of their daily routine). Participants who were carers had to consider how they could restructure their day and frequently returned to the past to relive memories of how life used to be prior to the illness. Charmaz (1991) refers to this as reaffirming of the past in an attempt to capture the ‘significance of self’. As previously mentioned living one day at a time was a common refrain for carers as they had lost the past and couldn’t yet imagine a future. It was safer to stay in the present, it prevented them from becoming overwhelmed with the illness and routine which accompanied it and it offered a degree of authenticity to their lives (Charmaz, 1991; Escandon, 2013). This may be a reason why people are initially loathe to consider respite until exhaustion from caring occurs. In addition, Charmaz (1991, p.235) stated ‘a past self takes on a fresh and expanded meaning when reconstructed and observed from the vantage point of the present’. These suggestions are similar to those given in the study where people adjusted in order to cope and respite was instrumental in bringing about a successful adaptation. They were able to look forward and reconfigure a different normal world (Olson, 2011). In addition, their personal world (small sphere) is centred on ‘escape’ which is shaped by recognising the need to get out, acquiring assistance to facilitate this and, most importantly, allowing themselves consent to leave that caring world (Strang & Haughey, 1998).
The hope is that respite will assist with transition to a new but different life, leading to a level of resilience which results in the ability to sustain the caring function. Sustainability works when new ways of approaching situations and moving through them, as well as allowing opportunities for self-care, becomes the norm and accepted practice. It can result in stronger relationships and empower people to own their position but equally it can be delicate and brittle (McMillan, 2013). The carers in the study varied in their reaction to continue caring. A mutually beneficial, successful respite was seen to be instrumental in sustaining carers and, coupled with the thought of regular quality respite at defined intervals, created resilience to continue (e.g. participants P7/C7; P8/C8 and P11/C11).

5.3 Emerging theory

5.3.1 A model of the relationship of caring and respite.

Throughout the study a mutually beneficial relationship between caring and respite has begun to emerge. There is interdependence on each one in order to make decisions and access respite which, in turn, delivers an outcome which can be therapeutic for both the patient and the carer.

This section details the model which has been developed about how respite was a beneficial therapeutic experience and had a positive influence on both the patient and carer. Each stage of the model is presented to explain the journey beginning with deciding if respite was an option, how and where to access it and the possible resulting therapeutic outcomes. This model is derived from research relating to
residential respite for patients with neurodegenerative diseases and their carers and is therefore only generalisable to that area of care.

5.3.1.1 Antecedents

The initial journey begins with a diagnosis of a neurodegenerative disease. As time moves on and the patient deteriorates, the informal carer (often a spouse or close family member) naturally tend to take on the role of caring. These study findings suggests that the caring duties sit on a continuum of desiring the role at one end, along to the other end and feeling obligated to undertake the role. As further deterioration and a loss of multiple functions occur, accompanied by the carer beginning to feel the burden of the role, respite is suggested or considered as an option. The needs and challenges of patients with neurodegenerative diseases are similar relating to muscle weakness leading to mobility, speech and swallowing problems, cognitive impairment and overwhelming fatigue (see Appendix 1 for more details).

5.3.1.2 Process to determine respite care and possible interventions

There are many reasons which prompt someone to consider respite. They may be related to either the patient (e.g. desire to address the ‘mind’ – social interest opportunities and/or ‘body’ - assessment and support due to deterioration, resulting in the need for review of care needs) or the carer (e.g. taking a break from the role or alterations / equipment required in home environment). Information and knowledge regarding options is sought which may be driven solely by the carer with minimal
support from professionals. It is particularly significant that patients and carers of a higher social class are more articulate and appear to receive better access to resources. For those who are less able to research the options potentially available, a decision making framework may be useful as a guide to assist their navigation (Appendix 16).

Some areas of deliberation may be the type of place chosen, any funding required, the flexibility of dates, the frequency of respite and the facilities available which serve both patient and carers needs. If these foundations are present and practicable, a decision may be made by the carer and patient to accept respite. This is followed by the mechanics of the referral process (which the carer may have to expedite) and preparing for the admission (packing of equipment, medication, feeds). Finally the carer is likely to provide a comprehensive handover of care needs to the professionals.

5.3.1.3 Outcomes from respite

Any model of interventions should have clearly identified outcomes in order to ensure transparency and intended benefits for the patient and the carer.

The study findings indicate that a successful respite experience contributes to a state of transition which aids patients to accept and adapt to a new normalcy that their disease progression has dictated. In addition, it assists the carer to find new ways to
manage and control the situation (including managing their own health needs if required), co-existing with contemporary approaches to caring and a new normalcy. These benefits work best if there is a concept of mutuality where the patient and carer can both embrace and welcome the opportunities that respite can offer.

Carers also appear to use this time to reflect on the past and consider the future. They frequently reminisce about altered life plans and how this has affected them and their relationship with their loved one. A sense of loss may be acknowledged and the letting go of what was before. This may lead to a state of adaptation and restoration which ultimately culminates in a level of resilience and sustainability that enables the carer to continue in the caring role.

There may be more respite experiences depending on the carer’s resilience levels and the patient’s disease progression, which will continue to strengthen the carer’s sustainability and support the patient.

5.3.1.4 Theory development

The theory developed as a result of data analysis is substantive as it is limited in its potential translation to other areas (Charmaz, 2006). As a result of this substantive theory, two models have been developed to illustrate the findings in a pictorial manner. This allows dissemination of the research findings to numerous stakeholders (e.g. commissioners, service developers) and is also useful for survive users (patients
and their carers) to understand how residential respite can be a therapeutic experience.

5.4 Summary of discussion & emerging theory chapter

The respite experience was found to be a form of restoration for most study patients as it enabled the opportunity to receive individualised care from the multi-disciplinary team, allowing them to target specific concerns and address them in a safe environment (Hicks & Corcoran, 1993; Aoun et al. 2006). Considering and experimenting with different and alternative care patterns was found beneficial during residential respite. Some patients however were extremely limited in their ability to change their functional status as they had already deteriorated to a level which was irretrievable but they were often motivated by having access to social interests such as quizzes, arts and crafts, topical discussions (e.g. daily news events) and meeting / talking to people who had led similar lives to them.

For carers the respite experience could be valuable in order to take stock of their lives and find a way of coping with the future. They were able to redefine their future and find a new sense of normalcy which respite encouraged them to do. This was a form of restoration and involved adapting to a new normalcy which, in turn, culminated in developing resilience, and ultimately sustainability, to continue caring.
Overall there have been insufficient studies designed to specifically clarify the benefits of regular respite for the patient (Barrett et al. 2009; Mullan et al. 2011), however the data from this study demonstrated that a well-planned, comprehensive and recurring respite experience (i.e. offered on a regular basis) was able to satisfy a tailor made set of needs for both patient and carer. Findings from the study led to the generation of a model illustrating the relationship between caring and respite and possible therapeutic outcomes. A decision making framework to guide patients, carers and professionals to determine when respite might best be considered and how to negotiate the process was also developed.
Figure 5.2: A Model of the Relationship of Caring and Respite

ANTECEDENTS
- Patient diagnosis: Neuro-degenerative
- Carer: Obligation vs desire

Deterioration
Exhaustion

PROCESS
Consider
Respite

Reasons:
- Carer break
- Patient assessment/support changes
- Alterations to home
- Patient socialisation

PLACE:
- Nursing home
- Hospice
- Specialist home

FUNDING:
- Free
- Continuing care
- Private
- Personal budget

TIMINGS:
- Dates
- Length of stay
- Frequency

FACILITIES AVAILABLE:
- Assessment and delivery of care
- Equipment
- Access to MDT
- Social interests
- Advance Care Planning
- Functional capacity
- Sign posting
- Communication

OUTCOMES
- Transition, Restoration and developing Resilience and Sustainability
- See ‘Therapeutic Model’
Figure 5.3: The Sustainability Model for Patients with Neurodegenerative Conditions and their Carers

Respite Experience

Transitional Process

Patient:
- Accept & adapt to new normalcy

Carer:
- Control, new ways of caring and normalcy

Time reflection:
- Present
- Reminiscing on past life and altered future plans

Concept of Mutuality

Adaptation and Restoration

Resilience and Sustainability

Continue Caring

OUTCOMES

Deterioration/carer exhaustion may occur, resulting in need for further respite

Carer involvement

Patient involvement
CHAPTER 6: CONCLUSION

6.1  Introduction

This chapter concludes the thesis and provides an overview of the study findings. The study examined patients with neurodegenerative disease and their carers’ experience of residential respite and developed a grounded theory resulting from interpretation of the data.

This chapter will include the study limitations and recommendations for further research, as well as dissemination of these results to a wider audience. It will also discuss the implications of this research for practice and explore opportunities for broader application.

6.2  Existing knowledge of respite and neurodegenerative disease

Due to financial constraints, respite has become a scarce commodity (Wolkowski et al. 2010). Organisations such as nursing homes are the main providers of respite but are often ill equipped to provide a meaningful and therapeutic experience. In addition, neurodegenerative patients require specialist care as their needs are often complex and rapidly changing and nursing home staff may not possess the level of expertise necessary (Castle & Anderson, 2011).

6.3  Key findings from this study

The study found that a successful residential respite experience for patients with neurodegenerative diseases and their carers depended on numerous factors: the
carer and patient identifying the need for respite, exploration of why it is needed and the information required to determine where, what, when and how respite can be accessed. The logistics of the referral process, preparation for respite and the handover of care needs to professionals were often undertaken by carers. The outcomes from the respite admission should reflect a symbiotic relationship where it is mutually acceptable to both the patient and carer, indicated by an opportunity to accept and adapt to a new normalcy for both, dictated by disease progression and reflecting on time present and time past. The onward journey sees a transitioning which involves restoration and building a level of resilience which all contribute to sustainability and being able to continue in the caring role. In this way, respite can be seen as a therapeutic, personalised experience.

6.4 Key contributions to existing knowledge

The new contributions to knowledge that have derived from this study are:

- The preparation and planning for residential respite can be extremely lengthy and burdensome. This can be a much improved experience for the carer if there is adequate and timely information related to potential and actual needs and appropriate support to expedite the admission.

- Therapeutic residential respite can result in restoration for both the patient and the carer. This is often a recurring and constant process, resonant of the neurodegenerative disease trajectory.

- The process of restoration is different for the patient and the carer but the outcome clearly reflects the individual’s needs. The patient is able to review and explore equipment requirements, experiment with communication aids
and begin planning for the future whilst the carer is afforded an opportunity
to repair their identity, create a new but different life, leading to resilience
and sustainability to continue in their caring role.

Residential respite may enable both the patient and the carer to adapt to a
new state of normalcy for a period of time until the disease progresses
and/or the carer becomes fatigued.

6.5 Policy and policy gaps

These study findings might be useful for policy makers. Much attention is focused on
keeping patients at home for as long as possible and avoidance of hospital
admissions which are expensive and often unnecessary. The preferred place of care
and death are presumed to be on the choice agenda but in reality this is often
difficult to achieve with lack of resources and limited access to 24 hour advice and
support (House of Commons Health Committee Palliative Care, 2004; DH, 2008a).

With increasing emphasis on caring for people at home, it is vital that informal carers
receive adequate support and information (Murtagh et al. 2012) which a respite
admission can do.

Adequate respite service provision needs to be explored, though in reality there are
unlikely to be additional resources to address the shortfall in this area of care. To
compensate for this, working with charities and third sector organisations will enable
the exchange of information and learning to take place. This will enable services that
do not possess the skills to care for these complex patients (e.g. nursing homes), the
opportunities to adopt and adapt to an alternative care approach.
A future funding option to support respite care may be the continued initiative of personal budgets which allows patients and carers to source and access their own choices around supportive care, based on their personal and frequently changing needs. Recent developments have resulted in people with complex health care needs having the ‘right to ask’ for personal health budgets if they are claiming continuing care. Personal advice and ongoing support are purported to be key elements of these improvements to the system (NHS England, 2014). For patients with neurodegenerative diseases and their carers, having control of their personal budget and respite facilities would ensure they had access to individual care options such as members of the multi-disciplinary team, depending on their particular care needs at that point in time. This may all be complemented by the findings from the palliative care funding review which is currently piloting tariffs. Respite care for carer break was not considered to be part of this package, however respite care with a focus on reviewing patient’s medical and nursing needs was felt to be worthy of funding as part of this project.

6.6 Strengths and limitations of the study

The strength of this study was the wide geographical area across South East England covered by the three sites of recruitment. The participants were extremely keen to tell their stories which were in depth and rich with experiences, thoughts and perceptions of their respite admission and were generally consistent. This greatly enhanced and strengthened the knowledge available and allowed the researcher to formulate relationship mapping and development of a model to illustrate the potential outcomes of respite.
Due to being assured of anonymity and the varied locations of recruitment, the participants could speak openly about their experience and not fear reproach from the place of respite, especially if they plan to return there for further episodes.

The limitations were that the study only recruited participants who had experienced residential planned respite and therefore the grounded theory generated can only be applied to this area of care. In addition, this research has produced a substantive theory (i.e. well planned residential respite can potentially have therapeutic outcomes) as it is a specific, well defined area of care. The theory has not been tested in other areas, therefore cannot and should not be applied generally without further exploration.

All participants spoke English and the majority were white British. This cohort of participants were mainly from a higher social class and were not from any minority ethnic or diverse backgrounds which may affect the efficacy of the model as different cultures may experience varied issues which could alter the perception of what a therapeutic outcome is. Religious and cultural influences may be indicative of the probable uptake of respite as the extended family concept often means families care for their sick.

Many patients had problems with communication as their conditions were very advanced. This created a shift to carer interpretation of the patient’s experience which may have been more subjective, although every effort was made to include and determine patient opinion whenever possible. Generally carers were over
represented in the study: a more balanced view of patients’ versus carers’ views might have been valuable.

6.7 Further research opportunities

This research has added to the breadth of knowledge on respite care but it has also led to more questions which require further exploration. These include:

- Measuring the impact on resources accessible for patients and carers with the continued emergence of personal budgets by using comparative effectiveness models.
- Testing of the model against other forms of respite, to assess if therapeutic outcomes can be achieved in day or home care and with ethnic minority and diverse cultures and backgrounds.
- Developing a tool to assess carers’ resilience that focuses on how they continue caring and the tenets that must be present. Resilience may be transient and this may blend well with work already completed on the personal characteristics possessed by carers (Nakagawa et al. 2014). Respite, in different settings (e.g. home or day respite) may provide additional information to support resilience.
- The consideration of carers’ needs and who assesses them. The use of care planning to assess carer’s needs in their own right is an integral part of the Care Act (DH, 2014a).
6.8 Implications for practice

As non-malignant diseases are increasingly recognised as requiring palliative care it is pertinent to consider how already stretched resources and facilities can best address their needs. The study has found that residential respite can provide a comprehensive and integrated intervention to support patients and carers, including addressing the psychological interventions and social interests to enable a well-rounded approach to care. However, realistically there are no more funds to create opportunities for new ventures such as respite and commissioners are unlikely to see this as a priority. Alternative approaches to respite care and recommendations are described below and summarised in table 6.1.

6.8.1 Nursing and care homes

Professionals need to work with establishments that offer respite and consider ways to improve and support innovation. Nursing and care homes are universally available nationwide with bed capacity to offer regular respite care. Preparing and training nursing / care home staff to deliver good quality respite (within their boundaries) may address some inequities of access for certain groups (e.g. marginalised patients and those patients living alone). Areas of need are identified as:

- improving assessments and developing programmes which offer an ‘MOT’ holistic approach
- understanding and managing communication difficulties
- planning and delivering appropriate and timely care for this cohort of patients (e.g. feeding, manual handling) and
- addressing the needs of the carers.
Up skilling of staff and links with other relevant services, such as the multi-disciplinary team in the local hospice, are essential to enable a holistic patient and carer approach. This could be expedited by offering rotational posts or sharing services across boundaries. Dissemination of new skills and utilising the existing staff workforce is fundamental to avoid unnecessary wastage of resources.

6.8.2 Hospices

Some hospices already offer a small number of respite beds and there has been recent interest in more dedicated respite beds in hospices who have secured funding to develop new buildings and innovation (personal communication 2014) as it is increasingly recognised that allowing people to remain at home will require additional support, information and advice. Hospices are able to offer specialist palliative care input and access to a comprehensive multi-disciplinary team; however their core business is concerned with caring for patients requiring symptom control and end of life care and therefore they may need guidance on refining and firmly embedding a rehabilitative approach to care. It is crucial that the concepts of enablement, self-management and empowerment for patients with neurodegenerative diseases and their carers are adopted.

6.8.3 Practice

Professionals also need to consider how they effectively ‘hand back’ the care of the patient to the informal carer so that any changes to care interventions and routine can be communicated in a timely and efficient manner. This will forge a reciprocal relationship between professionals and carers and acknowledge the informal carers
input into ongoing care. The National Audit Office advocated the use of individualised care plans (DH, 2011) which should be developed into providing carers with documentation of changes instigated during the respite admission. This would reinforce the handing back of the care to the carer and promote their mutual value in the relationship, thus viewing them as ‘co-workers’ in partnership with the professionals (Twigg & Atkin, 1994).

Table 6.1: Recommendations for practice

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<th>ISSUE</th>
<th>RECOMMENDATION</th>
<th>ACTION</th>
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<td>Use of available bed capacity for respite care.</td>
<td>Sharing of knowledge</td>
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<td>Up-skilling of staff to assess and manage patients with complex neurodegenerative diseases – e.g. feeding, communication, manual handling skills.</td>
<td>Education / dissemination of learning</td>
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<td>Cross boundary working for disciplines</td>
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<td>Hospices</td>
<td>Dedicated respite beds.</td>
<td>Developing a rehabilitative approach to care</td>
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<tr>
<td>Practice</td>
<td>Efficient and timely handing back of care from professionals to carers.</td>
<td>Development of care plans</td>
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<td></td>
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<td>Improved communication</td>
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6.9 Dissemination of findings

This doctorate has provided an avenue to further develop the researcher as an advanced practitioner. It is imperative that the findings are disseminated to relevant and interested colleagues locally, regionally, nationally and internationally. This has already been conducted via:
• An oral presentation at an international palliative care conference (EAPC, June 2014)
• An article in a peer reviewed, specialist, multi-professional European journal (Laverty, Faithfull & Arber, 2013)
• A lecture at a national organisation (Help the Hospices, 2014).

In addition, the researcher has created strong links with charitable organisations, including the Motor Neurone Disease Association (MNDA) and Multiple Sclerosis Society and further discussion will consider the best way to propagate these findings to their support staff and volunteers to enable continued learning.

The researcher also plans to conduct teaching sessions in the healthcare establishments who assisted with recruitment (e.g. National Hospital for Neurology and Neurosurgery and a West Sussex Hospice) to feedback the findings.

The hospice where she works has a dedicated nurse led unit which is evolving. We are constantly seeking ways to widen access to hospice services for the non-malignant population and this study will serve to inform practice development and strategic direction.

6.10 Summary of conclusion

This chapter has concluded the study and discussed future application of the findings. The model has been presented and discussed within the policy context and suggestions have been made regarding further opportunities for research.
Dissemination of the study has already happened in an international arena and future opportunities at local and national level are being explored.

A respite experience that does not provide a comprehensive assessment and intervention programme might be viewed as a missed opportunity for neurodegenerative patients and their carers. These are patients with complex needs and therefore require specialised respite care. This intervention has the potential to save money by helping to prevent emergency admissions which is a source of excessive expenditure in the National Health Service. In addition, informal carers are likely to become more of a feature within our health care structure and will significantly increase in numbers as our population ages and the needs change in accordance with this. In order to ensure their sustainability we urgently need to address their concerns to enable them to continue in their valuable and unsung role. Health care is undergoing much change. It appears that respite has a valuable part to play in future care options so now may be timely to consider its reinvention.
REFERENCES


Richards HM. & Scwartz LJ. (2002) ‘Ethics of qualitative research: are there special issues for health services research?’ Family Practice. 19(2), pp. 135-139.


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## APPENDIX 1
### TABLE OF NEURODEGENERATIVE DISEASES

<table>
<thead>
<tr>
<th>DISEASE</th>
<th>DESCRIPTION, INCIDENCE, CAUSE &amp; PROGRESSION</th>
<th>DEMOGRAPHICS</th>
<th>TREATMENT</th>
<th>LIFE EXPECTANCY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cortical basal degeneration (CBD)</td>
<td>Incidence: 6 per 100,000 Usually misdiagnosed as PSP. Symptoms develop gradually and become more severe over years, notably movement, speech and higher thought processes such as planning and understanding. Alien hand syndrome: – inability to control the hand and a feeling the limb is ‘alien’.</td>
<td>Affects women more commonly than men. Age of onset 50-80 years</td>
<td>Symptom management; e.g. spasms. Insertion of feeding tube. Communication aides.</td>
<td>Usually mature onset leading to curtailed life span but complications may shorten life considerably e.g. aspiration pneumonia.</td>
</tr>
<tr>
<td>Huntington’s Disease (HD)</td>
<td>Affects the ability to walk, talk and think. Genetic mutation, inherited. Incidence: &lt; 0.1 per 100,000 Prevalence: 0.1 per 100,000 Symptoms progress slowly and result in advanced dementia; bed bound and severely limited communication.</td>
<td>Affects both female and male Age of onset 40-50 years</td>
<td>Option of genetic counselling for family. Good nursing care. Symptom specific management e.g. spasms, pain. Insertion of feeding tube. Resources and support for carers.</td>
<td>15-20 years after onset of symptoms</td>
</tr>
<tr>
<td><strong>Motor Neurone Disease (MND)</strong></td>
<td>Progressive muscle wasting disease, cause unknown, though 5-10% are familial inheritance. Incidence: 1 - 2 per 100,000 Prevalence: 4–6 per 100,000 Rapidly changing physical and psychosocial needs, including muscle wasting resulting in problems with mobility, breathing, swallowing and speech. Drooling is also a significant problem.</td>
<td>Affects males slightly more than females. Age of onset mid 50’s – 70’s</td>
<td>Riluzole 50mg BD prolongs survival by months Insertion of feeding tube Communication aides Equipment Anticholinergic drugs Spasm management Non-invasive ventilation Early advance care planning</td>
<td>2-5 years after onset of symptoms</td>
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<tr>
<td><strong>Multiple Sclerosis (MS)</strong></td>
<td>Autoimmune disorder causing progressive inflammatory damage to myelin and eventual destruction of axons. Aetiology is interaction between genetic and environmental factors. Incidence: 7 per 100,000 Prevalence: 100-120 per 100,000. Different forms of MS – most common is relapsing and remitting disease causing symptoms including visual disturbances, neuropathic pain, spasms, fatigue, depression and cognitive impairment.</td>
<td>Affects females more than males (2:1) Age of onset 30 years.</td>
<td>Beta interferon – Natalizumab. Symptom management. Clinical attacks treated with Methylprednisolone. Good nursing care – observing for triggers that aggravate symptoms.</td>
<td>Can be 5-10 years less than normal life expectancy but often shortened by complications e.g. pneumonia.</td>
</tr>
<tr>
<td>Multiple Systems Atrophy (MSA)</td>
<td>Affects the movement, balance and autonomic functions of the body, cause unknown. Incidence: 3 per 100,000 Prevalence: 6 per 100,000 Initially diagnosed as Parkinson’s disease but symptoms develop much sooner than PD. Deterioration in mobility, balance, bladder &amp; bowel dysfunction and spasticity.</td>
<td>Favours males more than females Age of onset 40 – 69 years</td>
<td>Symptom review and management. Safety management – high risk of falls Communication aides Insertion of feeding tube 5-9 years after onset of symptoms</td>
<td></td>
</tr>
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</table>
## Appendix 2

### Literature search results

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### APPENDIX 3

**Summary grid for research papers**

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<thead>
<tr>
<th>Author(s)</th>
<th>Year of publication</th>
<th>Title of paper</th>
<th>Name of Journal</th>
<th>Main points about the study</th>
<th>Theory / definition</th>
<th>Comments on the methodology used</th>
<th>Main findings</th>
<th>How reliable &amp; valid is the study?</th>
<th>Any other comments</th>
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</thead>
<tbody>
<tr>
<td>Payne, S., Ingleton, C., Scott, G., Steele, k., Nolan, M &amp; Carey, I.</td>
<td>2004</td>
<td>A survey of the perspectives of specialist palliative care providers in the UK of inpatient respite</td>
<td>Palliative Medicine 18(692-697)</td>
<td>Clear aim – part of a programme of research looking at this area of care</td>
<td>Occasional or intermittent temporary relief from the perceived responsibilities for the ‘wellbeing and safety of a person with life-threatening illness where the primary beneficiary is a carer’.</td>
<td>Descriptive cross sectional questionnaire survey – postal (Quantitative &amp; qualitative data) (To uncover facts not known)</td>
<td>80% offered respite – 1 week admissions and no sig diff between size of service, amount of beds &amp; duration of respite. 20% no respite, regarded as: lower priority than SC / TC, perceived lack of demand, funding decisions by PCT to provide it in CH, lack of dr’s, respite not ‘specialist’.</td>
<td>Describe pilot, structure of questionnaire Analysis – content and independently reviewed Results presented with verbatim quotes</td>
<td>Significant ambivalence about purpose &amp; delivery of IP respite care. Limitations – views of service managers (mostly nurses) – may have been diff if views of users or other profs Concerns re: do CH have expertise to provide suitable venues for respite provision Pts &amp; carers</td>
</tr>
<tr>
<td>Year</td>
<td>Study Title</td>
<td>Journal</td>
<td>Methodology</td>
<td>Sample Size</td>
<td>Results and Discussion</td>
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<tr>
<td>2008</td>
<td>Lung cancer, caring for the caregivers. A qualitative study of providing pro-active social support targeted to the carers of patients with lung cancer.</td>
<td>Palliative Medicine 22 (233-238)</td>
<td>Evaluation in response to a new project to support the emotional and practical needs of caregivers whose partner had been diagnosed with lung cancer.</td>
<td>No definition for ‘respite care’. Non clinical, individualised social support – focus on carers psychological welfare</td>
<td>138 pts diagnosed and 20 were interviewed as per inclusion criteria. Majority of carers were spouse or partner (59%) or children (25%). Service was well received by carers and filled a gap</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Qualitative methodology with case study design – appropriate for investigating a new service. The case studies did not supply quantitative</td>
<td>Changed sampling to improve range of carers captured. Data triangulation – carer’s professionals &amp; methodology-ical</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Referrals from HCP (self ref not the norm). Used for carer need, few offered as planned admissions. Some services offered fewer staff, less facilities, diff policies – not viewed as so important &/or specialist. Perceived benefits for pts & carers. Defined period of stay, stable pts. Lack of consensus about purpose of respite between med & nursing staff.

Lack of consensus about purpose of respite between med & nursing staff expressing choice Focus on carers beliefs / demands Lack of regular audit / views of users Agree definition & clear criteria for respite. The study questions the attention/priority that carers needs have had from SPCS
| Skilbeck, JK. | 2005 | An exploration of family carers’ experience of respite services in one specialist palliative care unit | Palliative Medicine 19 (610-618) | To explore family carers’ expectations & experiences of respite services provided by 1 hospice Carers perception of caring for relative Identify carers understanding of respite provision | The temporary physical, emotional or social care of a dependent person in order to provide relief from care giving to the primary care provider. | Prospective exploratory study using qualitative & quantitative methods. This allowed detailed analysis of family carers’ experiences & expectations of respite. | in comp with their taking on this role 25 patients recruited, most cancer, most married or widowed carers. Qualitative data: Found caring ‘hard work’, physically & emotionally. For just under half caring had had a moderate impact on their lives. | Pilot interviews conducted to assess appropriateness & feasibility of interview schedules. Analysis using constant comparison & independent coding to determine themes. | Discussion re; other forms of respite care, timing & considering needs of carers. Supporting carers in own home on a regular basis instead of just periodic blocks of time. |
Palliative respite services using nursing staff reduces hospitalisation of patients and improves acceptance among carers.  
Internation al Journal of Palliative Nursing 15(8); 389-95  
Carer concern over skill level of respite carer providers is a common barrier to uptake & satisfaction. Consideration of the use of trained staff to provide respite care in the home setting  
An interval of rest or relief from carer duties.  
– offered 7hr respite per week patient  
41 pts over a 25 week period, mostly cancer pts. 14 scored high enough for respite, 12 accepted. 2 pts refused (had existing support), 5 scored high on screening tool but not high enough on  
All compared & contrasted for evidence of outcomes relating to research objectives.

| Barrett, B., Wheatland, B., Haselby, P., Larson, A., Kristjanson, L & Whyatt, D. 2009 | Palliative respite services using nursing staff reduces hospitalisation of patients and improves acceptance among carers. | International Journal of Palliative Nursing 15(8); 389-95 | Carer concern over skill level of respite carer providers is a common barrier to uptake & satisfaction. Consideration of the use of trained staff to provide respite care in the home setting | An interval of rest or relief from carer duties. | – offered 7hr respite per week patient | 41 pts over a 25 week period, mostly cancer pts. 14 scored high enough for respite, 12 accepted. 2 pts refused (had existing support), 5 scored high on screening tool but not high enough on | All compared & contrasted for evidence of outcomes relating to research objectives. | Focused on carer wellbeing so not tailored for pts living alone. Refusal was associated with less carer fatigue, supportive family network and a continent pt. Pts who received care were able to spend more time in their |
| Payne, S., Smith, P & Dean, S. | 1999 | Identifying the concerns of informal carers in palliative care | Palliative Medicine 13: (37-44.) | Purpose of preliminary study was to identify the perceived support needs of the informal carers of cancer patients receiving palliative care in the community. | No respite definition. Focus on caring and burden and what perception did carers have of the support they required. | Cross-sectional design, in the homes of patients. Semi-structured interview focused on activities involved in caring & areas of personal concern. Used the General Health 39 participants, 15 male & 24 female, mean age 60yrs. Younger carers & female carers were found to have higher levels of psychological distress & caring burden. Carers below 60 yrs & women generally needed more support. Carers are generally | and the assessment tool was adapted from a previously used tool. Carer evaluations were ascertained using a form – little detail regarding robustness of form and how it was analysed. | Balance of viewing carers as ‘experts’ in their knowledge of patients vs. supporting them appropriately. | PPC. Carers valued competency of the respite provider |
| | | | | Questionnaire standardised measure of physical & psychological morbidity & the Caregiver Strain Index. | treated as ‘co-workers’ as opposed to ‘co-clients’. | referrals for patients with advanced disease. |
10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- Are the results of the review valid?
- What are the results?
- Will the results help locally?

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

There will not be time in the small groups to answer them all in detail!

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Screening Questions

1. Was there a clear statement of the aims of the research?  
   □ Yes □ Can’t tell □ No  
   HINT: Consider  
   • What was the goal of the research?  
   • Why it was thought important?  
   • Its relevance

2. Is a qualitative methodology appropriate?  
   □ Yes □ Can’t tell □ No  
   HINT: Consider  
   • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants  
   • Is qualitative research the right methodology for addressing the research goal?

Is it worth continuing?

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Detailed questions

3. Was the research design appropriate to address the aims of the research?

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research?

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)
5. Was the data collected in a way that addressed the research issue? □ Yes □ Can’t tell □ No

HINT: Consider
- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide?)
- If methods were modified during the study, if so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered? □ Yes □ Can’t tell □ No

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions
  (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

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7. Have ethical issues been taken into consideration?  

   □ Yes  □ Can’t tell  □ No

HINT: Consider:
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained.
- If the researcher has discussed issues raised by the study (e.g., issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study).
- If approval has been sought from the ethics committee.

8. Was the data analysis sufficiently rigorous?  □ Yes  □ Can’t tell  □ No

HINT: Consider:
- If there is an in-depth description of the analysis process.
- If thematic analysis is used, if so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process.
- If sufficient data are presented to support the findings.
- To what extent contradictory data are taken into account.
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation.
9. Is there a clear statement of findings?

☐ Yes  ☐ Can’t tell  ☐ No

HINT: Consider

- if the findings are explicit
- if there is adequate discussion of the evidence both for and against the researchers arguments
- if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- if the findings are discussed in relation to the original research question

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used
APPENDIX 5
FUNDING ARRANGEMENTS FOR CARE IN THE COMMUNITY (UK)

PATIENT DETERIORATES
(Requires additional support at home)

**Health care needs**
(nursing care)

**Social care needs**
(personal care)

**CONTINUING CARE**

Checklist (assess number of high level needs and determine further forms)

- High input of care
  - (patient expected to live ≥ 6 months)
  - Decision Support tool (DST) completed
    - (HCP specifies level of care required)
    - Goes to Panel
    - Funding agreed & POC agreed
    - Reviewed every 6 months

- Fast track pathway
  - (patient expected to live 3-6 months)
  - Statement & care plan completed
    - (HCP specifies level of care required)
    - Goes to Panel
    - Funding agreed & POC agreed

**PERSONAL BUDGETS**

Paperwork completed by Social Worker

Panel meeting

Decision made regarding amount of funding per annum

- Family determine how to spend money
  - (may be specific regarding what areas of care or social activities (e.g. certain amount for respite))
  - Family must keep receipts and run as a business
    - (may be subject to external auditors)
Appendix 6
Examples of availability of respite care for patients with neurodegenerative diseases & their carers in the UK

<table>
<thead>
<tr>
<th>Place for respite</th>
<th>Details</th>
<th>Number of beds in UK</th>
<th>Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospices</td>
<td>Philosophy focused on holistic care for patients, carers &amp; family. Some hospices have dedicated respite beds, depending on the size and use of beds. Mix of trained / untrained staff and access to many disciplines.</td>
<td>223 hospices 3200 beds</td>
<td>No funding required. Approximately 40% funding from the NHS and the remainder is charitable funding.</td>
</tr>
<tr>
<td></td>
<td>All hospices will provide respite depending on bed availability but this is generally not considered a priority over patients requiring end of life care and symptom control. A small number of hospices offer dedicated respite beds although no data is available (MDS communication, 2014)</td>
<td></td>
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<tr>
<td>Leonard Cheshire Homes</td>
<td>Philosophy of disabled people having freedom to live lives as they choose - with the opportunity and support to live independently, contribute economically and participate fully in society.</td>
<td>Over 100 care homes (with and without trained nurses)</td>
<td>Requires funding – continuing care or private funds.</td>
</tr>
<tr>
<td>Sue Ryder (Neurological centres)</td>
<td>Specialist centres which has trained / untrained staff mix, focused on providing activities’ and access to many disciplines to maximise functionality and quality of life.</td>
<td>5 specialist centres with 1-2 dedicated respite beds in each.</td>
<td>No funding required. Approximately 40% funding from the NHS and the remainder is charitable funding</td>
</tr>
</tbody>
</table>
Care Homes (specialising in Huntington’s disease, MND & MS)

| Care Homes (specialising in Huntington’s disease, MND & MS) | Periods of respite can range from one or two nights to a week or a fortnight. The care needs are met by mostly untrained staff, supported by trained nurses / the home manager who may also have specialist training in neurological diseases. They have limited access to disciplines. (Many people who choose this option may subsequently decide to choose long term care in this institution.) | 57 homes throughout the UK, totalling 3000 beds. Specialising in HD, MND and MS conditions. | Requires funding - continuing care or private funds. |

Sources:


Personal communication:

- Sue Ryder Homes
- Care Homes UK
- Leonard Cheshire Homes
- NCPC minimum data sets (MDS)

This list is not exhaustive.

All nursing / care homes offer general respite if beds are available.
# APPENDIX 7
## HIERARCHY OF EVIDENCE AND RECOMMENDATIONS GRADING SYSTEM
(Adapted from Eccles & Mason, 2001)

<table>
<thead>
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<th>LEVEL</th>
<th>TYPE OF EVIDENCE</th>
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<tr>
<td>I</td>
<td>Evidence obtained from a single randomised controlled trial or a meta-analysis of randomised controlled trials</td>
<td>A</td>
<td>At least one randomised controlled trial as part of a body of literature of overall good quality and consistency addressing the specific recommendation (evidence level I) without extrapolation.</td>
</tr>
<tr>
<td>IIa</td>
<td>Evidence obtained from at least one well-designed controlled study without randomisation</td>
<td>B</td>
<td>Well-conducted clinical studies but no randomised clinical trials on the topic of recommendation (evidence levels II or III); or extrapolated from level I evidence.</td>
</tr>
<tr>
<td>IIb</td>
<td>Obtained evidence from at least one other well-designed quasi-experimental study</td>
<td></td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>Evidence obtained from well-designed, non-experimental descriptive studies, such as comparative studies, correlation studies and case-control studies.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>Evidence obtained from expert committee reports or opinions and/or clinical experiences of respected authorities.</td>
<td>C</td>
<td>Expert committee reports or opinions and/or clinical experiences of respected authorities (evidence level IV). This grading indicates that directly applicable clinical studies of good quality are absent or not readily available.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>GPP</td>
<td>Recommended good practice based on the clinical experience of the Guideline Development Group.</td>
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</tbody>
</table>
APPENDIX 8
THE PROCESS OF GROUNDED THEORY

THEORETICAL SAMPLING & TRANSCRIBING OF DATA

ANALYSIS

CODING
- Initial (line by line)
- Focused (synthesize & explain)
- Theoretical (develop into concepts)

CONSTANT COMPARISON
- (comparing like with like)

Identify CONCEPTS (& relationships to other concepts)

MEMOS

THEMES & relationships identified

CORE CATEGORY (should be traceable back to data)

SATURATION reached

THEORY emerging (check back with data)
01 June 2012

Mrs Diane Lavery
Nurse Consultant in Palliative Care
St Joseph's Hospice
Mare Street
Hackney
London
E9 4SA

Dear Mrs Lavery


REC reference: 12/L0/0742

Protocol number: N/A

Thank you for your letter of 30 May 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/ASC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study:

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

A Research Ethics Committee established by the Health Research Authority
Ms Rachel Taylor  
National Hospital for Neurology and Neurosurgery  
Queen Square  
London

Dear Ms Taylor,

Project ID: 12/0260 (Please quote in all correspondence)  
REC Ref: 12/LO/0742  
Title: Respite Care for Patients with Neuro-Degenerative Disease: A grounded theory study.

Thank you for registering the above study with the Joint Research Office (UCLH site). I am pleased to inform you that your study now has local R&D approval (NHS permission) to proceed and recruit participants at University College London Hospitals NHS Foundation Trust.

Please note that all documents received have been reviewed and this approval is granted on the basis of the key documents provided which are ethically approved by the Research Ethics Committee:

<table>
<thead>
<tr>
<th>Document</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>REC approval and REC approved documents</td>
<td>01/06/12</td>
</tr>
</tbody>
</table>

As Principal Investigator you are required to ensure that your study is conducted in accordance with the requirements on the attached sheet.

Please find enclosed the conditions of your NHS permission and do not hesitate to contact a member of the team with regards to any queries.

Yours sincerely

[Signature]

Professor Monty Mythen  
Director of Research and Development  
UCL/UCLH/Royal Free Joint Research Office

---

UCL Hospitals is an NHS Foundation Trust comprising: The Eastman Dental Hospital, The Heart Hospital, Hospital for Tropical Diseases, National Hospital for Neurology and Neurosurgery, The Royal London Hospital for Integrated Medicine and University College Hospital (incorporating the former Middlesex and Elizabeth Garrett Anderson Hospitals).
Date 02/08/2012

Name Diane Laverty
Student in Doctorate Clinical Practice
FHMS
University of Surrey
GU2 7XH

Dear Diane

Ref: – EC 2012 27
Title: – Respite Care for patients with Neuro-degenerative diseases
Supervisors: Anne Arber & Sara Faithfull

On behalf of the FHMS Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation: 25/07/2012

The list of documents reviewed and approved under its Fast Track procedure is as follows:-

<table>
<thead>
<tr>
<th>Document Type</th>
<th>Version</th>
<th>Dated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proposal</td>
<td>1</td>
<td>07/07/2012</td>
</tr>
</tbody>
</table>

This opinion is given on the understanding that you will comply with the University’s Ethical Guidelines for Teaching and Research, and with the conditions set out below.

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected, with reasons.

You are asked to note that a further submission to the FHMS Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Prof Peter Goldfarb
Chair, FHMS Ethics Committee

cc: Anne Arber, Sara Faithfull
21st January 2013

Ms Diane Laverty  
Student in Doctorate Clinical Practice  
FHMS  
University of Surrey  
GU2 7XH

Dear Diane

Ref: EC 2012 27  
Title: Respite Care for patients with Neuro-degenerative diseases  
Supervisors: Anne Arber & Sara Faithfull

On behalf of the FHMS Ethics Committee, I am pleased to confirm a favourable ethical opinion to the amended protocol submission received on 13th January 2013.

Date of confirmation of ethical opinion: 16th January 2013

The list of documents reviewed and approved by the Chair are as follows:-

Document Type: Amendments to proposal and supporting documents  
Version: 2  
Dated: January 2013

This opinion is given on the understanding that you will comply with the University's Ethical Guidelines for Teaching and Research, and with the conditions set out below.

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected, with reasons. Please notify the Committee of the BSc student researchers for the project once they have been named.

You are asked to note that a further submission to the FHMS Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Dr Anne Arber  
Chair, FHMS Ethics Committee  

cc: Anne Arber, Sara Faithfull, Supervisors, FHMS
APPENDIX 11

PARTICIPANTS INFORMATION SHEET

Research Study: Respite Care for Patients with Neuro-Degenerative Diseases.

A Grounded Theory Study.

My name is Diane Laverty and I am a doctorate student and I would like to ask you if you would agree to take part in a research study related to your experience(s) of respite care. Before you decide you need to understand why the research is being done and what it will involve for you. Please take the time to read this information sheet and talk to others (e.g. your friends and family) if you wish.

What is this research study about?

I am trying to find out about respite services available, who uses them and what the person using them and their carers think of them and the care they offer. My research is being supervised by the University of Surrey. It has been reviewed by the ethics committees based at the National Hospital for Neurology & Neurosurgery (NHNN) and the University of Surrey.

Do I have to take part?

No, you do not have to participate. If you agree to be involved you can keep this information sheet. I will ask you to sign a consent form but I will explain everything to you as many times as you would like. At any time, you can change your mind (you do not need to give me a reason) and this will not affect your treatment or care in any way.

Your General Practitioner will be informed of your involvement in this study with your permission.
What would I have to do?

You would have to talk to me about your experiences of respite care. It would take the form of a conversation and I may ask a few questions in order to help me understand what you are telling me. This will take between 45 to 60 minutes. I would be happy to come to your home or meet you somewhere mutually convenient. The conversation will be recorded but anything you say will not be linked to your name or personal details. All recorded and written information will be stored and destroyed in accordance with the Data Protection Act 1998. **We must, however, inform you that if you disclose information that indicates there was a problem with the care you received (e.g. you experienced abuse) we may have to inform the appropriate authorities.**

What are the possible benefits of taking part?

I cannot promise that there will be any benefits for you if you agree to take part, however many people do feel a benefit from being able to talk about their experiences. My hope is that the information I get from this research study will help me and others create a model of care to benefit people who use respite services. I can provide you with feedback of the findings of the study results if you wish.

Contact Details.

If you would like to discuss any of the information provided here, please don’t hesitate to contact me via e-mail d.laverty@stjh.org.uk or phone 07931 888 543 where you can leave your contact details and a message and I will get back to you as soon as possible.

What happens if I am unhappy in any way about the study?

The Patient Advocacy and Liaison Service (PALS) are available for you to talk to if you feel unhappy in any way. They can be contacted on 020 3448 3237. In addition, the University of Surrey supervise this research and the Head of Faculty of Health and Medical Sciences, Professor Karen Bryan (01483 682507), can also be contacted to discuss your concerns.

More information and taking part in the research.

If you would like to take part in this research and learn more about it please complete your details below and give the tear-off slip to the CNS or Nurse Consultant.

I will contact you to discuss further and answer any of your queries and, if you are then happy to proceed, I will arrange a mutually convenient time to meet you and conduct the interview.
CONSENT FORM

Project Title: Respite Care for Patients with Neuro-Degenerative Diseases. A Grounded Theory Study.

Name(s) of Researchers: Diane Laverty, Nurse Consultant; Professor Sara Faithfull, University of Surrey; Dr Anne Arber, University of Surrey.

Description of research project:

- Participant(s) are being asked to take part in an interview which will last between 45–60 minutes. The interview will be recorded and transcribed.
- The transcriptions of the interview will be kept at a secure password protected, work computer and will be stored and destroyed in accordance with the Data Protection Act 1998.
- Only the researchers on this project will have access to this material.

I have been given information about the research project and the way in which my contribution to the project will be used.

Please tick the boxes below.

☐ I confirm that I have read and understood the Information Sheet, dated --------------- for the above study. I have had the opportunity to consider the information, ask questions, and have had those questions answered satisfactorily.
☐ I understand that my participation in the study is voluntary and that I am free to withdraw at any time, without giving any reason, without my care or legal rights being affected.

☐ I understand that the information I provide during my interview will be looked at by Diane Laverty (the researcher), the supervisors from the University of Surrey and any relevant regulatory authorities. I give permission for these persons to have access to the information I have given today.

☐ I consent to audio recording

☐ I consent to my GP being contacted regarding my involvement in this study.

☐ I agree to take part in the study

☐ I would like to know the results from this study.

☐ I give my permission for the information I am about to give to be used anonymously for research purposes only (including research publications, teaching and reports)

☐ I hereby assign the copyright in my contribution to the researcher for research purposes.

Signature of Participant……………………………………………………Date:……………………………..

Signature of Researcher:………………………………………………….Date:……………………………..

This information will be retained separately and securely from the information given during the process of the research.

Version 2 May 2012
APPENDIX 13

BROAD INTERVIEW GUIDE - PATIENT

Demographics:

- Age
- Ethnicity
- Gender
- Occupation
- PS

Social situation

- Live alone
- Informal carer – who? (Spouse, other)
- POC – quantity / frequency

Length of time with disease

Personal coping mechanisms

Respite

- Frequency
- Place
- LOS
- Planned
- Triggers
- Who referred
- Any difficulties or barriers to accessing respite?
- How did you get what you got?
- Did you know about services? How?

Respite experience

- Therapies – specify
- Any review by professionals during respite (medical, nursing,. medication, care needs, therapies)?
- Social activities during stay
- Functionality
- Comfort
- Outcome

What were your expectations of respite?

What could make a difference for you from the respite stay?

Would you recommend it to others?
APPENDIX 13

BROAD INTERVIEW GUIDE - CARER

Demographics:
- Age
- Ethnicity
- Gender
- Occupation
- PS

Informal caring role
- Relationship to relative
- Understanding of disease
- Length of time relative has had condition
- Length of time of carer role
- Evolution of carer role
- Any personal ill health?
- Other dependents?

Respite
- First episode?
- Frequency?
- Place?
- LOS?
- Planned?
- Triggers for identifying need for respite?
- Who referred?
- Any difficulties or barriers to accessing respite?
- Carer role in deciding place / frequency / initiating referral?
- How did you get what you got?
- Did you know about services available? How?

Respite experience
- Flexibility – options / dates / planned in advance
- Planning / preparation – for patient
- Planning / preparation - for carer
- Visiting
- What happened for you during respite stay (personal activities)?
- Feelings regarding placing relative in respite stay
- Any review (medical, nursing, therapies) by professionals during stay?
- Any barriers / difficulties during stay
R: Ok, so you’ve had a long time when you were doing all of the caring and doing a great job. Philip, can I just ask you, did you recognise that Sylvia was getting to the point where she needed a break?

Pt: Yes

R: You did. Did she look tired?

Pt: She kept getting upset

P: Yes, that’s right actually.

R: So did you both decide together that respite was good?

P: Yeh, I think we did, we certainly discussed it, I didn’t inflict it on him (pt says ‘yes’ too)

R: And how did you feel Philip, about the thought of respite?

Pt: Initially I was worried but they’re very good

R: So you went to look round Burnlock first but that didn’t happen so St C’s was your first experience of respite so you could probably have got better. You get very good care when you are there Philip?

Pt: I do

R: Ok, so the first time you went in, if you can cast your mind back, how did that feel? How about the work up to going in, the arrangements of it, packing everything that Philip needed, making sure his medicines and everything were ready... can you recall how that felt for you?

P: Ummm.. practicalities are fine, that’s not a huge problem, ummm......yeh, just not quite knowing quite what to expect............ ummm....wanting to not to have control or have to have control of everything but actually being quite nervous of losing control of everything....if that makes sense? I’m a bit of a control freak, being worried that things wouldn’t be done properly, ummm.... You know, knowing that if he doesn’t have the cream on his face his skin falls off.... ummm you know, just worrying that things would be worse when he came out than when he went in.

R: So when Philip first went in, did you go with him for that first one?

P: Yes

R: And what happened? Did you give them......all sit down together, you and nurse and a doctor and talk about what Philip’s day looked like?

P: Yes, you see the nurse and you go through all the sort of day to day stuff, ummmmm.....like feeding and bowels and all that sort of practical stuff, ummm....but you also see the doctor who does a quick physical and goes through the medication and any concerns and does the more kind of medical side of it...that.... And that’s fine, that’s quite reassuring. They’re always happy for you to go in and visit and I cannot remember...you see, for the last 4 years we’ve only had that 2 weeks and I can’t remember whether I went away or stayed here that first week, the first time he ever went to respite, I can’t remember what I did, I really can’t, ummmm... I’m quite
Able to access family property abroad

‘Having house to myself’
(reference to invasion of carers)
Reassured re: handover but length of time to see everyone if prohibitive
Cutting into my time?

Settle him in & handover

Acknowledge constant change
Delivery & handover – personal advocate

No booking in advance
Pre-planning would be useful

Give up a holiday

Other identified system of booking on advance
Acceptance of

fortunate because my sister has property in Madeira so I can go there at any time so I’ve been over there with her and my mum’s a widow so I can go over with her, so I’ve got things... I don’t have to be here but sometimes it just so nice to have the house to myself so now I can just share it around, I mean, I will go away one time and stay here another time.

R: When you went in and the nurse went through everything, do you feel reassured by that?

P: Yes, I did and the down side if it, and it has happened several times since, is that process seems to take up nearly a whole day.

R: Because you are waiting for the nurse to arrive?

P: Not waiting for the nurse, waiting for the doctor. If it’s ward round day particularly. One experience of going there,...........they say come between 10 and 11 so we do and we’re seen by the nurse relatively quickly and lunch comes along and he has lunch and on one occasion we didn’t actually see the doctor until half past 4. They were very apologetic and I would never, ever book to go anywhere the same day he goes to respite because of that.

R: So you always go in with him?

P: Yes I always go in with him

R: And you always go through everything, even if there no changes?

P: Ummm, there usually has been, it’s progressive so there’s usually something. Yes, I do and I just feel more comfortable seeing him settled. I don’t think I could cope so well with him being collected and taken. And he can’t speak for himself very well, and his voice has always fluctuated so if I say the things I know they’ve been said and I have admitted to being a control freak already (laughs)

R: I understand because you are his main advocate. Isn’t she Philip? She’s your voice and if you hear that she’s said that, is that reassuring for you Philip that Sylvia has gone through everything and you can actually hear that?

Pt: Yes

R: How many days do you normally get at St C’s?

P: One week

R: One week twice a year. And do you book that up in advance or do you have special times to go or what happens?

P: That has been an issue, in that initially we were told that ummm, we should ask about 6 weeks before we wanted it and it would be like generally possible umm, and then.... But when I go to Madeira I really want to book my flights 6 months in advance ‘cos they’re so much cheaper and I have to book it off at work and put the dog in kennels, you know there is stuff you have to do before you go away and I did have to give up a holiday because I had booked a flight and although I said 10 weeks in advance, could I have that week I couldn’t, and I accept that – I gave the holidays to my mum (laughter and banter about mum taking holiday and suitcase......) but having said that Philip did say that I do recognise, the next time he said I do recognise what kind of happened he said so next time you want something in advance use the day hospice as your advocate, book it in with them, they
the way it has to be – carer is 2nd priority – put up with it

Not coping – disease progression

Acknowledge needing more help

Justifying yourself is upsetting

Acknowledge truth at face value but no thinking around the edges

Did get help with forms

Familiarity

Limited knowledge of other places

Understanding from a professional

Having a named person to contact

will flag it up with us early and they did that and it worked and I went to Madeira in April when Philip was booked in with them

R: So do you sort of do the 6 months apart….at St C’s?

P: I have done as it is all I have had, obviously I didn’t want the 2 weeks close together and have a chunk of time but then having got to October 12, through the summer of 2012, I could really see that I was just not coping so well…ummmmm… Philip’s illness had progressed, I’d gradually had to have more care and I’d gone for a council managed budget and then when I needed more help I had direct payments so that was where I was and so I rang social services and said look I really need this package increased and I rang them direct, ummmmm… so they said ok, would I just describe my circumstances and I got really upset on the phone and I was talking to this young chap who said I really think I’d better get one of my managers to phone you (laughter) a howling woman on the end of the phone but they rung back and they were fine but then I suppose I didn’t really have the resources to stick up for myself enough but they said to me, and it was true, what they said to me was completely true, they said we are almost certain you would qualify for continuing health care so go for that but nobody said to me this is what we can do in the meantime……………..and I think I got to the point where I actually couldn’t say

R: And unfortunately they didn’t recognise that. They were being helpful in suggesting continuing care but they should have put something in place before that was settled. How long did you wait for continuing care? How long did it take to get organised?

P: From the beginning of October till the end of December – 3 months

R: That sounds about normal

P: Yes but having said that we had a really good social worker who came & did all the paperwork with us and said you know I can help with the forms. I know what to tick. And it went through really quickly. She was great, really good.

R: So that was increased and that entitled you to more respite?

P: Yes.

R: More respite where?

P: Umm, the place of my choice really.

R: But not St C’s?

P: No.

R: Ok and would St C’s have been the place of your choice to have all your respite or you’re not worried?

P: Probably because I knew it and then it was a bit scary thinking right how do I know somewhere. How do you know somewhere apart from talking to people? So I ended up, when I needed to contact continuing health care I had a really good conversation with someone called Debbie S who worked for them and she just knew what I was saying, do you know what I mean… some people just…. she had obviously got a really good picture of my situation, she knew what I was up against and she knew what I wanted and that was really helpful and I must admit if I need to contact them I always e-
mail or phone and ask for her, ummm... just because, ...she did say to me that they are in the process of giving people caseloads so that they would have......you would work with someone you knew. So I said to her that I don’t really know quite where to look and you hear real horror stories, I mean we have a friend at the MS society who ended up going into respite where she had been before but it was a nursing home and they hadn’t got an air mattress and they wouldn’t let her take hers because of cross contamination, she had such bad pressure sores she ended up having skin grafts at East Grinstead, I mean that’s really scary.....and at that time Burnlock had been closed for a while, bought up by a private company and was just re-opening, that was January of this year. So we went there, and it was amazing, it was completely different, they were saying all the right things, the environment was really good, the staff were nice and so we booked for him to go for a week there, end of February and on the day he should have gone there he was admitted to hospital with pneumonia (ironic laughter) so it didn’t happen so we were like OK, I’d already got the week booked at St C’s in April so by the time he’d recovered we’d got round to there so the beginning of April he went to St C’s and by then I knew I had respite for another 4 weeks with continuing care so I thought I’ve got to start using this,. I have to slot it in and so, ummm.... I re-booked with Burnlock for him to go on the 16th May and on about the 1st May we got a phone call from them saying it was being closed on the 3rd May – it was closing – completely – for financial reasons, ummmmm, so Burnlock wasn’t going to happen so I thought I’ve got a week’s leave booked, I wasn’t actually going away because I’d said when he goes somewhere new I’d have the week off because his speech is so bad now, I’d drop in, and just check on things, make sure they were understanding him, make sure he was happy, you know because it was quite local, ummm... so that wasn’t going to happen so I rang Debbie and said ok, when I spoke to you initially you did talk about Hackley Cheshire homes and there’s one at Copthorne and you said that you knew of people with similar conditions who had been happy there and she said yeh, that’s right so I got their details and we went up there, went to see them and ummm......we were really impressed actually, I was particularly impressed with the manager, Jenny. She’s just very warm, very open, I don’t think she’s been there very long but in the time she’s changed huge amounts of things

R: Is it a nursing home?

P: No it’s a specialist ummm..... Leonard Cheshire or Cheshire homes – the 2 things amalgamated, didn’t they? It’s a Victorian mansion set in 17 acres of beautiful grounds. It’s got half a dozen bungalows in the grounds that disabled people have but it’s not like you share one, you have the bungalow, that’s your home within the grounds and you have support from the staff there and then they have people there of varying degrees of disability and it’s all about quality of life and Jenny & I – we have quite a lot in common in kind of things we’re interested in and all sorts of other things, we just got on really with her, didn’t we and that really helped hugely ummm... and all the
connection with person you are leaving your husband with staff we met we were very impressed with so we bit the bullet and booked a week there and we could have that same week in May so we had that and Philip went there and I went in everyday for the first 2 or 3 days and then left a day and what have you, and other members of the family went in and he was just so relaxed and everything was so........one day I jumped up and down a bit because I couldn’t see how they could have showered him without getting the dressing wet as he had a preventative dressing on his behind and they were just so lovely with me they were just, no we’ll check and you can see that were checking and they kind of de-escalated the whole thing really nicely and you know....I wasn’t jumping up and down and I wasn’t rude but they could see I was like ooooooooky, you know....

R: And did you follow the same pattern as St C’s where you went in with Philip and go through the whole routine of his day tell them what his day looked like?

P: Well I did a 7 page care plan (laughter) they were really good about it and they said that’s great and actually they kept it and then gave it back to me and said............I did a page on bowels, a page on skin viability, I did medication, I did everything, cos in that way I knew it was all there.

R: He didn’t see a doctor when he went in there?

P: No, because they don’t have a doctor on site, he had to be registered with the local GP. I had to ask our GP if she would be prepared to go from here – she’s just up the road, to Copthorne and they said no, they wouldn’t do that. He would have to be registered with the local GP, temporary registration, and I had to get written permission for them to crush his medication to put it through his PEG, from my GP to say that was OK, which obviously I don’t for St C’s. So more sort of medication issues, more things to make sure I’d done in that respect but now I’ve done it I’ve got a copy of the letter on file and that’s fine.

R: Did that feel like a burden at the time?

P: Umm, it is an extra job isn’t it? Everything’s an extra job, ummmm but now I’ve done it I’ve just kept a copy of the letter and I’ve kept the care plan that I wrote and will just add to it. So it was good it was the first time really.

R: So he’s just been in there once?

P: Yes he’s just been in there once

R: And that was a success? Philip, would you say that was a success for you?

Pt: Yes

Pt: Hackley

R: Ok, would you prefer St C’s or Hackley? Or no preference?

Pt: Hackley

R: Gosh, that is impressive.

P: They are just so lovely there

R: What about you Sylvia? Do you have a preference?

P: I was really impressed with them actually. I like the fact that the doctor’s on site at the hospice because I know that if something goes wrong with Philip it goes wrong quickly, yeh, so that’s very reassuring. Ummm.......it’s an interesting thing... I did make a few notes before you came, to try and sort of square a few things in my mind and the hospice is palliative care and
most of the stuff is round the quality of dying. Hackley is all about the quality of living – they have profoundly disabled people there but they take them up to London to football matches and all sorts of things I mean….whatever they are interested in. They make such a huge effort on that quality of life. Ummmm... I like both places. I don’t think I like one more than the other but I can see different strengths in the different places. I like the fact that Hackley have lots of quite blokish male staff and that’s really nice for him. Men of his age, ummmm....
## APPENDIX 15
### DEMOGRAPHICS LOG

<table>
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<tr>
<th>Participant ID</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Diagnosis</th>
<th>Occupation/Location in UK</th>
<th>PS</th>
<th>SES</th>
<th>Place of respite</th>
<th>Date of Interview</th>
<th>Time since last respite</th>
<th>Duration of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1 Patient Chris</td>
<td>85</td>
<td>Male</td>
<td>WB</td>
<td>MND</td>
<td>Retired advertising (London)</td>
<td>3</td>
<td>A</td>
<td>NH</td>
<td>28/9/12</td>
<td>3 months</td>
<td>24mins</td>
</tr>
<tr>
<td>C2 Carer Pat (of P1)</td>
<td>72</td>
<td>Female</td>
<td>WB</td>
<td>(MND)</td>
<td>Retired advertising (London)</td>
<td>0</td>
<td>A</td>
<td>(NH)</td>
<td>28/9/12</td>
<td>3 months</td>
<td>37mins</td>
</tr>
<tr>
<td>P3 Patient Sean</td>
<td>67</td>
<td>Male</td>
<td>WB</td>
<td>MSA</td>
<td>Retired Insurance Broker (Herts)</td>
<td>3</td>
<td>A</td>
<td>NH</td>
<td>12/02/13</td>
<td>4 months</td>
<td>20mins</td>
</tr>
<tr>
<td>C4 Carer Sam (of P3)</td>
<td>63</td>
<td>Female</td>
<td>WB</td>
<td>(MSA)</td>
<td>Financial work (Herts)</td>
<td>0</td>
<td>C1</td>
<td>(NH)</td>
<td>12/02/13</td>
<td>4 months</td>
<td>33mins</td>
</tr>
<tr>
<td>P5/ C5 Carer Mary / Gary (Patient present limited contribution)</td>
<td>64/66</td>
<td>Male</td>
<td>WB</td>
<td>(HD)</td>
<td>Export management / housewife (Herts)</td>
<td>0/4</td>
<td>C2/ C2</td>
<td>Hospice</td>
<td>08/03/13</td>
<td>6 months</td>
<td>1.20hrs</td>
</tr>
<tr>
<td>Ref</td>
<td>Carer</td>
<td>Patient</td>
<td>Gender</td>
<td>Age</td>
<td>Role</td>
<td>Condition</td>
<td>Contribution</td>
<td>Relationship</td>
<td>Start Date</td>
<td>Duration</td>
<td>Sessions</td>
</tr>
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</tr>
<tr>
<td>P6/C6</td>
<td>Paul / Sally</td>
<td>66</td>
<td>Female</td>
<td>64</td>
<td>House wife / Sales engineer</td>
<td>(MND)</td>
<td>Limited contribution</td>
<td>Carer</td>
<td>11/5/13</td>
<td>5 weeks</td>
<td>50 mins</td>
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<tr>
<td>P7/C7</td>
<td>Isaac / Elsa</td>
<td>56</td>
<td>Female</td>
<td>57</td>
<td>Practice manager in solicitors</td>
<td>(MSA)</td>
<td>Limited contribution</td>
<td>Carer</td>
<td>21/6/13</td>
<td>2 months</td>
<td>47 mins</td>
</tr>
<tr>
<td>C8</td>
<td>Sylvia</td>
<td>57</td>
<td>Female</td>
<td>57</td>
<td>HCA</td>
<td>(MS)</td>
<td>Limited contribution</td>
<td>Carer</td>
<td>05/07/13</td>
<td>Hospice: 3 months Neuro home: 6 weeks</td>
<td>1.04 hrs</td>
</tr>
<tr>
<td>P8</td>
<td>Philip</td>
<td>55</td>
<td>Male</td>
<td>55</td>
<td>Carpenter</td>
<td>MS</td>
<td>Limited contribution</td>
<td>Patient</td>
<td>05/07/13</td>
<td>Hospice: 3 months Neuro home: 6 weeks</td>
<td>38 mins</td>
</tr>
<tr>
<td>P9/C9</td>
<td>Daniel / Deirdre</td>
<td>64</td>
<td>Female / Male</td>
<td>56</td>
<td>Administrator, NHS / Outreach worker for MH</td>
<td>(MND)</td>
<td>Limited contribution</td>
<td>Carer</td>
<td>19/07/13</td>
<td>NH: 4 months Hospice: 1 month</td>
<td>1.06 hrs</td>
</tr>
<tr>
<td>Patient ID</td>
<td>Carer ID</td>
<td>Carer Name</td>
<td>Carer Age</td>
<td>Carer Gender</td>
<td>Carer Relation</td>
<td>Carer Condition</td>
<td>Carer Role</td>
<td>Patient Name</td>
<td>Patient Age</td>
<td>Patient Gender</td>
<td>Patient Condition</td>
</tr>
<tr>
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</tr>
<tr>
<td>P10</td>
<td>010</td>
<td>Joy</td>
<td>78</td>
<td>Female</td>
<td>(of P10)</td>
<td>(Cortico Basal Degeneration, CBD)</td>
<td>Headmistress (Herts)</td>
<td>0</td>
<td>B</td>
<td>NH</td>
<td>02/08/13</td>
</tr>
<tr>
<td>P10</td>
<td></td>
<td>Patient Bert</td>
<td>81</td>
<td>Male</td>
<td></td>
<td>CBD</td>
<td>Senior maths advisor for county (Herts)</td>
<td>3</td>
<td>B</td>
<td>NH</td>
<td>02/08/13</td>
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<tr>
<td>C11</td>
<td></td>
<td>Patsy</td>
<td>67</td>
<td>Female</td>
<td>(of P11)</td>
<td>(MND)</td>
<td>Church secretary (Surrey)</td>
<td>0</td>
<td>C1</td>
<td>Hospice</td>
<td>03/08/13</td>
</tr>
<tr>
<td>C11</td>
<td></td>
<td>Carer Patsy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Church secretary (Surrey)</td>
<td>4</td>
<td>C1</td>
<td>Hospice</td>
<td>03/08/13</td>
</tr>
<tr>
<td>P11</td>
<td></td>
<td>Jim</td>
<td>66</td>
<td>Male</td>
<td></td>
<td>MND</td>
<td>Church manager (Surrey)</td>
<td>4</td>
<td>C1</td>
<td>Hospice</td>
<td>03/08/13</td>
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<tr>
<td>P12</td>
<td></td>
<td>Penny</td>
<td>45</td>
<td>Female</td>
<td></td>
<td>MND</td>
<td>Midwife (Husband – Engineer) (Surrey)</td>
<td>4</td>
<td>(0)</td>
<td>Hospice</td>
<td>09/08/13</td>
</tr>
<tr>
<td>C13</td>
<td></td>
<td>Rose</td>
<td>72</td>
<td>Female</td>
<td>(of P13)</td>
<td>(MND)</td>
<td>Warden (Herts)</td>
<td>1</td>
<td>D</td>
<td>Hospice</td>
<td>2/10/13</td>
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<tr>
<td>P13</td>
<td></td>
<td>Cliff</td>
<td>79</td>
<td>Male</td>
<td></td>
<td>MND</td>
<td>Project manager (Herts)</td>
<td>4</td>
<td>C1</td>
<td>Hospice</td>
<td>02/10/13</td>
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Total Interviews:
17 (4 joint interviews); **Patients:** 7; **Carers:** 10; **Matched pairs:** 6; **Joint Interviews:** 4

Diseases:
MND: 9; MS: 2; HD: 1; MSA: 3; CBD: 2

Non-participant observation

**St C’s Hospice**

<table>
<thead>
<tr>
<th>Method</th>
<th>People observed</th>
<th>Date</th>
<th>Duration</th>
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</thead>
<tbody>
<tr>
<td>Participant Observation</td>
<td>Staff &amp; patients receiving respite care</td>
<td>17/05/2013</td>
<td>0700 – 1400hrs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>28/06/2013</td>
<td>0700 – 1400hrs</td>
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<tr>
<td></td>
<td></td>
<td>26/07/2013</td>
<td>0700 – 1400hrs</td>
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<tr>
<td>Interviews</td>
<td>Ward Sister</td>
<td>28/06/2013</td>
<td>38 mins</td>
</tr>
<tr>
<td></td>
<td>Staff Nurse</td>
<td>28/06/2013</td>
<td>45 mins</td>
</tr>
<tr>
<td></td>
<td>Health Care Assistant</td>
<td>28/06/2013</td>
<td>26 mins</td>
</tr>
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### ECOG PERFORMANCE STATUS

<table>
<thead>
<tr>
<th>Grade</th>
<th>ECOG</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all pre-disease performance without restriction</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited self-care, confined to bed or chair more than 50% of waking hours</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Dead</td>
<td></td>
</tr>
</tbody>
</table>

### Social class

<table>
<thead>
<tr>
<th>Grade</th>
<th>Social class</th>
<th>Chief income earner's occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Upper middle class</td>
<td>Higher managerial, administrative or professional</td>
</tr>
<tr>
<td>B</td>
<td>Middle class</td>
<td>Intermediate managerial, administrative or professional</td>
</tr>
<tr>
<td>C1</td>
<td>Lower middle class</td>
<td>Supervisory or clerical and junior managerial, administrative or professional</td>
</tr>
<tr>
<td>C2</td>
<td>Skilled working class</td>
<td>Skilled manual workers</td>
</tr>
<tr>
<td>D</td>
<td>Working class</td>
<td>Semi and unskilled manual workers</td>
</tr>
<tr>
<td>E</td>
<td>Those at the lowest levels of subsistence</td>
<td>Casual or lowest grade workers, pensioners, and others who depend on the welfare state for their income</td>
</tr>
</tbody>
</table>
APPENDIX 16: INFORMATION SEEKING AND DECISION MAKING FRAMEWORK FOR THE RESPITE JOURNEY

- **Do we need Respite?**
  - Yes
    - **What information do we require?**
    - **Choose Respite Place and Dates**
    - **What is the outcome/onward journey?**
  - No
    - **Continue with current care. Consider increased package.**
    - **What? How? Funding?**
    - **Where? When?**
    - **Preparation required? Handover of care needs?**
    - **Moving on and readaptation?**
    - **Patient**
      - New routine/equipment/care?
      - Future respite?
    - **Carer**
      - Reminiscing/losses
      - Previous roles and relationships
      - Coping strategies
      - Future respite?
    - **Onward Journey and caring role?**
      - Different forms of respite?
      - Sustainability?

- **Decide no to respite**
Appendix 17:

Researcher’s thoughts on respite care

- Respite is both a **process** and an **outcome** and can **benefit both patient and carer(s)**.

- It can **empower** and **sustain** patients to reach their maximal **functionality** and/or **mental agility** by providing appropriate and timely services, interventions, activities and opportunities.

- It takes the emphasis away from **time** measured in days, weeks, months and years, and shifts to time quantified by contentment and short term **realistic achievements**.

- The carers can gain valuable personal time which can bring a **sense of normalisation** to their life and prepare them to **continue in their caring role**.
Developing respite care at an inner London hospice

If patients’ preferred place of care is their home, then it is crucial to help carers cope with their roles – which is what respite care should do. Diane Laverty, Sara Faithfull and Anne Arber look at the approach to respite care adopted by St Joseph’s Hospice in London.

In the UK, palliative care plays an important role in supporting patients and their carers during the course of a progressive and life-threatening illness. There has been much research into people’s preferred place of care and death, the future care needs of an aging society and the lack of resources and services in the community to support people’s wishes. There have also been numerous national drivers to emphasise and promote community-based care. Government documents and policies recognise the role of flexible respite care to maintain and sustain carers in their unending roles, especially as they care the healthcare system a significant amount of money, particularly towards the end of life. The End of Life Care Strategy emphasised care in and by the community and avoidance of hospital admissions whenever possible, primarily to stick to patient preferences, but also to reduce the cost of inpatient hospital care. The 2005 National Service Framework for Long-term Conditions stated that ‘carers have the right to obtain the support and services they require for the person they care for and to have themselves as carers’. However, respite care, which provides support to patients (and their carers) and helps ensure they can remain in their own home, is a scarce resource.

What is respite care?
The most frequently adopted definition of respite care is that proposed by Miller as ‘the temporary physical, emotional or social care of a dependent person in order to provide relief from care giving to the primary provider’. This is supported by research. The beneficiary of respite care is usually considered to be the informal carers (although there may also be benefits for the care recipient), as respite care decreases their burden, promotes their well-being and provides them with ongoing support.

Respite services may not necessarily be a ‘discrete intervention’ (one defined area of care) but a range of services in a variety of settings – day care in a center on a weekly basis; intermittent care in the person’s home, which may be a few hours at weekly intervals; or residential care in an institution, which may be from a few days to two weeks. It is vital that the correct service is identified to provide the appropriate support.

Respite care at St Joseph’s Hospice
St Joseph’s Hospice in East London has developed a strategic plan aimed at strengthening the existing service provision by offering a full range of services to meet the varying needs and expectations of all patients, their carers and families, and to provide extra support for carers. The hospice wanted to put in place a facility that would allow each patient to maintain or regain as much independence as possible, with a comprehensive multidisciplinary team focused on rehabilitation working with the...
patient, their carer and family. This was an ambitious aim that would require careful thought relating to the appropriate use of the hospice's beds. The emphasis of care would remain firmly entrenched in promoting a patient's self-care and control over their life, including the patient's and carer's family's ability to cope with a life-threatening illness. It was also acknowledged that carers need to have time out from their caring role so that they can maintain good health and continue to care for the patient on an ongoing basis.

To understand respite care at the hospice, and in view of the increasing amount of literature, research and government documents supporting care at home, it was timely to review the inpatient respite care by conducting a retrospective case review (Phase 1). The purpose of the case review was to examine and agree appropriate bed usage and the feasibility of setting up a nurse-led respite service for the local boroughs served by the hospice. The goals were to determine what type of patients were being referred for 'respite', the actual reason for admission (determined at initial assessment), the length of stay, their needs during their stay and the outcome of the admission. This was followed by a pilot study (Phase 2), which involved establishing two additional beds in the existing inpatient wards to begin the development of a new respite service.

Setting
St Joseph's Hospice is situated in a large deprived urban area with people coming from diverse ethnic, cultural, religious, social and economic backgrounds. At the time, the hospice had a 32-bed inpatient unit. There are three community palliative care teams based at the hospice which work across three boroughs, and the hospice provides inpatient care for a further six boroughs. There is also a day hospice and an evolving outpatient service. In addition, the local communities are invited to utilise a non-clinical area offering information, advice and support to maintain the impact and consequences of progressive and life-threatening conditions.

Historically, at St Joseph's Hospice, no beds were specifically allocated to respite care. Beds would be made available if they were vacant and if there were no patients waiting to be admitted for symptom control or terminal care, who were considered the priority.

Phase 1 – Case review
The details of all patients referred for ‘respite care’ between April 2009 and March 2010 were obtained from the PalCare data system and the clinical notes were accessed. A proforma was developed to capture the data required for the case review. There were 55 patients referred for respite care during the study period, but 12 sets of notes were missing, resulting in 43 patients being reviewed. The age range was 46–97 years (mean 73 years). There was very little difference in gender (23 males, 20 females). The majority of patients were White British (22 patients, 51%) and lived across six of the nine boroughs. Thirty-four patients (79%) had been diagnosed with malignant disease and nine (21%) with non-malignant disease.

The main source of referral was acute hospital doctors (11 referrals, 25%), with GPs and specialist hospital or community teams also referring. Out of the 43 patients reviewed, 27 (63%) were admitted and 16 (37%) were not, due to a variety of reasons (no bed available, patient still undergoing active treatment with curative intent, family declining a hospice admission and patient not deemed to be appropriate for admission). Out of the 27 admitted patients, 18 (67%) lived with a carer (13 with a spouse, three with a daughter and two with a son) and nine (33%) lived alone with no informal carers. Eleven patients with informal carers had no paid carers and four informal carers had their own health concerns.

The length of stay ranged from one to 85 days (mean 19 days). Most patients (34, 51%)
were known to the hospice. On admission, 17 (6.3%) patients were identified as having physical problems and two as being in the terminal stage. A recent deterioration had been documented in 11 (40%) of the patients.

Some patients had a predetermined date of discharge (13, 48%); out of these 13 patients, three (23%) died at the hospice and 10 (77%) were discharged. Conversely, there were 14 (52%) patients who had no predetermined date of discharge; eight of them (57%) died, only three (21.5%) were discharged and the remaining three (21.5%) were transferred to an alternative care setting as they were not well enough to return home (see Table 1).

When there was a social reason documented for admission, those reasons were: carer not coping (eight, 29%), carer in hospital (four, 14%), and carer on holiday (three, 11%). The actual documented reasons for admission (determined after assessment on admission) were: respite in 12 (44.5%) cases, symptom control in 10 (37.5%) and terminal care in five (18%) (see Table 2).

Phase 2 - Pilot study
In view of these findings and the recent appointment of a nurse consultant, a pilot study was conducted over ten months to trial a nurse-led service for patients requiring inpatient respite care. An additional bed on the existing two wards in the hospice was created and utilised for this purpose. Specific respite care referral criteria were devised (see Box 1). Referrals were triaged by a multidisciplinary team and, if they were considered appropriate, dates of admission and discharge were determined. The patient, carer and referrer were informed of these dates. The patient received an information leaflet detailing, for example, the importance of their continued routine, what to bring with them (medication, walking aids) and the aim of maximising their independence and functionality during their planned stay.

A multidisciplinary steering group was established to begin developing plans for this new service, in conjunction with the ongoing development of an operational policy.

According to an analysis of data from the first seven months of the pilot study, 24 patients were admitted for 29 episodes of care (five patients had more than one planned respite care admission). The majority of patients (22) stayed for a period of two weeks.

The mean age of the 13 female patients was 65 years (range 44–76 years) and the mean age of the 11 male patients was 73 years (range 46–82 years). The majority of patients were White British, which is indicative of the general occupancy of the hospice (but not of the local population). The referrers were mainly the community teams (i.e., the respite service had not been widely advertised externally at this point). Forty-two per cent of patients lived alone and came for a break from the context of their care; 51% of admissions were to give carers respite; the remaining patients were admitted because of complex situations requiring a review of the care at home. Fifty-eight per cent of admitted patients had a non-diagonal diagnosis (mainly respiratory and neurological).

During their planned stay, most patients required a low level of symptom control and rehabilitative or functional interventions. Only two had to be transferred to a medical colleague due to a deterioration of their condition and the need for higher-level medical intervention (such as intravenous antibiotics for sepsis). Most patients benefited from a wide multidisciplinary input. No patients died.

The respite programme involved a comprehensive multidisciplinary admission process (by a nurse consultant, staff grade doctor, ward nurse and therapist), a review of disease status and symptoms, the setting of goals that patients would like to achieve during their stay (review of functional status, introduction to the day hospice programme, and so forth) and the planning of activities and therapies (complementary interventions, review by a dietician in case of poor appetite, weight loss or taste changes, and so forth). The day hospice and volunteers played an active role in the programme.

Discussion
Although specific referral criteria were not initially available, guidelines for referral and a general description of respite care were
available on the hospice’s website (the referral criteria on the website were broad in scope, mentioning ‘a structured approach to care’ and recommended planned admission and discharge dates). Pressure on acute beds and a desire to get patients out of hospital and to a place of safety may have been foremost in healthcare professionals’ minds when referring patients to the hospice for respite care, which may have resulted in patients being admitted with minimal thought for the type of admission required.

In Phase 1, most referrers were external, despite the busy community teams based at the hospice. Most patients had a cancer diagnosis rather than a non-cancer diagnosis – the former traditionally attracting more funding and resources. The hospice’s strategic plan aimed to widen access to patients with non-cancer diagnoses; therefore, a stronger focus on these conditions was required.

Respite care is often linked with a ‘crisis intervention’ when the caring role breaks down at home. Lack of planning leads to a ‘fire-fighting situation’ where emergency support becomes necessary, which may not be viewed as a ‘respite care’ intervention.

In Phase 2, the pilot project provided an opportunity for patients to benefit from the input of a large multidisciplinary team and enabled patients to remain at home for long periods of time by providing their carers with time off and thereby supporting them to continue in their caring role.

Respite is described as both a ‘service’ (depending on the setting) and an ‘outcome’ (relief from care-giving), where additional therapies and interventions (such as physiotherapy and occupational therapy) can also be accessed. Patients who receive respite care are generally not considered to be medically complex; more emphasis is put on rehabilitation and functionality. Flexibility of timing, frequency and activities is considered crucial. At the time of referral, patients were thought to be medically stable and without overwhelming symptom control problems; therefore, their stay was suitable for rehabilitation and a general overview.

The fact that a date of discharge could be predetermined possibly shows that patients had been appropriately referred. No patients died during respite care and this may be indicative of referral criteria providing clarity and a triage system ensuring patients are appropriate for this type of admission. There was a significantly higher proportion of patients with non-malignant disease in Phase 2. This widening of access is encouraging; patients with long-term progressive diseases that do not have such a well-defined disease trajectory as cancer frequently need ongoing support and breaks.

There were a significant number of patients who had no informal carers. The literature suggests that respite care may be beneficial with regard to keeping carers well and able to continue in their role, especially as this involves cost-savings to the health service, particularly towards the end of life, but there has been minimal attention paid to, or studies looking at, respite services for patients living alone, despite this being acknowledged as an area of increasing need.

Kristjanson et al. conducted a national descriptive survey of patients and carers of people with neurodegenerative conditions using numerous assessment tools to identify and compare the needs for supportive and palliative care services. One finding was the significant proportion of patients with
multiple Sclerosis who were living alone with no carers at all. The benefits of receiving respite care when living alone are to give patients a break from the context of their usual place of care, providing a holistic assessment to review their care needs and signposting them to ongoing alternative support, such as befriending services and day services. More work is required in this area.

There were several challenges in Phase 2. The fact that the respite bed was in an ‘acute’ ward meant that the nursing staff needed to adopt a change of mindset when caring for respite patients. This was poorly achieved and, on reflection, mixing two philosophies of care was thought to be a cause of concern.

Although this was a nurse-led service, as the respite patients were on an ‘acute’ ward, the default position was to contact the ward doctor to address any issues that could and should have been managed by nurses. Finally, respite patients found it difficult at times to focus on rehabilitation and maximising functionality, especially if they were in areas where other patients may be dying.

Respite care can be a poor relation to care related to more complex needs, such as symptom control; however, numerous documents, including the End of Life Care Strategy, refer to the importance of keeping patients in their preferred place of care, which frequently is their home. This may be more readily achieved if patients and their carers (when applicable) receive adequate support and timely intervention to ensure that they are able to stay at home for as long as possible.

Future plans

A dedicated nurse-led respite unit with eight beds has now opened at St Joseph’s Hospice, which is widening access to all types of conditions that are life-threatening and progressive. Feedback from caregivers and patients has been very positive. Formal evaluation using a validated outcome measure (St Christopher’s Index of Patient Priorities), qualitative interviews and focus groups are ongoing and involve patients, informal carers, referees and staff.

In addition, further research is under way to look at patients with neurodegenerative diseases (as these patients and their carers would benefit from, and require more access to, respite care) and the role that a dedicated respite care programme may play for them.

Declaration of interest

The authors declare that there is no conflict of interest.

References

OVERVIEW OF THE INTEGRATION OF KNOWLEDGE, RESEARCH AND PRACTICE

7.1 Introduction

This chapter provides an overview of the researcher’s integration of knowledge, research and practice during five years of doctorate study. The taught components and the research study will be explored, with emphasis on how this has been instrumental in the researcher’s personal and professional development.

The researcher had recently been appointed to a nurse consultant post in palliative care. Nurse consultants spend a minimum of 50% of their time working directly with patients. In addition, their role entails developing clinical practice, being involved in research and contributing to the education, training and development of nurses. It was essential that this doctorate programme adequately prepared the researcher for this challenging, senior role.

7.2 The taught components of the doctorate programme

The doctorate programme is comprised of four taught modules, culminating in the final research project. The assignments prepared the researcher for conducting the research study by examining current policy, acquiring research acumen and strengthening critical analysis of literature and research.

Each module will be briefly explored in relation to the researcher’s learning.
7.2.1  Communities of practice

This initial module looked at examining the researcher’s knowledge and understanding within her field of practice. It addressed how tacit and acquired knowledge influences the ability to be actively involved in health care debate and how to become more engaged with colleagues, relating to the intricacies of working in a complex and unpredictable area of practice.

It was a valuable introduction to the higher level of study and utilised the use of ULearn, the university’s electronic programme for creating dialogue between peers and academic lecturers. The researcher had no previous experience with this mode of communication but has since been able to benefit from similar systems when required in the work place.

7.2.2  Policy review in a specialist field

Policy analysis is an integral part of health care and this module afforded the researcher an opportunity to develop skills in appraising documents by utilising and justifying the use of tools for critiquing policy. The researcher was able to examine a current topical policy relevant to her area of practice. This allowed an opportunity to consider and discuss the shift in power bases related to policy making and implementation and develop a critical approach to the policy appraisal process. This proved valuable in the future planning of the strategic direction of the hospice which the researcher was involved with.
7.2.3 Advanced research methods

This module was instrumental in assisting the researcher to explore, in depth, research methodology and methods. The researcher was previously inexperienced with many research approaches, particularly related to quantitative research. The data management workshops offered were extremely informative and delivered by staff who were regular and proficient users of these systems. This enabled the researcher to have ongoing dialogue with the appropriate programme users, extending into the research project.

Although the approach adopted for the study was qualitative, an increased appreciation of other learned research avenues led to a change in her understanding of health care research and selecting / applying appropriately to the context of care being studied. Fresh discussion with medical colleagues meant that audits were planned as collaborative ventures with potential to develop into mixed method research studies.

7.2.4 Service evaluation and leadership

This module introduced tools for service evaluation and created a timely and beneficial opportunity to apprise an existing nurse led unit which was practising respite care. The researcher had previously never led an evaluation project and this proved to be an excellent experience. In addition, the researcher’s new senior role required exceptional leadership skills to support the nurses who were working in a historical, established environment, consider a new way of providing palliative and
end of life care. Leading service redesign and a novel approach to care in a palliative setting was inspiring and the underlying economics related to this (which had previously never been considered by the researcher) added depth and completeness to the project.

These taught modules contributed greatly to the final thesis. The researcher was exposed to several different research approaches and methods of data collection and analysis which made her more confident in considering the methodology required to address the research questions and develop critical awareness.

7.3 The research study

The scale and scope of the research process was new to the researcher. The patient population was outside of the researcher’s expertise and meant embarking on contemporary relationships with clinicians in a specialist trust. The researcher was required to deliver presentations to the medical consultants and site specific clinical nurse specialists in order to provide them with relevant information and guarantee their involvement at an early stage. The researcher found this an exciting, stimulating process, specifically working with specialist clinicians and learning how to be succinct in the pertinent facts they required to make informed decisions and advise about potential directions the research could take.

Devising and refining research questions, identifying a theoretical framework and producing a proposal were new key skills achieved. A workshop on Good Clinical
Practice (GCP) ensured the researcher was adequately prepared to undertake a higher level research study.

Previous academic study to master’s level had proffered limited experience with the local ethics committee. The higher level doctorate study meant embarking on the electronic method of central ethics application and presenting the study to the committee which was extremely daunting. The local research and development committee and the university ethics committee also had to be approached and approval applied for. The issue of poor recruitment resulted in an application to extend:

- the sites of study and
- to patients with all types of neurodegenerative diseases.

All of these processes were unfamiliar for the novice researcher but formed an integral part of her learning.

The grounded theory approach was new territory and created a steep learning curve. Regular supervision, including from an academic who was expert in this area, was extremely advantageous and provided appropriate learning circumstances.

Insufficient recruitment to the study was disappointing and did not reflect original scoping of potential participants. A valuable lesson learned was affirmation of the ever-changing face of health care, resulting in fewer resources available for respite.
The difficult and challenging concerns occasionally encountered at the interview stage relating to patient / carer disagreements regarding access to, and availability of, respite ensured the researcher became sensitised to hidden tensions and power dynamics within these relationship(s). This was worthwhile learning and insight which could be embedded in everyday clinical practice. The researcher gained valuable additional insight into how empowering it was for the participants to have the opportunity to tell their story. Similarly the non-participant observation felt unfamiliar and uncomfortable territory but presented the researcher with useful time to reflect on the practice of respite care and be able to absorb and appreciate the environment in which it is delivered.

The divide between the researcher and clinician roles proved very demanding. Questions posed by participants during interviewing felt natural to answer as the role of the clinician with the relevant knowledge. The ongoing practice of reflexivity, particularly immediately post interview, highlighted this transcending of boundaries and consequent discussion with the academic supervisors and peers regarding distancing oneself from an ingrained clinical position.

The vast amount of data to be managed felt overwhelming but the data management programme, NVivo, appeared to be a solution that would teach the researcher new skills. Unfortunately, after completing the inputting of the data and the consequent coding process, the overall programme failed. Despite seeking information and support from the manufacturing company and the researcher
development team it was not deemed suitable to continue. Time constraints meant it was not possible to repeat the data inputting and coding process so the researcher had to resort to manual handling of the data. This was extremely time consuming but did allow the researcher to become intensely close to the data. Further reflection demonstrated positively the researcher’s inherent ability to adapt to rapidly changing circumstances which is essential in the current health care system.

Finally, the university researcher development team programme offered courses and workshops to sharpen and perfect research skills. The preparation for the viva voce was particularly useful and encouraging, especially the face to face support available.

7.4 The development of the researcher

7.4.1 Professional development

The researcher’s appointment to the nurse consultant post in a hospice had been accompanied by high expectations of this new role. The hospice had embarked on an ambitious strategic plan which was focused on developing respite care (in response to local demand) and widening access for patients with non-malignant diseases. Doctorate studies were a requirement of the job although this had been a desire of the researcher for a period of time as she believed that such a programme of study would enhance her higher level practice. The consequent raising of the profile of nursing within the organisation has encouraged the embedding of critical thinking as an essential skill which has been strengthened through the research study. Furthermore, it has allowed a deep exploration of her epistemological and
ontological viewpoints through extensive reading of the literature and working at consultant level with external agencies, producing significant broadening of horizons.

Much of research in palliative care leans towards the qualitative approach due to its emotive nature but one size rarely fits all and it has been useful to consider different approaches which can add to the value of research activity. In addition, there has been a heightened understanding of the environment in which to conduct research. This has been helpful as increasingly the hospice has been approached with requests for researchers to conduct studies. The improved knowledge base has resulted in more studies being accepted due to the researcher’s advice and support in achieving a more sophisticated approach to research within the hospice generally.

### 7.4.2 Personal development

The skill of capturing hearts and minds of interested parties in a short space of time was particularly challenging but straddles the boundaries of learning achieved through knowledge, research and practice. Conducting a research study at doctorate level has also honed the researcher’s organisational and leadership skills. Transcending several sites of research activity and different professionals, involved considering, appreciating and respecting the clinicians’ competing priorities.

The researcher’s increasing clinical knowledge of neurodegenerative diseases has been phenomenal. The opportunity to attend and participate in specialist clinics and collaborate with other professional colleagues has culminated in establishing fresh
relationships. This has been beneficial for mutual referrals and information sharing related to daily clinical work.

Working with esteemed academic colleagues at the university who are passionate about well conducted research in the palliative care setting has been an invigorating experience and has added significantly to the researcher’s tacit and overt research proficiency. Regular supervision has developed and honed research skills and provided an arena for open communication and encouragement.

Finally, experiencing the privilege of meeting the participants and hearing their stories has left the researcher feeling humble and with enormous respect for these people and the lives they have.

7.5 Dissemination

The researcher felt extremely privileged to be able to deliver a lecture at an international research conference with eminent clinical and academic colleagues from the field of palliative care. The questions arising from the presentation and subsequent conversation made the researcher aware of the many cultural influences of her work and how that might be translated in other areas. It was a stimulating and thought provoking experience which added to the discussion and emerging theory of the study.
The publication of the article (Laverty, Faithfull & Arber, 2013) resulted in several interested correspondence about this area of care. Further publications are planned and a recent master class workshop proved influential for a wide and diverse audience of professionals.

7.6 Conclusion

The doctorate studies have been invaluable in honing research skills, promoting critical reasoning and decision making and working at a senior nursing level. Many levels of learning have been achieved, along with ongoing and developing skills (see figure 7.1).

The doctorate programme has been an inspiring adventure for the researcher, primarily due to forging new relationships with peers and experiencing new knowledge which felt constructive and valuable. Sharing information and insight with peers and academic colleagues from different areas of health care was also stimulating and motivating.

References

Figure 7.1: Doctorate studies and learning

REFLEXIVITY

Taught components + Honing research skills + Peer support + Academic supervision + Engaging with external colleagues

EXISTING KNOWLEDGE

Learning

Professional & Personal Development

NEW KNOWLEDGE

Improving critical appraisal + Strategic planning + Leadership skills + Increased awareness of NDD
RESEARCH LOG

8.1 Introduction

This research log describes the story of the researcher’s journey over five years of doctorate studies. It illustrates the planning that went into the development of the thesis and the acquiring of research knowledge and skills. The thesis was submitted in December 2014.

8.2 The beginning of the journey

The structure of the doctorate programme provided a baseline for the researcher to gain an understanding of higher level study and consider the research questions. The researcher used the modules as a platform to work from. Activities such as attending the support groups and specialist neurological clinics were instrumental in building up a significant knowledge base of the patient and carer’s experience of living with neurodegenerative diseases. Further exploration of the area of respite care, which the researcher had some prior knowledge of, resulted in the beginnings of new relationships with professionals. These became key stakeholders and proved fruitful for networking (see Appendix 1). Understanding the value of scoping (e.g. audit; problems encountered regarding equipment, communication; access for respite) before embarking on the research study proved interesting and useful learning.

Undertaking higher level studies whilst being employed full time in a senior nursing position was extremely challenging. Study leave was sparse and limited funding was only available from external sources which the researcher had to independently apply for.
8.3 The literature review and research questions

The researcher had some skills related to reviewing the literature from past academic study at Masters level, however she could identify shortfalls and gaps in knowledge necessary to undertake this research project. The researcher development team at the university offered workshops to improve these techniques, particularly relating to using MESH terms and appraising literature using the Critical Appraisal Skills Programme tools (CASP). This provided a framework for critique.

8.4 Gaining ethical approval

The ethics process was long and convoluted at times and there were several different committees that needed to be approached in order to satisfy the ethical procedure. The National Research Ethics Service (NRES) required a central electronic application which was then processed and culminated in a presentation to the committee. This was extremely daunting as there was representation from several different areas, including patients and carers. This proved to be a sound test of the researcher’s proposal and planned data collection. The local research and development committee, based at University College London needed to be approached next, followed by the University of Surrey ethical committee. Each ethical committee required different evidence and forms which proved time consuming and laborious but was a valuable lesson to remind the researcher that these groups serve a valuable purpose of protecting the public from badly managed research.
Recruitment was extremely slow which led to the researcher considering alternative ways of seeking participants. Discussion with key stakeholders revealed scarce resources available for respite, contrary to scoping results achieved a year prior to the commencement of data collection. Fortuitously the specialist centre had connections with other professionals in neurodegenerative diseases and these proved invaluable as they worked in different establishments (the community and a hospice) which afforded diverse areas in which to access respite care. This created two necessary amendments to the proposal, namely:

- to open up recruitment to all neurodegenerative diseases and
- to increase the number of sites accessible for recruitment.

The amendments were agreed and fresh opportunities for recruitment were instigated.

### 8.5 Data collection, management and analysis

The data collection process lasted one year and felt long and arduous, mainly due to problems with recruitment. In order to handle such vast amounts of data from the transcripts the data management system, NVivo, was utilised. The transcripts were exported in and coding was performed on all interviews. Unfortunately there was a fault in the programme and each interview showed up as being coded from beginning to end. The researcher tried to solve these issues with expert advice but it was suggested that the only resolution was to download another version of NVivo and start the process again. This was not possible with time constraints so the researcher had to manually handle the data. This was exhausting, however the
researcher felt a great affinity with the information and in hindsight felt this may have been an unexpected advantage.

Theoretical sampling was difficult to achieve as there was a dearth of participants to select from and the researcher was mindful of time limitations. As each section of analysis was conducted the researcher noted emerging similar themes and discussed these with the professionals assisting with recruitment. This led to the selection of participants who may be able to deepen understanding of these elements of respite care.

The development of subcategories and categories arose from original memos and the reflective diary, coupled with constant comparative analysis. Key words from the initial analysis remained throughout and became the bedrock of the emerging themes (e.g. sustainability, transition, restoration).

8.6 The reflective journal and learning

The researcher was keen to experience the respite episode with the patient and carer in order to see it through their eyes. It was extremely difficult for her to divorce herself from the clinical nurse role and become a detached researcher but the reflective diary played a valuable function in this process. Thoughts and feelings were recorded at the earliest opportunity after meetings with key people and post interviews when views and notions were fresh in the researcher’s mind.

Examples of questions posed after an interview was:
• Initial impressions of the interview?

• What was key about the relationship between the patient and the carer?
  Were there tensions visible?

• What were the main points emerging from the interview?

• Were there residual issues / concerns?

• How did the researcher feel post interview?

The researcher’s interviewing skills became more honed as time progressed.

Academic supervision and reading of transcriptions highlighted areas of weakness, especially related to the divide between clinician and researcher.

The researcher became acutely sensitive to the burdens of these patients and carers. She was mindful of the additional worry of being interviewed and the strain that can have when prognosis maybe short. The researcher was aware of literature findings that demonstrated patients’ desire to be involved in research even at late stages of disease progression but from a humanistic point of view it felt uncomfortable at times. The researcher considered whether their role in the research study gave them a sense of purpose and a lasting legacy.

The non-participant observation was a new experience. The researcher did not feel uncomfortable in the hospice setting as this is her usual place of work but was unsure generally of her position with that method of data collection and whether she was an unwelcome intruder or would manage to blend in sufficiently.
There were questions arising about the role of respite and whether it should be viewed differently from symptom control and terminal care. The nurses interviewed felt there was little or no difference as these patients’ needs were so complex and therefore required a high level input into their care. Conversely the patients and carers felt they should be treated with a contrasting frame of mind and as a package. The patient’s nursing and medical needs required specialist input but both patients and carers felt that they should enjoy an alternative approach to care, namely focus on living with the disease and how elements of care could be reviewed and improved, as well as offering a break from caring duties and their mundane life. This contrast in care avenues was thought provoking and stimulated much discussion. It reminded the researcher not to polarise patients and carers but consider both sets of needs together in mutual appreciation and benefit.

The researcher also kept an additional journal which included key learning points, adding to the depth of her understanding and enlightenment. This journal focused on such issues as the literature, articles and books which were examined and support groups and clinics attended. There was a vast amount of reading and gathered information which was précised and used throughout the study as a reference point for creating topic guides for interviews and building on existing knowledge, leading to the development of new knowledge.
The establishment of new knowledge

Knowledge (Developing - research)       Knowledge (Existing - clinical)

Knowledge (Original, new)

Translation (Practice and Dissemination)

The researcher had no previous experience of using grounded theory as a methodology so this created a steep learning curve. Continuous engagement with other researchers who were expert in this approach, as well as repeated referral back to the literature, (particularly pertaining to constructivist grounded theory which was the approach adopted for this study) was conducted. The literature presented multiple opinions of the advantages and disadvantages of using this methodology which afforded her a balanced view. In addition, the researcher endeavoured to attend any presentations or lectures held at the university from novice researchers who described their own journeys related to grounded theory research.

The reflective diary was also used for planning work schedules and meeting deadlines and to project manage the research process.
8.7 Academic supervision

The provision of supervision by two experienced researchers (one of which was an expert in grounded theory) was powerful and supportive for the novice researcher. The use of numerous modes of communication (e.g. face to face, e-mail, SKYPE) facilitated regular and encouraging sessions to aid the research journey and as this progressed, they became more focused and positive (see Appendix 2). The main achievements from supervision were:

- To develop methodology and possible data collection methods
- To firm up the research question(s)
- To direct areas of work
- To assist in decision making
- To suggest useful contacts
- To guide the novice researcher
- To keep within determined time frames

8.8 Concluding thoughts

The doctorate took five years to complete, including the taught modules. The final few months were the most intense as these involved developing theory and writing up the thesis. The fluidity of the research project and emerging concepts has added excitement and intrigue to the process, which has markedly enhanced the journey.
The researcher is able to appreciate her much improved research abilities. She also has increased confidence with applying skills learnt, particularly relating to leadership, research and critical appraisal. On a personal note she has developed more poise and tenacity within her profession and greater belief in herself and her abilities generally.
## Appendix 1: Key Stakeholders

<table>
<thead>
<tr>
<th>STAKEHOLDERS</th>
<th>THEIR ROLE IN THE RESEARCH STUDY</th>
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<tbody>
<tr>
<td><strong>Nurse Consultant</strong></td>
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<tr>
<td>Huntington’s Disease Specialist hospital</td>
<td>Principal Investigator (PI) for UCLH</td>
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<td></td>
<td>Access &amp; attendance to specialist clinics</td>
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<td></td>
<td>Recruitment</td>
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<tr>
<td><strong>CNS: MND</strong></td>
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<td>Specialist hospital</td>
<td>Scoping exercise</td>
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<tr>
<td></td>
<td>Recruitment</td>
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<td></td>
<td>Networking with other professionals</td>
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<tr>
<td><strong>CNS: Rare &amp; progressive neurological diseases</strong></td>
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<tr>
<td>Hertfordshire</td>
<td>Recruitment</td>
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<tr>
<td></td>
<td>Discussion &amp; understanding of community issues/concerns</td>
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<td></td>
<td>Equipment problems</td>
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<td><strong>Medical consultants</strong></td>
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<tr>
<td>Neurodegenerative diseases Specialist hospital</td>
<td>Approval for access to patient population</td>
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<td></td>
<td>Access &amp; attendance to specialist clinics</td>
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<td><strong>Discharge &amp; respite planner</strong></td>
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<tr>
<td>Hospice</td>
<td>Recruitment</td>
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<td></td>
<td>Access to hospice for non-participant observation</td>
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<td></td>
<td>Hospice based respite care</td>
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<tr>
<td><strong>Director of Care</strong></td>
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<tr>
<td>Hospice</td>
<td>Approval for access to hospice – non-participant observation and patient population</td>
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<tr>
<td><strong>Rare &amp; progressive neurodegenerative diseases</strong></td>
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<tr>
<td>group North East England</td>
<td>Awareness and understanding of neurodegenerative conditions and potential / actual problems &amp; concerns</td>
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<tr>
<td></td>
<td>Local respite care strategies</td>
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<tr>
<td></td>
<td>Reviewing emerging theory and models.</td>
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<tr>
<td><strong>MNDA</strong></td>
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<tr>
<td>North East London</td>
<td>Application for small grants (research funding)</td>
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<tr>
<td></td>
<td>Understanding of equipment/ complex needs at home</td>
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<td></td>
<td>Access to support groups</td>
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<tr>
<td><strong>Neurological social worker</strong></td>
<td></td>
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<tr>
<td>Specialist hospital</td>
<td>Understanding of funding process (continuing care and personal budgets)</td>
</tr>
</tbody>
</table>
## Appendix 2: Examples of supervision sessions

<table>
<thead>
<tr>
<th>Date</th>
<th>Supervisors present</th>
<th>Focus of discussion</th>
<th>Actions required</th>
</tr>
</thead>
<tbody>
<tr>
<td>7/10/2011</td>
<td>SF, AA</td>
<td>Good literature overview and clear topics identified. Focus review on research literature, need to pull in policy. Proposal good start – revise questions. Question cultural issues re: inequalities and gender issues.</td>
<td>Revise proposal and literature review. Look at IRAS and guidance on information sheet / consent process. Aim submission to IRAS 1/2012</td>
</tr>
<tr>
<td>21/11/2011</td>
<td>SF, AA</td>
<td>Explored literature review and fed back in relation to critical analysis of studies. Reflected on methodology - focus groups and the processes for undertaking or whether participating enquiry to help develop topic guide.</td>
<td>Meet with CNS to look at practicality of how best to capture data and organise set up. Consider sample size &amp; how recent respite has to be. Theoretical sampling.</td>
</tr>
<tr>
<td>20/11/2012</td>
<td>SF, AA</td>
<td>Considered sample, small numbers so far identified. Discussed re: widening the inclusion criteria and number of sites.</td>
<td>Explore possibility of other sites for respite and widening study. Continue interim transcript analysis.</td>
</tr>
<tr>
<td>11/02/2013</td>
<td>AA</td>
<td>Discussed the recruitment of participants and extending recruitment                                                                                                                                                                                                                                                                -expanded focus in subsequent interviews.</td>
<td></td>
</tr>
<tr>
<td>19/04/2013</td>
<td>SF, AA</td>
<td>Reviewed first 5 interviews transcripts. Reflected on questioning style and need for open approach. Discussed coding and ways to group codes and further exploration of areas.</td>
<td>Continue interviews and focus still on residential ones. Explore more about personal budgets and how carers make discussions about respite and their expectations.</td>
</tr>
<tr>
<td>19/07/2013</td>
<td>SF, AA</td>
<td>Increased number of interview – transcripts Undertake observations of respite – attention to detail was high; nurses saw respite as care except WM – emphasis on physical care. Discussion of analysis</td>
<td>Explore how data could be presented incorporating observation and context of care. Write to university ethics to extend diagnosis and sites</td>
</tr>
<tr>
<td>11/10/2013</td>
<td>SF, AA</td>
<td>Looked at initial themes – discussed ideas around ‘passing the baton’ Thinking about secondary levels and how these fit in</td>
<td>Take ‘routine’ and tell a story and narrative of a theme to send as an email and for supervisors to give feedback. Following discussion had revealed saturation, no more interviews.</td>
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