

# **Dementia and Physical Health Care: Carer Accounts of the Inpatient Experience**

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## **Abstract**

Dementia is a growing global concern and a high proportion of people with dementia come in to contact with acute medical care settings. However, little is understood of how people with dementia experience hospital stays. The current study therefore set out to explore the experiences of people with dementia when they are hospitalized for physical health conditions. Due to the limitations in the cognitive capacity of those with moderate or advanced dementia, the experiences were studied indirectly through accounts with family carers.

Semi-structured qualitative interviews were undertaken with eight carers from across England and Wales. In each case they cared for a person with dementia who had been admitted to hospital for a physical health condition at least once within the last eighteen months or who was currently in hospital. A Constructivist Grounded Theory approach was used to analyze the data and three key themes were identified: 'course of illness in the community,' 'experience of organization care' and 'transitions in care.'

The themes were discussed in the context of the results of previous related studies, including studies that were included in a systematic review of the existing literature. The findings were suggested to have a number of implications for delivering inpatient services to people with dementia. These include implications related to: staff training and the monitoring of the effectiveness of training interventions; clinical practice in hospitals; the involvement of people with dementia and their carers in care and discharge planning; and the engagement of carers with formal support organizations. Limitations of the current study are discussed and a number of recommendations are made for further research on topics related to the current research.

# Contents

	<u>Page</u>
<b>Chapter: 1 Introduction</b>	12
1. Overview of Chapter	12
1.1 Dementia	12
1.1.1 What is Dementia?	12
1.1.2 Diagnostic Criteria	13
1.1.3 Stages of Dementia	15
1.1.4 Assessment and Diagnosis	16
1.1.5 The Prevalence of Dementia	16
1.1.6 The Cost of Dementia	17
1.2 Dementia and Hospital Stays	18
1.2.1 Statistics	18
1.2.2 Reasons for Hospital Admission	18
1.2.3 Associated Risks of Hospital Admission	19
1.2.4 Length of Hospital Stay	21
1.3 Dementia and Policies	21
1.3.1 Dementia and Older Adult Policies in Wales	23
1.3.2 Policies in England	25
1.4 Models of Care in Hospital Settings	25
1.4.1 Person Centered Care	25
1.4.2 Compassionate Care	28
1.5 Patient Experience and Associated Dilemmas	29
1.6 Systematic Review	30
1.6.1 Aims	30
1.6.2 Search Methodology	30
1.6.2.1 Study Criteria	31

1.6.3 Results and Quality Framework	32
1.6.3.1 Summary of Included Studies	32
1.6.3.2 Design and Method	33
1.6.3.3 Sample	34
1.6.3.4 Quality of the Research	34
1.6.3.5 Narrative Quality of the Research	39
1.6.3.5.1 Research Aims, Methodology and Design	39
1.6.3.5.2 Recruitment and Data Collection	39
1.6.3.5.4 Ethical Issues	40
1.6.3.5.5 Data Analysis	41
1.6.3.5.6 Findings and the Value of Research	41
1.6.3.5.7 Summary of the Quality of Research Review	42
1.6.3.6 Synthesis of Studies	42
1.6.3.6.1 The Experience of Transition	42
1.6.3.6.2 Communication and Staff Interactions	43
1.6.3.6.3 Power and Control	44
1.6.3.6.4 Staff Attitudes and Style of Care Provision	45
1.6.3.6.5 Carers Conceptualisation of the Quality of Care and Dissatisfaction	46
1.6.3.6.6 Interaction Between Expectations and Experience	48
1.6.3.6.7 PWD and Carer Affect	50
1.6.3.6.8 Recommendations for Practice	50
1.6.3.6.9 Implications for Future Research	50
1.6.3.6.10 Limitations	51
1.6.3.6.11 Summary of Systematic Review Synthesis	51
1.7 Study Rationale and Aims	52
<b>Chapter 2 Methodology and Method</b>	<b>54</b>
2. Overview of Chapter	54
2.1 Qualitative Methodology	54
2.1.1 Philosophy	54
2.1.2 Rationale for Qualitative Methodology	55
2.2 Constructive Grounded Theory	56

2.2.1 An Overview of the Approach	56
2.2.2 Rationale for Using Constructivist Grounded Theory	57
2.3 Ensuring Quality in Qualitative Research	58
2.4 Personal and Professional Reflexivity	60
2.4.1 Reflexivity	60
2.4.2 Researcher's Position	62
2.5 Design	63
2.5.1 Overview	63
2.5.2 Context	64
2.6 Research Governance	64
2.6.1 Ethics and Risk Assessment	64
2.6.2 Inclusion and Exclusion Criteria	65
2.6.3 Consent, Confidentiality and Debriefing	66
2.7 Participant Information	66
2.7.1 Sample	66
2.7.2 Description of the Participants	67
2.8 Procedure	67
2.8.1 Recruitment Procedure	67
2.8.2 Construction of the Interview Schedule	69
2.8.3 Interview Procedure	70
2.8.4 Data Recording and Management	71
2.9 Analysis of Data	71
2.9.1 Analysis of Interview Data	71
2.10 Summary	73
<b>Chapter 3 Results</b>	74
3. Overview of Chapter	74
3.1 Analysis	74
3.1.1 Theme One: <u>COURSE OF ILLNESS IN THE COMMUNITY</u>	76
3.1.2 Theme Two: <u>EXPERIENCE OF ORGANISATIONAL CARE</u>	84
3.1.3 Theme Three: <u>TRANSITIONS IN CARE</u>	105
3.2 Summary of Results	118

<b>Chapter 4</b>	119
4. Overview of Chapter	119
4.1 Research Findings and Existing Research	119
4.1.1 Theme 1: Course of Illness in the Community	119
4.1.1.1 Core Category: PWD Deterioration	120
4.1.1.2 Core Category: Caregiver Involvement	122
4.1.2 Theme 2: Experience of Organizational Care	124
4.1.2.1 Core Category: Caregiver Tasks	126
4.1.2.2 Core Category: Forming Judgments on the Quality of Care	130
4.1.2.3 Core Category: PWD Experience of Belonging, Safety and Physical Care	131
4.1.3 Theme 3: Transitions in Care	134
4.1.3.1 Core Category: Emergency Services	134
4.1.3.2 Core Category: Discharge	135
4.1.3.3 Core Category: Life After Discharge	136
4.2 Implications for Practice	138
4.3 Strengths and Limitations of the Current Study	139
4.4 Recommendations for Future Research	142
4.5 Conclusions	143
References	144



## List of Tables and Figures

<b><u>Figures</u></b>	<b><u>Page</u></b>
Figure 1.1 Distribution of Dementia Sub-Types in the U.K.	13
Figure 3.1 A Diagrammatic Summary of Constructivist Grounded Theory	75
Figure 3.2 A Diagrammatic Overview of Theme One: <b><u>COURSE OF ILLNESS IN THE COMMUNITY</u></b>	78
Figure 3.3. A Diagrammatic Overview of Theme Two: <b><u>EXPERIENCE OF ORGANISATIONAL CARE</u></b>	86
Figure 3.4 A Diagrammatic Overview of Theme Three: <b><u>TRANSITIONS IN CARE</u></b>	107
 <b><u>Tables</u></b>	
Table 1.1 Diagnostic Features of Dementias in DSM-IV-TR	14
Table 1.2. Staging Statistics of Late Onset Dementia	15
Table 1.3. Systematic Review Exclusion and Inclusion Criteria	31
Table 1.4. Critical Appraisal Skills Programme Qualitative Research Checklist (2013a).	36
Table 1.5. Critical Appraisal Skills Programme Randomised Controlled Trials Checklist (2013b).	38
Table 2.1 Revised Study Inclusion and Exclusion Criteria	65
Table 2.2 Carer and PWD Demographics	68

# List of Appendices

## **Appendix 1**

- 1.1 Summary Table of Welsh Policies
- 1.2 Summary Table of English Policies
- 1.3 Flow Chart of Systematic Review Process
- 1.4 Summary Table of Studies Included in the Systematic Review

## **Appendix 2**

- 2.1 Research Diary Extracts
- 2.2 Interview Schedule and Revised/Additional Questions
- 2.3 Risk Assessments
- 2.4 Cardiff School of Psychology Research Ethics Committee Approval
- 2.5 Cardiff School of Psychology Research Ethics Committee Revised
- 2.6 Information Form
- 2.7 Consent Form
- 2.8 Debrief Form

# Chapter 1

## Introduction

### 1. Overview of Chapter

Concepts of dementia are discussed in the context of hospital stays. Relevant policies are presented within a global context with a specific focus on English and Welsh strategies and frameworks. A systematic review of studies exploring inpatient care of people with dementia (PWD) for physical conditions is presented. The chapter concludes with the aims and rationale of the study.

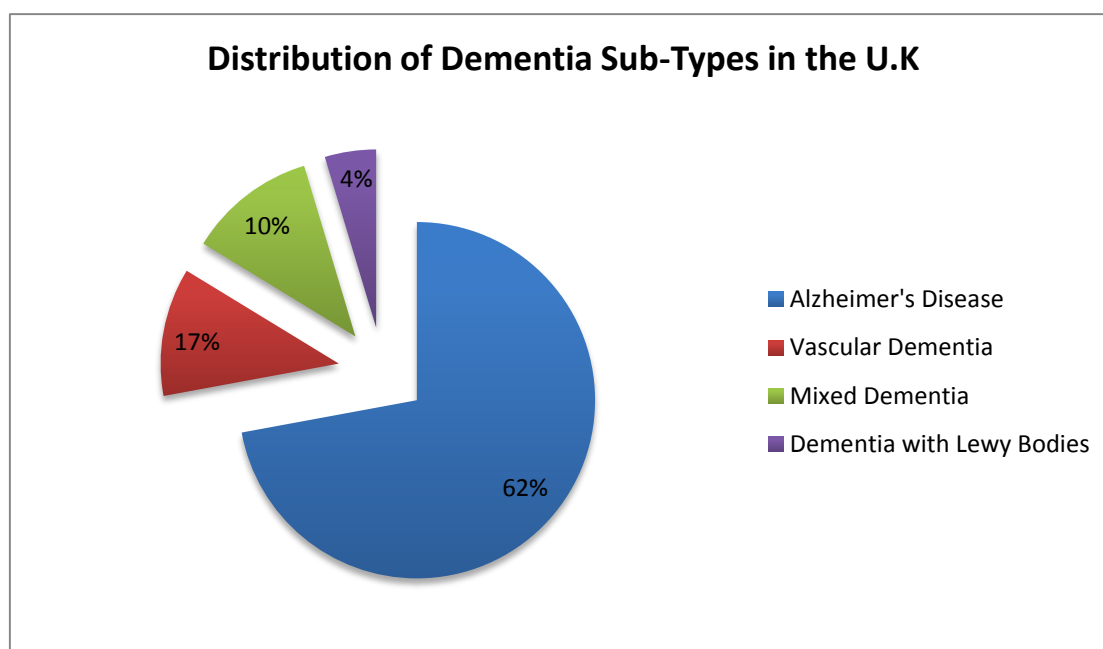
### 1.1 Dementia

#### 1.1.1 What is Dementia?

'Dementia' is a Latin descriptive and diagnostic term (Gustafson, 1996) used to describe a progressive, largely irreversible chronic syndrome, which can be described and understood as 'brain failure' (Department of Health, 2014a). The syndrome is usually, although not always, associated with older age (Public Health England, 2014a). It leads to global cognitive decline in functioning, impacting on social and occupational functioning (American Psychological Association (APA), 2000; Chertkow, Feldman, Jacova *et al.*, 2013; National Institute for Health Care and Excellence (NICE), 2006; World Health Organisation (WHO), 2012a). The syndrome is not a consequence of age-related cognitive decline (APA, 2000; WHO, 2012a), but is instead a consequence of primary or secondary disease e.g. Alzheimer's disease or stroke (APA, 2000; WHO, 2012a); and/or persisting side effects of a substance (APA, 2000); and/or multiple aetiologies (APA, 2000). There are many sub-types of dementia syndrome. The distribution of dementia sub-types across the United Kingdom (U.K) is presented in Figure 1.1.

Symptoms of the syndrome are observable, manifesting in changes associated with cognitive skills (memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment), emotions and conative functioning. These symptoms can precede the onset of the syndrome (Gustafson, 1996; WHO, 2012a). Symptoms are dependent on the affected brain area and the aetiology (Alzheimer's Society, 2014a). Syndrome aetiology and co-morbidities impact on life expectancy (Olde Rikkert *et al.*, 2011). Despite variable expressions of the syndrome, a person with dementia, consciousness remains unaffected (WHO, 2012).

Figure 1.1 Distribution of Dementia Sub-Types in the U.K. Adapted from; APA (2000); Alzheimer's Society (2014a, 2014b); NICE (2006); and World Alzheimer's Report (2009).



### 1.1.2 Diagnostic Criteria

NICE (2006) recommend a range of classification systems to diagnose sub-types of dementia. These include, but are not limited to, the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) (APA, 1994; 2000) criteria. For the purpose of brevity, the full range of diagnostic systems and associated differential criteria is not presented. However, because the DSM-IV system provides diagnostic criteria for both vascular and Alzheimer's dementia approved by NICE (2006), the shared diagnostic features of both

these disorders and all other dementia subtypes are presented below (Table 1.1).

Table 1.1 Diagnostic Features of Dementias in DSM-IV-TR (APA, 2004, p.157).

<p>A diagnosis of dementia is reliant on both A and B criteria being present:</p> <p>A) 'The development of multiple cognitive deficits manifested by both:</p> <ol style="list-style-type: none"><li>1. Memory impairment (impaired ability to learn new information or to recall previously learned information)</li><li>2. One (or more) of the following cognitive disturbances:<ol style="list-style-type: none"><li>a. Aphasia (language disturbance)</li><li>b. Apraxia (impaired ability to carry out motor activities despite intact motor function)</li><li>c. Agnosia (failure to recognize or identify objects despite intact sensory function)</li><li>d. Disturbance in executive functioning (i.e., planning organizing, sequencing, abstracting)</li></ol></li></ol>
<p>B) The cognitive deficits in criteria A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.</p>

The DSM stipulates that identified cognitive disturbances 'must be sufficiently severe to cause impairment in occupational or social functioning and represent a decline from previously higher level of functioning' (APA, 2000, p.148). However, these disturbances must not be a consequence of delirium or caused by another medical, psychiatric or neurological condition (APA, 2000; Chertkow *et al.*, 2013).

More recently, DSM-V (APA, 2013a) was published, with dementia re-labelled under the heading of 'Major and Mild Neurocognitive Disorder' (NCD). Criteria associated with both mild and major vascular and Alzheimer NCD have been retained, whilst criteria for other sub-types of NCD have been revised (APA, 2013b). The distinction between mild and major NCD, has provided an arbitrary divide between those who present with symptoms that do not cause sufficient disruption in occupational and social roles and those who are more severely compromised by cognitive decline (APA, 2013b; Regier, Kuhl and Kupfer, 2013). However, there is concern that the re-categorisation and re-construction of the syndromes will confuse service

users, professionals and service providers (Siberski, 2012). Furthermore, given that the DSM-V (2013a) is still relatively new, it is not clear how many lay people have adopted the term NCD in place of dementia. Therefore, for the purpose of this study the term ‘dementia’ has been utilised, rather than NCD.

### 1.1.3 Stages of Dementia

WHO (2012b) categorise the signs and characteristics of dementia into three stages: early, middle and late (see Table 1.2). These characteristics can be exaggerated by psychological distress as a consequence of a change in personal circumstances e.g. changes in financial status and/or abode and bereavement (NICE, 2006).

Table 1.2. Staging Statistics of Late Onset Dementia (65 years >) in the U.K. Adapted from; Alzheimer’s Society (2014b); NICE (2006); WHO (2012a; 2012b).

Stage	Characteristics	U.K. Prevalence
Early stage or mild dementia (years 0-2).	Forgetfulness, losing track of time, becoming lost in familiar places.	55.4%
Middle or moderate stage dementia (years 2-4/5).	Forgetting people’s names, becoming disorientated or lost in their own home, behavioural changes, needing assistance to attend to personal care and difficulties with communication.	32.1%
Late stage or severe dementia (>5 years).	Complex problems, total dependence on others, lack of activity and morbidity, becoming unaware of the time and place, having difficulty recognizing relatives and friends, having an increasing need for assisted self-care, having difficulty walking and behaviour changes that may escalate and include aggression.	12.5%

The concept of staging, however, has been criticised for lacking standardised biomarkers and for failing to clarify the needs of the patient. The limitation is partly because of the challenging nature of staging a syndrome which has numerous subtypes and variable trajectories (Olde Rikkert, Tona *et al.* 2011). Despite the concerns over lack of validity and reliability of formal measures of

dementia staging, it is generally recognised that staging provides a framework to track progressive deterioration.

#### **1.1.4 Assessment and Diagnosis**

Within the United Kingdom, National Institute for Health and Care Excellence (NICE; 2006) provides a framework for the assessment and diagnosis of dementia. The prescriptive service delivery guidelines address issues of consent, assessment and implementation of interventions, whilst also considering systemic issues which include the integration of care provision across services to individuals i.e. person centred care, inpatient and palliative care; and also the caregivers.

#### **1.1.5 The Prevalence of Dementia**

Dementia has been identified as a growing 'major concern for health and social care services' not only in the UK (1000 Lives Plus, 2010), but also globally (Lin and Lewis, 2015). In the U.K. it is estimated there are approximately 800,000 - 850,000 people with dementia (PWD) (Alzheimer's Society, 2014b; Department of Health, 2015). In terms of the U.K, it is estimated that 84% of those with dementia live in England and 5% live in Wales.

Currently it is understood, from data collected in 2013, that the prevalence of dementia in people aged 65+ in the U.K is 7.1%. Furthermore, it is estimated that 1.3% of the entire U.K population have a dementia and that this increases to 1 in every 14 for those aged 65+ years (Alzheimer's Society, 2014b). Over 40,000 people in the U.K have a diagnosis of early on-set dementia i.e. dementia which affects those younger than 65 years (Alzheimer's Society, 2014b).

Statistics forecast by 2021, in Wales alone, 50,000 people will have dementia (UK Dementia Report, 2007). This, however, may be a gross under estimation. The Alzheimer's Society (2012) suggest that there are already 55,941 people diagnosed and un-diagnosed with dementia in Wales alone. Other U.K. provisional projections forecast that, by 2025, the number of PWD will reach 1 million; and it is estimated that these rates will increase to over 2

million by 2051 (Alzheimer's Society, 2014b). Furthermore, within a global context, it is predicted that the number of PWD across the world will exceed 115 million by 2050 (Alzheimer's Disease International, 2013).

### **1.1.6 The Cost of Dementia**

The costs of caring for PWD within Wales, by both formal agencies and informal carers, has reached £700 million a year (1000 Lives Plus, 2010). The collective social and economic cost of dementia is estimated to be between £23 billion (Department of Health, 2015) to £26+ billion a year in the U.K, with two-thirds of this cost being met by carers and families (Alzheimer's Society, 2014b). These costs are divided over healthcare (£4.3 billion), social care (£10.3 billion) and unpaid carers (£11.6 billion). Based on these statistics, it is thought that the average annual cost per PWD is £32,250 (Alzheimer's Society, 2014b). In addition, there are hidden costs in medical care settings where PWD often stay longer than required (1000 Lives Plus, 2010; National Audit Office, 2007). Globally, dementia is thought to cost £356 billion, which is 1% of global gross domestic product (Public Health England, 2014).

The cost of dementia goes much further than financial cost for carers, who are people who 'provide unpaid care to a family member or friend in need of care and support because they are ill, frail or have a disability' (Independent Lives, 2015). Numerous reports have shown that carers commonly experience psychological distress and changes in their own physical health. They can also experience bereavement of the sufferer in both life and death (1000 Lives Plus, 2010; WHO, 2012b). Based on this premise, within this study the term 'caregiver' will be used to describe relatives who care for PWD. Thus, throughout this thesis the term 'caregiver' is used interchangeably with 'relative', as all of those who participated in the study provided some form of care to the PWD.

The personal costs of the syndrome are well recognized by the public, with two thirds of the U.K worried about dementia, with 66% of those 55+ years expressing high concern (YouGov, 2012). Therefore, dementia is of significant concern, which affects both local and global, health and social care



economy (Burns, 2015).

## **1.2 Dementia and Hospital Stays**

### **1.2.1 Statistics**

Statistics demonstrate that 65%-70% of all general hospital beds are occupied by people aged 65+ (Commission for Healthcare Audit and Inspection, 2006; Department of Health, 2001), with more than 25% of beds being occupied by those aged 85 years and over (Commission for Healthcare Audit and Inspection, 2006). Older adults, therefore, are a core patient group who use acute hospital beds, a high proportion of whom, have dementia (CHKS, 2013; Department of Health, 2001; Alzheimer's Society, 2009). Research shows that 40% of older adults in acute beds have a dementia syndrome, with the number of PWD occupying a bed increasing with age (Alzheimer's Society, 2009; Holmes and House, 2000; Sampson, Blanchard, Jones *et al.* 2009). Statistics show that a quarter of all acute beds are occupied with a person with dementia (Burns, 2015; Dementia Action Alliance, 2012; Mezey and Maslow, 2007); however, these rates may be under estimated due to low rates of screening for dementia in some hospitals (Andrews and Butler, 2014).

### **1.2.2 Reasons for Hospital Admission**

PWD are at increased risk of being admitted to hospital compared to people without dementia. Predictors of admission for PWD include: changes in their routine and environment; and also, increased dependency on others to complete daily activities (Andrieu, Reynish, Nourhashemi *et al.*, 2002; Orell and Bebbington, 1995). However, it has been shown that is often a single trigger event which leads to hospital admission (Royal College of Nursing, 2010). Statistics show that the common reasons for admission are falls (14%), broken/fractured hip or hip replacement (12%), urine infection (9%), chest infection (7%) and stroke or minor stroke (7%) (Alzheimer's Society, 2009). Other reports have found that 43 % of PWD are admitted with pneumonia and a urinary tract infection (Sampson *et al*, 2009).

### **1.2.3 Associated Risks of Hospital Admission**

PWD are at increased risk of admission to hospital compared to those without dementia following illnesses, which could be treated in the community. However, often illnesses are not diagnosed in time in the community, which means PWD become significantly more ill than those without dementia and subsequently require inpatient care. Within Wales, there is little support to prevent these admissions or to support families at home (Andrews and Butler, 2014). Furthermore, older PWD are at increased risk (compared to people without dementia) of experiencing a range of complications whilst in hospital, such as dehydration, urinary-tract infections, pressure sores, delirium and hospital acquired infections (CHKS, 2013; Mecocci, von Strauss, Cherubini *et al.*, 2005; Mezey and Maslow, 2007).

Reports suggest that whilst in hospital, PWD are 3 times more likely to have a fall than people without dementia (CHKS, 2013); they are also at increased risk of having insufficient nutrition, untreated pain, and medication-related problems (Mezey and Maslow, 2007). In addition, PWD who are in hospital for physical conditions, are more likely than other cohorts to 'wander', to display aggression and agitation, to experience further cognitive decline and they are also at greater risk of institutionalization (Mezey and Maslo, 2007; Ruchinskas, Singer and Repetz, 2000).

PWD are at increased risk of mortality after hospital admission, compared to people of the same age without dementia (Ruchinskas *et al.* 2000). For example, 50% of people with moderate dementia who are admitted to hospital with an acute illness die within six months (Stewart, Bartlett and Harwood, 2005). However, data on comparison of death rates needs to be treated with caution, because PWD have shortened life expectancies (WHO, 2012b). People with Alzheimer's disease have been found to have, on average, a post-hospitalization survival of 7.1 years and people with vascular dementia 3.9 years (Fitzpatrick, Kuller, Lopez *et al.* 2005). Furthermore, death certificates can be unreliable and the cause of death may be associated with co-morbid illnesses rather than with dementia (WHO, 2012b).

Finally, PWD are less likely to be referred for palliative care intervention and,

therefore, are at greater risk of not being prescribed palliative care medication or given optimal medical intervention (Sheehan, Stinton and Mitchell, 2009).

#### **1.2.4 Length of Hospital Stay**

Dementia impacts on the pattern of hospital care and the trajectory of stay. For example, PWD have been reported to stay, on average, a week longer in hospital than those without dementia (Burns, 2015). Furthermore, PWD have been found to be 11% more likely than those without dementia to remain in hospital for more than a day for a non-elective admission, with average stays being 25% longer for PWD than for those without dementia (CKHS, 2013).

Longer hospital stays are of significant concern, as they are associated with physical deterioration and an increased risk of prescription of anti-psychotic medication, which is often used to manage symptoms of acute confusion and anxiety that is often a response to a sudden and traumatic change of environment (CKHS, 2013). The prescribing of anti-psychotics for PWD, however, is controversial as a number of anti-psychotics are not licensed to be used with PWD (Alzheimer's Society, 2012b); furthermore, audit demonstrates that staff often fail to complete appropriate risk assessments (Andrew and Buttler, 2014) and a quarter of nurses surveyed reported inappropriate usage of these medications (Alzheimer's Society, 2009). This is of particular concern as people are at risk of becoming over sedated, leading to a loss of function, whilst also increasing the risk of falling and avoidable death (Alzheimer's Society, 2012b; CKHS, 2013). Furthermore, PWD are also at risk of anti-psychotics being prescribed as an inappropriate long-term medication, on discharge (CKHS, 2013).

With regards to discharge, PWD are more likely than people without dementia to be discharged to a setting, other than their home environment from which they were admitted (CKHS, 2013). The Alzheimer's Society (2009) reported that just over half those admitted from home, returned back to their home from hospital.

Furthermore, the likelihood of re-admission for a PWD within a thirty-day time frame, following discharge for elective and non-elective treatments, is

significantly higher than for those without dementia (CKHS, 2013). Therefore, for PWD, admission to hospital comes at a serious personal cost with associated risk of further illness, re-admission and discharge to a different environment (Alzheimer's Society, 2009); this is accompanied by significant health and social care costs, e.g. hospital beds for PWD cost on average £231 a day (CKHS, 2013).

### **1.3 Dementia and Policies**

WHO has long campaigned for governments, policy makers and other relevant stakeholders to take note of the growing threat of dementia to public health (e.g. WHO, 2012b). More recently, WHO (2015) have described dementia as an international 'burden'; the concerns of the health and social costs of the syndrome are so great that a Ministerial Conference on Global Action Against Dementia was called in March 2015 to bring the economic cost of dementia to the forefront of the global public health agenda.

Global policies have informed strategies, frameworks and plans at sub-national level (WHO, 2012b). Due to Government devolution, England, Scotland and Wales have separate strategies to manage the growing impact of dementia. Political action in these countries has led to the development of integrative approaches addressing awareness, education, timely diagnosis, support, quality of care, development of workforces, research, treatment, financial pledges, and also ethical dilemmas and human rights (WHO, 2012b). The concept of development of such strategies has been partly driven by a spend-to-save ethos and driven by an agenda to improve the quality of lives for both PWD and their carergivers (Department of Health, 2009).

#### **1.3.1 Dementia and Older Adult Policies in Wales**

Welsh Assembly Government (WAG) announced a landmark, ten year 'Strategy for Older People' in 2003, to prepare for the needs of an ageing society. The two-phased Strategy (2003) has since been expanded to a third stage, spanning 2013-2023. The focus has continued to be enabling older people to contribute to family life and the community, to have a voice and to influence decision making and to have their needs met. These later phases of the strategy were developed in the context of the WAG's pledge to invest an

extra £1.5 million a year to support the development of 'Dementia Supportive Communities' (WAG, 2011) (see Appendix 1.1 for an overview of the targets and objectives of the policies outlined in this section).

The Dementia Supportive Communities' vision pledged a commitment to invest in dementia through developing services, delivering training, increasing awareness and supporting research (WAG, 2011). The vision was located in the context of the 'Strategy for Older People' (WAG, 2003; 2013) which collectively focused on social, environmental and financial factors, to build and contribute to a good quality of life for this age group, as outlined in Appendix 1.1 (Welsh Government, 2013).

Furthermore, these strategies were supported by the National Framework for Older People in Wales to address the health and social care needs of those aged 50 and over, to try to improve service standards and equity of access to services across the country through the development of an evidence base and national standards (WAG, 2006). The recognition of the need to improve care and services for older adults and also PWD in Wales led to the formation of a Task and Finish group from which a 'National Dementia Action Plan for Wales' was produced (Welsh Assembly Government, 2009). These national frameworks, strategies and task groups collectively acted to inform the development of the 1000s Lives Report: Improving Dementia Care (WAG, 2010). The Report provided healthcare organizations with a number of interventions to improve the safety and quality of care of service users (see Appendix 1.1).

However, despite Welsh Governments' attempts to generate change at both organisational levels and the frontline, there still continue to be significant issues of poor care provision for the elderly and frail. The Andrews Report (Andrews and Butler, 2014) highlighted how some hospital staff are 'ill equipped to meet the needs of patients with dementia and other frail older people and were unclear what to do about it' (p.2, 2014) with some nurses being described as lacking awareness of the need and skills to manage problems such as dementia, incontinence, low mobility, and hygiene and nutrition difficulties. The report also described how, in the hospitals

investigated, there were few activities for people of this age group (Andrews and Butler, 2014).

Despite efforts to introduce dementia awareness strategies, the Andrews Report (Andrews and Butler, 2014) found the up-take of such schemes to be variable e.g. the Butterfly Scheme, which enables staff to easily and discreetly identify a PWD, alerting staff to the existence of an easy to use carer-sheet and reminding them to utilise a specific 5 point target response to interact more effectively with the PWD.

In response to these findings the Andrews Report indicated a need for the development of 'staff and ... public understand[ing of] the needs of older people within a hospital setting' (Andrews and Butler, p.3, 2014), to be achieved with staff through 'intensive education programme[s] on delirium, dementia and dying in hospital' (Andrews and Butler, p.4, 2014). Furthermore, a 'review [of] how well ward accommodation supports care for those with dementia, delirium, cognitive impairment or dying at ... hospitals, covering physical design of the clinical spaces and equipment available' was recommended, to create a more dementia friendly environment (Andrews and Butler, p.4, 2014).

### **1.3.2 Policies in England**

In 2007 the Department of Health (DoH) declared dementia a national public health and social care priority (National Audit Office, 2010). However, it was not until 2009 that the DoH announced a five-year 'National Dementia Strategy' to significantly develop dementia services suitable for the needs of a population of the 21<sup>st</sup> Century (DoH, 2009a; 2009b) (see Appendix 1.2 for an overview of the targets and objectives of the policies outlined in this section). The strategy was developed within and informed by existing debates, frameworks and policy including: 'Our NHS, Our Future, Putting People First: A shared vision and commitment to the transformation of adult social care ... the National Institute for Health and Clinical Excellence (NICE) commissioning guide on memory assessment services, the Carers' Strategy (Carers at the heart of 21st century families and communities) and the National End of Life Care Strategy' (DoH, 2009b, p.10).

The National Dementia Strategy (DoH, 2009b) was designed to target audiences regardless of their age, gender and ethnicity; however, was specifically designed for PWD, people affected by dementia, carers and health and social care professionals (DoH, 2009a, 2009b). Overall, the policy outlined 17 key objectives, focusing specifically on improved awareness, earlier diagnosis and intervention, and a higher quality of care, all of which were to be implemented at local level (DoH, 2009b). This pledge to develop services was supported with a £150 million investment (Alzheimer's Society, 2015). However, the extent to which the Strategy was implemented at local level varied (National Audit Office, 2010) and the development was hampered by austerity (MHP Health Mandate, 2011).

A review hosted by MHP Health Mandate (2011) with relevant stakeholders and associated with the Alzheimer's Society, recommended that in order for the strategy to be implemented across England, a number of reforms needed to happen (see Appendix 1.2). Following these recommendations, Prime Minister David Cameron announced an ambitious 'challenge' to significantly improve dementia care and research (DoH, 2012a; Alzheimer's Society, 2015).

In 2015 the Prime Minister announced the Government's challenge on dementia 2020 (DoH, 2015), which describes targets introduced in a bid to continue to improve the care of PWD and their caregivers (see Appendix 1.2). However, there is a wide gap between policy and compliancy (Francis, 2013; Royal College of Psychiatrists, 2011). The findings of the Francis Report (2013) have had serious ramifications for health and social care providers, with a broad range of organizational recommendations being produced to target service delivery in the areas of cultural change, delivery of training and education, compliancy and accountability. Such findings, therefore, beg the question as to the experience of PWD who enter hospital, specifically in the light of evolving policies to improve service user care and experience (Francis, 2013).

## **1.4 Models of Care in Hospital Settings**

The policies outlined in Section 1.3.2 and 1.3.3 reflect a move towards a 'whole hospital approach' to the care of PWD in hospital settings (Royal College of Nursing, 2010). This has taken the form of evidenced-based change to make wards dementia friendly in order to enhance the healing environment and also through the development of psychologically informed models to support the work of hospital staff in caring for PWD.

### **1.4.1 Person Centered Care**

The notion of person-centered care (PCC) emerged from Kitwood's concept of 'personhood', defined as: 'a standing or status bestowed upon one human being, by others, in the context of relationship and social being ... imply[ing] recognition, respect and trust' (Kitwood, p.7, 1997). The underpinnings of the model, therefore, aim to maintain a PWD's sense of personhood in the context of cognitive decline (Kitwood, 1997). This requires a focus on values, independence and wellbeing, whilst also empowering both the service user and their caregiver (Mitchell, 1999).

It is argued that models which attend only to the physical aspect of the disease neglect personhood and are, therefore, potentially damaging (Epp, 2003). This is because reductionist biomedical models are said to reinforce negative perceptions and treatment, which assume that PWD are passive casualties of the syndrome. This is thought to reduce selfhood to nothing (Davis, 2004) which is argued to be detrimental to the PWD (Epp, 2003). For example, if a PWD is viewed not to have selfhood, they are at risk of being objectified, which can lead to malignant social interactions, where the PWD is depersonalised and invalidated (Clarke, Hanson and Ross, 2003; Clissett, Porock, Harwood *et al.*, 2013a; Penrod, Yu, Kolanowski, *et al.*, 2007). This can impact on a caregiver's ability to provide meaningful care which increases the risk of care providers focusing on only meeting basic needs. This approach can lead to a greater emphasis on medical interventions to manage the PWDs' need, rather than trying to understand the meaning driving the behaviours (Eriksson, Minthon, Moksnes *et al.*, 2000). Such biomedical reductionist notions are challenged by research findings documenting



moments of lucidity where even in the later stages of dementia, PWD respond to another person's behaviour (Normann, Norberg and Asplund, 2002; Normann, Henriksen, Norberg *et al.*, 2005).

In contrast to neuro-pathological models of dementia, PCC is built upon the premise that all humans deserve respect and are of value, regardless of disability. The model conceptualises the PWD's personality as being concealed rather than lost to the syndrome (Edvardsson, Winbald and Sandman, 2008); thus suggesting that PWD can live fulfilling lives within the context of decline (Kitwood, 1996),

PCC is a holistic and individual-centered model and is identified as the best practice form of care for PWD (McCormack, 2004). PCC sits within a social interaction paradigm and supports the development and maintenance of self-esteem, something that has been identified as important for overall wellbeing for PWD (Sabat, Fath, Moghaddam *et al.*, 1999). PCC recognizes the importance of the rights, values and beliefs of people, considering the self across time, whilst also being inclusive and focusing on the person's abilities rather than their deficits and recognizing that there is meaning to their actions and behaviours (Edvardsson *et al.*, 2008). The model therefore helps workers to recognize the qualities of each individual, with the concept of personhood valuing a broad range of characteristics, including autonomy (Hofland, 1994), mean-making (Lyman, 1998), social and personal identity (Sabat, 1998) and sexuality (McLean, 1994).

The relational aspect of PCC is supported by therapeutic principles of validation, holding and facilitation. The model is used to recognize the qualities the PWD brings to the interaction within the relationship; in this context, the qualities are recognized as the creation of the interaction and the sharing of positive and helpful emotions (Kitwood, 1999). In terms of clinical practice, PCC often takes the form of collating biographies of PWD (Clarke, 2000), facilitating reminiscence, personalizing the environment, managing sensory stimulation, developing psychosocial environments, providing appropriate activities, and providing nursing which is both task and relationship orientated (Edvardsson *et al.*, 2008). Within this model, such

practices are used to develop and contribute to the experience of attachment, inclusion, identity and comfort for the PWD (Brooker, 2007).

The approach has been found to enhance quality of life (Burgener and Dickerson-Putnam, 1999), to reduce agitation (Matthews, Farrell and Blackmore, 1996), to improve sleep patterns (Richards, Sullivan, Phillips *et al.*, 2001) and to contribute towards the maintenance of self-esteem (Sabat *et al.*, 1999). In a randomized control trial it was found that, compared to the control group, staff were more gentle, verbally supportive and were at greater ease when adhering to a PCC model, thus supporting the notion that the belief of personhood in PWD can positively affect care provision (Hoeffler, Talerico, Rasin *et al.*, 2006). Furthermore, staff training in PCC has been found to significantly reduce the prescribing and administration of neuroleptic medication at 12-month follow up (Fossey, Ballard, Juszczak *et al.*, 2006). This is thought to be because PCC enables staff to better understand the mechanisms driving the patient's distress e.g. pain rather than challenging behaviour per se (Alzheimer's Society, 2012).

However, the model has been criticized for failure to consistently define PCC or the concept of personhood (Downs, Small and Froggatt, 2006; Schwartz, Jacobson and Holburn, 2000; Slater, 2006). The lack of clarity is argued to have prevented the development of effective assessment tools to measure the validity, effectiveness and quality of the model (Edvardsson, *et al.*, 2008; Pedlar, Hornibrook and Haasen, 2001). Furthermore, the mechanisms of the model are still to be understood and its effectiveness with diversity i.e. age, gender, stage of syndrome and ethnicity remains to be investigated (Epp, 2003).

The lack of consensus has impeded the ability to identify and measure the extent to which the model has been adopted (Epp, 2003) and adhered to in clinical practice (McBrien, 2009). This may have contributed to staff believing they are delivering PCC when the care they are providing is actually task-based (Skaalvik, Normann and Henriksen, 2010.). This is coupled with the concern that PCC may conflict with pressures of organisational constraints within the NHS, due to breadth of staff responsibilities and clinical routines

(Clissett *et al.*, 2013a; Williams, Cattell, Greenwood *et al.*, 1999). For example, it is recognised that the focus of acute settings may impact on staff's ability to deliver PCC, because care is diagnosis orientated, focusing on treatment and discharge and with meeting financial and productivity targets (Clissett *et al.* 2013a; Francis, 2013). Such findings have led the Alzheimer's Society to campaign for a need for 'strategic leadership to make the shift from task-driven to person-centred care' (2012, p.2).

Despite these limitations, it is recognized that the framework is 'gold standard' (Evardsson, Fetherstonhaugh, McAuliffe *et al.*, 2011), providing a structure for good ethical practice, which is respectful and appears to be associated with few risks (Clissett *et al.*, 2013a; Edvardsson *et al.*, 2008). Furthermore, PCC is supported by policies outlined in the previous section e.g. NICE (2006) which directed acute NHS Trusts to deliver services 'address[ing] the personal and social care needs and the mental and physical health of people-with-dementia who use acute hospital facilities for any reason' (NICE, 2006, p. 11); these guidelines for utilising PCC principles are also supported by the National Dementia Strategy (2009). Despite these policy guidelines, there is a lack of clarity as to how these models have been utilised in acute physical health settings (Clissett *et al.* 2013a).

Further research is required to understand how the PCC is being adopted, supported and implemented in acute general health wards, given the variability in the interpretations and implementations of PCC.

### **1.4.2 Compassionate Care**

The vision and concept of compassionate care has been central to the delivery of NHS care and policy development (DoH, 2012b). The Compassion in Practice Strategy (DoH, 2012b) is said to build on PCC (Alzheimer's Society, 2012), encompassing the promotion of 6 core values and beliefs (6 C's): care, compassion, competence, communication, courage and commitment. Six areas were targeted for the development and implementation of these values; 'helping people to stay independent, maximising well-being and improving health outcomes; working with people to provide a positive experience of care; delivering high quality care and

measuring the impact of care; building and strengthening leadership; ensuring that we have the right staff, with the right skills, in the right place; and supporting positive staff experience' (DoH, p.14, 2012b).

However, the 6 C's were designed with a view to improve the care of all individuals across NHS health settings. There are few statistics to show if and how compassionate care has directly impacted on the care of PWD. However, a review of the Strategy (DoH, 2012b) highlighted how the NHS are working with third sector organisations to develop compassionate care for people with dementia (NHS England and Nursing Directorate, 2014).

## **1.5 Patient Experience and Associated Dilemmas**

There is limited research onto the understanding of PWD's experience of hospital stays. Instead, studies have focused more closely on the systems that support PWD. Aggarwal *et al.* (2003) assert that this is in part a consequence of prejudices held by society surrounding the understanding of memory loss, which has led to the failure to recognise a PWD's human-ness. Corner (2002) suggests there is a historic reluctance to include PWD in studies, due to the assumption that their cognitive deficits are an obstacle to valid and reliable data collection i.e. communication, memory recall etc (Hubbard, Downs and Tester, 2003; Nygard, 2006). These suppositions are relevant to ethical dilemmas associated with issues of capacity and consent (Godfrey, 2013).

Despite the reluctance to involve PWD in studies, Cotrell and Sholtz (1993), suggest that certain methodological modifications could enable first hand qualitative research to be meaningful when conducted with this service user group. Despite their advice, few have pursued this avenue of research (Nygard, 2006). This goes some way to explaining why there is a dearth of studies exploring the service users' inpatient experience in general hospitals.

However, studies with carers have found that 77% of caregivers are dissatisfied with the overall quality of care for PWD in acute hospital settings (Alzheimer's Society, 2009), with many expressing concern with regard to nurses' failure to recognise or understand dementia, lack of PCC, limited

availability of meaningful activities and social interaction for PWD, staff not helping PWD to eat and drink, and inadequate collaborative working in relation to decision making. Furthermore, one survey found that 36% of carers were concerned that their family member was being treated with a lack of dignity and respect, whilst in hospital (Alzheimer's Society, 2009). However, these studies go little way to contribute to our understandings of the experience of people with dementia when they are inpatients on a physical health ward.

## **1.6 Systematic Review**

### **1.6.1 Aims**

A systematic review of literature was conducted to explore the evidence base for the experience of physical health inpatient care for PWD. It was assumed there would be few papers on this topic and the systematic review question was therefore broad in order to capture any research in this area. Due to the limited number of studies conducted with PWD, the concept of 'experience' was broadened to include (unpaid/non-professional) carers' and care-givers' perspectives of the PWD experience of hospitalization. However, to keep the PWD at the centre of the work, papers which focused purely on staff accounts were excluded, as these papers tended to examine the staff's experiences of challenging behaviours.

### **1.6.2 Search Methodology**

The following databases were accessed on 29th March 2015: Social Care Online; SCOPUS; British Nursing Index; and OVID SP which included: PsychINFO; Psycharticles Full Text; Ovid Medline; EMBASE; and Cardiff University Full Text Journals.

Additional journals were also searched on 30<sup>th</sup> March 2015; Alzheimer Disease and Associated Disorders; Alzheimer's Research and Therapy; Dementia; and Alzheimer's & Dementia; American Journal of Alzheimer's Disease and Other Dementias. Additional searches were also conducted on: Google and Google Scholar on 30<sup>th</sup> March, 2015, together with searches of reference lists of relevant articles in order to identify papers, which met the

relevant inclusion/exclusion criteria.

The following Boolean operators and search terms were used: (inpatient OR inpatient care OR treatment OR services OR hospital\* OR ward OR nursing OR medical OR care provision OR interventions) AND (Alzheimer\* OR dement\* OR cognitive decline OR cognitive impairment) AND (experie\* OR phenomenology OR accounts OR account OR story OR stories OR perspective\* OR family).

### 1.6.2.1 Study Criteria

Papers and grey literature were scrutinised using the criteria outlined in Table 1.3.

Table 1.3. Systematic Review Exclusion and Inclusion Criteria

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Qualitative and quantitative analysis studies exploring inpatient care of PWD for physical conditions; Carer and patient experiences; Transitions times in hospital e.g. admission, discharge and transfer; Suspected dementia i.e. those with significant memory problems who are undiagnosed with dementia.	Unpublished studies; Books, chapters, conference abstracts where no full paper is available; Books and studies not published in English (see below); Studies with non-dementia populations, including studies comparing experiences of people with and without dementia; Non-hospital environments e.g. care homes, nursing homes, community dwellings; Experience of diagnosis of dementia; Treatment for dementia; Admission to hospital for a non physical health condition; Staff experiences; Papers on how to measure/better understand experience/quality of care; and Non-acute health conditions e.g. palliative care.

The exclusion of non-English papers has been argued to bias significant results, for example Egger, Zellweger-Zahner, Schneider, Junker, Lengeler and Antes (1997) found that non-English studies are more likely to be translated in to English if the findings are significant. However, it is recognised that there is now a global shift for papers to be published in the English

language and, therefore, the extent to which language restrictions impact on systematic reviews is questionable (Higgins and Green, 2011).

As many areas of ward experience were captured as possible. However, the focus remained on the experience of acute care of PWD and, therefore, papers examining palliative care were excluded. Using the search terms above, 8218 papers were identified; seven papers were retained through the process of review based on criteria (see Appendix 1.3 for a flow chart of systematic review process).

### **1.6.3 Results and Quality Framework**

A descriptive account of each of the studies is presented and a quality framework is then used to assess the quality of the studies and reports of the papers included in the systematic review. A synthesis of the studies follows.

#### **1.6.3.1 Summary of Included Studies**

Seven articles were included in the review (see Appendix 1.4 for description of studies). Bloomer, Digby, Tan *et al's* (2014) studies aimed to explore the caregiver's experience when the person they cared for was a hospital inpatient. Norman's (2006) publication detailed the first phase of three studies which collectively aimed to explore how PWD are cared for in general hospitals; this phase aimed to explore what happened to a PWD when they were admitted to a hospital ward. Clissett, Porock, Harwood *et al.* (2013b) aimed to explore experiences of family carers of older people with mental health problems (a term used within their paper to describe cognitive impairment), in an acute general hospital. In contrast, studies produced by Whittamore, Goldberg, Bradshaw *et al.* (2014) and also Jurgens, Clisset, Gladman *et al.* (2012) examined dissatisfaction of carers with acute hospital care. Finally Bauer, Fitzgerald and Koch (2011) and Digby, Moss and Bloomer (2010) examined time of hospital transfer; the former aimed to explore whether discharge practices met the needs of the family carer of the PWD, whilst the latter aimed to develop an understanding of how older adults with dementia experienced transfer between acute care and sub-acute care.

### 1.6.3.2 Design and Method

Qualitative methodologies were employed by six of the seven research publications reviewed here (Bauer *et al.* 2011; Bloomer *et al.* 2014; Clissett *et al.* 2013b; Digby *et al.* 2010; Jurgens *et al.* 2012; Norman, 2006). Only Whittamore *et al.* (2014) employed quantitative methods (specifically secondary analysis of data from a randomised control trial) to address the aims and objectives of the study.

A proportion of the researchers employed semi-structured schedules and in-depth interviews to explore (i) key areas that carers found problematic in areas related to discharge (Bauer *et al.*, 2011); (ii) family carers' experiences of mild-moderate cognitively impaired older adults who had been admitted to general hospitals (Clissett *et al.*, 2013b); (iii) family carers of PWD and the carers' experience of when the PWD is in hospital and the change in the caring role (Bloomer *et al.*, 2014); (iv) experiences of care on a variety of ward sub-types (Jurgens *et al.*, 2012); and (v) PWD's experience of transfers from acute to sub-acute wards and the settling-in period (Digby *et al.*, 2010).

In addition to the use of interviews, both Clissett *et al.* (2013b) and Jurgens *et al.* (2012) conducted seventy-two hours of non-participant observations of care; however, the observations were not included in the reports. In contrast, Norman (2006) used observations following what was described as a hybrid observational approach of participants and non-participants, consisting of more than a hundred hours of observation across three ward settings, to explore what happened to a PWD when admitted to a general hospital ward.

A range of methods was used across the studies to analyse the data. With regards to the qualitative studies, methods of constant comparison (Bauer, *et al.*, 2011; Clissett *et al.*, 2013b), thematic analysis (Bloomer *et al.*, 2014), content analysis (Digby *et al.*, 2010), and grounded theory (Jurgens *et al.*, 2012; Norman, 2006) were all employed. Whittamore *et al.* (2014) utilised a range of statistical measures to analyse data including univariate and multivariate tests.



### 1.6.3.3 Sample

Participants were recruited through a variety of means including: screening at emergency admission to general or geriatric medical wards or trauma orthopaedic wards (Clissett *et al.*, 2013b n= 34, age range= 46-79, population= carers; Jurgens *et al.*, 2012: n= 35, age range= 46-79, population= carers); purposive i.e. non-probability sampling techniques (Bauer *et al.*, 2011: n= 25, age range=not reported, population= carers; Bloomer *et al.*, 2014: n=30, age range= 34-92, population= carers; Digby *et al.*, 2011: n=8, age range= 77-92, population= mild-moderate PWD); and through convenience sampling (Norman, 2006: n=8, age not reported, population=people with no formal diagnosis of dementia). With regards to Whittamore *et al.* (2014), participants were randomly assigned to either a specialist geriatric unit or internal medical wards (n=600, population= cognitively impaired, age= 65+ N.B. range not reported) and related caregivers (n=488, age not reported).

Four of the studies were U.K based (Clissett *et al.*, 2013b; Jurgens *et al.*, 2012; Norman, 2006; Whittamore *et al.*, 2014) and the remaining three studies were undertaken in Australia.

### 1.6.3.4 Quality of the Research

There is little consensus as to how to assess the quality of qualitative research (Munro, Lewin, Smith *et al.*, 2007; Khakbazan, Taghipour, Latifnejad *et al.*, 2014). However, the Critical Appraisal Skills Programme (CASP) has been recognised as a robust tool to provide a framework to assess the validity and usefulness of qualitative and quantitative studies for synthesis (Khakbazan, *et al.*, 2014). Findings are presented in Table 1.4 (qualitative) and Table 1.5 (quantitative).

The qualitative research checklist (2013a) consists of ten questions with 34 prompts and the randomised control trials checklist (2013b) consists of 11 questions and 22 prompts. The application of these tools enables the researcher to screen for poor quality and inappropriate papers for systematic review (Campbell, Pound, Pope *et al.*, 2003). For the purpose of brevity, table cells are marked with a 'X' to indicate the papers met a high proportion, if not

all, of the prompts associated with each category; where the score of prompts were evenly weighted, an 'X' was marked in the 'can't tell' category. The scoring of both subtypes of CASP involves noting whether areas of quality were either addressed or not addressed in the paper. There is also an option to indicate that it was not clear from the data (labeled: 'can't tell'). A narrative account describing the quality of the studies follows.

Table 1.4. Critical Appraisal Skills Programme Qualitative Research Checklist (2013a).

	Bauer, Fitzgerald and Koch (2011).			Bloomer, Digby, Tan <i>et al.</i> (2014).			Clissett, Porock, Harwood <i>et al.</i> (2013b).			Digby, Moss and Bloomer (2010).			Jurgens, Clisset, Gladman <i>et al.</i> (2012).			Norman (2006).		
Quality	Yes	No	Can't tell	Yes	No	Can't tell	Yes	No	Can't tell	Yes	No	Can't tell	Yes	No	Can't tell	Yes	No	Can't tell
Was there a clear statement of the aims of the research? – 3 prompts	X	--	--	X	--	--	X	--	--	X	--	--	X	--	--	X	--	--
Is a qualitative methodology appropriate? – 2 prompts	X	--	--	X	--	--	X	--	--	X	--	--	X	--	--	X	--	--
Was the research design appropriate to address the aims of the research? – 1 prompt	X	--	--	X	--	--	X	--	--	X	--	--	X	--	--	X	--	--
Was the recruitment strategy appropriate to the aims of the research? – 3 prompts	X	--	--	X	--	--	X	--	--	X	--	--	X	--	--	X	--	--
Was the data collected in a way that addressed the research issue? - 7 prompts	X	--	--	X	--	--	X	--	--	X	--	--	X	--	--	X	--	--
Has the relationship between researcher and participants been adequately considered? – 2 prompts	--	--	X	X	--	--	--	--	X	X	--	--	--	--	X	--	--	X
Have ethical issues been taken into consideration? – 3 prompts	--	X	--	X	--	--	X	--	--	X	--	--	X	--	--	X	--	--

<b>Quality</b>	Bauer, Fitzgerald and Koch (2011).			Bloomer, Digby, Tan <i>et al.</i> (2014).			Clissett, Porock, Harwood <i>et al.</i> (2013b).			Digby, Moss and Bloomer (2010).			Jurgens, Clisset, Gladman <i>et al.</i> (2012).			Norman (2006).		
<b>Was the data analysis sufficiently rigorous? – 6 prompts</b>	X	--	--	X	--	--	X	--	--	--	X	--	X	--	--	X	--	--
<b>Is there a clear statement of findings? – 4 prompts</b>	X	--	--	X	--	--	X	--	--	--	--	X	X	--	--	X	--	--
<b>How valuable is the research? – 3 prompts</b>	X	--	--	--	X	--	X	--	--	X	--	--	X	--	--	X	--	--

Table 1.5. Critical Appraisal Skills Programme Randomised Controlled Trials Checklist (2013b).

	Whittamore, Goldberg, Bradshaw <i>et al.</i> (2014).		
Quality	Yes	No	Can't tell
Did the trial address a clearly focused issue? – 4 prompts	X	--	--
Was the assignment of patients to treatments randomised? – 2 prompts	X	--	--
Were patients, health workers and study personnel blinded? – 2 prompts	X	--	--
Were the groups similar at the start of the trial? – 1 prompt	X	--	--
Aside from the experimental intervention, were the groups treated equally? - 0 prompts	X	--	--
Were all of the patients who entered the trial properly accounted for at its conclusion? - 2 prompts	X	--	--
How large was the treatment effect? – 4 prompts	Ward type was significantly associated with dissatisfaction of overall care.		
How precise was the estimate of the treatment effect? – 2 prompts	95% confidence intervals, p-values significant.		
Can the results be applied in your context? (or to the local population?) – 2 prompts	X	--	--
Were all clinically important outcomes considered? 2 prompts	X	--	--
Are the benefits worth the harms and costs? – 1 prompt	X	--	--

### **1.6.3.5 Narrative Quality of the Research**

#### **1.6.3.5.1 Research Aims, Methodology and Design**

Overall, the studies reported outlined clear research aims; however the aims of Jurgens *et al.* (2012) were harder to interpret, because the data had been analysed prior to the study. The research team identified a sub-category of interest through earlier analysis concerning carers' dissatisfaction with general hospital care, which was analysed to build a model to explain the phenomenon. Similarly, data presented by Norman (2006) constitute the first phase of a bigger study and thus the overall aims of the study were specific to the phase presented. In addition, Whittamore *et al.* (2014) conducted a secondary analysis of data which had been collected for another purpose.

The aims of the studies, although often explicit, were sometimes difficult to find, as they were embedded in the literature review. The literature presented in the studies, however, did aid the understanding of the wider context of the data. Despite the variation in the way the aims were presented, all of the studies had identified aims (see Appendix 1.4 for a table summarizing the aims) and presented research with a view to interpreting and illuminating the actions and/or subjective experiences of participants, with consideration also given to the rationale of the methodology. However, all of the studies failed to critically analyze their own bias in the development of the research question under investigation.

#### **1.6.3.5.2 Recruitment and Data Collection**

All of the studies provided an overview of how participants were recruited to the study, although not all described details of the process of recruitment. However, others discussed screening and details of recruitment in the context of being linked to larger studies, with different objectives (e.g. Clissett *et al.*, 2013). A variety of recruitment methods were cited including non-probability sampling techniques (Bauer *et al.*, 2011; Bloomer *et al.*, 2014; Digby *et al.*, 2011) and convenience sampling (Norman, 2006). None of the studies addressed the potential of researcher bias or the influence of power in the recruitment process, although Clissett *et al.* (2013) recognized that recruitment rates may have been affected by carers' competing priorities and

also, their availability to participate due to the bereavement of person with dementia.

Notably, participants may increase the risk of 'elite bias' (Sandelowski, 1986), where the views expressed only represent the ones of those most passionate about the topic on which they are speaking (Bauer *et al.*, 2011). Furthermore, it was acknowledged by Whittamore *et al.* (2014) that carers' perspectives may be biased because they often only see a snap shot of the patient's day. Additionally, any feedback from the PWD that could act to inform carers opinion could be biased due to inaccuracies in PWD recall.

#### **1.6.3.5.4 Ethical Issues**

Studies varied in terms of the explicitness of ethical approval, with some embedding the name of the approving ethics committee in the article (Bauer *et al.*, 2011; Bloomer *et al.*, 2014; Clissett *et al.*, 2013; Digby *et al.*, 2011; Norman, 2006; Whittamore *et al.*, 2014), whilst other provided this information as a separate reference point at the end of the article (Jurgens *et al.*, 2012). The depth with which consent was addressed varied across studies. For example, some researchers documented but not all, how they sought continual consent throughout data collection (e.g. Digby *et al.*, 2011; Norman, 2006). This was perhaps made more explicit in some papers, because the focus of the research was with people on cognitive impairment, rather than on their carers.

Whittamore *et al.*'s (2014) paper described how consent was sought from PWD for the RCT component of the wider study (findings of which were not presented in the paper), in the context of the Mental Capacity Act (The National Archives, 2005). Where PWD were unable to consent, agreement was sought from family members. Whittamore *et al.* (2014) described how consent was also sought from carers for the study presented in the paper; therefore, in this case, consent was a two-fold process.

None of the articles discussed processes of debriefing.

#### **1.6.3.5.5 Data Analysis**

All of the studies discussed the process of data analysis, except Digby *et al.* (2010) who reported the findings of a content analysis without discussing the process or providing any in-depth account of the analysis. Similarly to the other qualitative studies examined here, Digby *et al.* (2010) failed to explain how the quotes presented represented the data sets and, also, how quotes were chosen to reflect the findings of the analysis. However, it is of note that the findings of all of the qualitative studies were illustrated with direct quotes to support emerging themes.

With regards to the quantitative data, Whittamore *et al.* (2014) employed univariate and multivariate analysis. Some of the findings, however, lacked precision due to wide 95% confidence intervals on effect sizes.

#### **1.6.3.5.6 Findings and the Value of Research**

All of the studies discussed how the research contributed to existing literature, whilst some explicitly highlighted how the investigation broke new ground in an area where there was a dearth of research (Bauer, *et al.*, 2011; Clissett *et al.*, 2013; Digby *et al.*, 2011; Norman, 2006; Whittamore *et al.*, 2014). Authors also highlighted how the research might contribute to the development of clinical practice and policy.

Five of the six qualitative studies outlined the limitations of the findings, which included low response rates (Clissett *et al.*, 2013) and small sample sizes (Digby *et al.*, 2011), data not representative of wider populations and queries about generalisation to wider settings e.g. to other people's experiences, other hospital sites and different wards (Bauer *et al.*, 2011; Jurgens *et al.*, 2012; Norman, 2006). Whittamore *et al.* (2014) further identified the fact that carers were not always best positioned to provide a representative account of PWD care, as they only witness a part of a day and previous experiences may also impact on the way they interpret and share their perspectives. Therefore, similarly to other studies (e.g. Bauer *et al.*, 2011) this highlighted ways in which carer bias may impact on findings.



#### **1.6.3.5.7 Summary of the Quality of Research Review**

In sum, not all of the studies consistently met the threshold associated with high quality research, as indicated by the CASP (2013a; 2013b) frameworks. Therefore, the findings reported in the section that follows should be interpreted with caution.

#### **1.6.3.6 Synthesis of Studies**

The themes of the research findings are presented below, in relation to the systematic review objective: consider the existing literature that explores PWD experiences on physical health wards.

##### **1.6.3.6.1 The Experience of Transition**

The studies captured different stages of hospital stays (e.g. inpatient stay vs discharge) through a variety of methods. The findings collectively highlighted how adjustment to transition and change was a theme throughout hospital stays.

Through critical review it emerged that events leading up to hospital admission and the process of admission, lead to a disruption of the care pattern for both the carer and the PWD. This was demonstrated by Clissett *et al.* (2013) who reported that such disruptions, were a consequence of illness (both prior and during admission), admission and change in care pattern,

Carers reported an increased level of challenging behaviour prior to admission, especially when delirium was present, which was difficult for carers to manage (Clissett *et al.*, 2013; Jurgens *et al.*, 2012). It was unclear from the studies how delirium impacted on caregivers coping prior to admission, although Whittamore *et al.* (2014) did report that caregiver strain and poor psychological wellbeing were associated with dissatisfaction with aspects of hospital care.

The process of PWDs' transition from outpatient to inpatient care was reported to exacerbate caregiver stress and distress. Sources of stress included increased travel time (Clissett *et al.*, 2013; Jurgens *et al.*, 2012) and loss of care role (Bloomer *et al.*, 2014). Carers also described admission as

disruptive and recalled negative experiences of waiting in Accident and Emergency settings (Clissett *et al.*, 2013).

In terms of the PWD, Digby *et al.* (2011) found that they experienced a range of distressing emotions in relation to transition to a new ward, including disorientation, loneliness, alienation and bewilderment. PWD also described anxiety and difficulty in adjusting to unfamiliar sounds and spaces (Digby *et al.*, 2011).

#### **1.6.3.6.2 Communication and Staff Interactions**

A number of the studies highlighted how carers' experience of communication with staff varied throughout the PWD hospital stay. Through critical review it was identified that communication was more informative and helpful at the point of admission (Bauer *et al.*, 2011). However, early communication was not always helpful, with caregivers describing their frustration with staff, because conversations were often discharge focused rather than care orientated (Jurgens *et al.*, 2012). Conversely, Bauer *et al.* (2011) found that carers experienced poor communication in relation to discharge planning, with many neither being involved in the process nor provided with a discharge summary. Whittamore *et al.* (2014) found that, overall, a quarter of carers surveyed were dissatisfied with how well they were kept informed and that a third were dissatisfied with discharge arrangements. Thus, based on these findings it could be argued that the timing, consistency, level and the orientation of communication are all important factors in clinical practice, when engaging with a carer.

Bloomer *et al.* (2014) and Bauer *et al.* (2011) found that carers were at times confused about which staff members to talk to in relation to specific aspects of the PWD's care. This led them to respond through repeatedly asking different people questions (Bauer *et al.*, 2011). Carers also struggled to share knowledge about the PWD with professionals because they experienced staff as being resistant to this information (Clissett *et al.*, 2013). Furthermore, carers described being surprised that staff did not actively seek out this information (Bloomer *et al.*, 2014; Jurgens *et al.*, 2012), as they recognised that personal information about the PWD would have improved the quality of

care whilst also making it easier for the nursing staff to deliver care (Brauer *et al.*, 2011). Bloomer *et al.*, (2014) and Clissett *et al.*, (2013) identified that carers are an important facet of PWD care, based on this premise it could be argued that there is a greater need for nurses to recognise the importance of triadic working.

The quality of communication was found to vary with carers, with some describing being ignored by staff (Bauer *et al.*, 2011; Jurgens *et al.*, 2012). Others reported that the nursing staff were patronising (Jurgens *et al.*, 2012), an experience that was also shared by PWD (Digby *et al.*, 2011). Patients who experienced patronising care were less likely to ask for help and were likely to become passive (Digby *et al.*, 2011). Norman reported that PWD would use communication to express their self and their identity on the ward; it was recognised that PWD would use various forms of communication, including passivity, to maintain a sense of power and control whilst in hospital (Norman, 2006). In terms of quality of communication, staff were noted by some carers as lacking in patience with the PWD (Bloomer *et al.*, 2014).

#### **1.6.3.6.3 Power and Control**

Digby *et al.* (2011) described how PWD reported feeling powerless whilst in hospital; this was related to loss of control in relation to decision-making, provision of treatment and care, this sense of lack of control was exacerbated by staff not listening. Digby *et al.* (2011) noted how at these times PWD may become passive, which could be interpreted as aiding coping. As noted above, Norman (2006), however, described passivity, along with other forms of communication, as a method for promoting and expressing identity, whilst also controlling treatment provision.

Changes in the care patterns of PWD, once admitted to hospital, were identified as problematic by carers (Bauer *et al.*, 2011; Clissett *et al.*, 2013). Caregivers reported experiencing a loss of control in relation to decision-making about care (Jurgens *et al.*, 2012); the failure to consult with carers about care decisions, coupled with the environment of the hospital and associated disruption in the care routine, were reported to have contributed to the PWD expressing higher levels of problematic behaviour (Clissett *et al.*,

2013). Furthermore, changes in care pattern were identified as causing caregiver concern about how they would cope at discharge, as they feared that the PWD would lose a sense of routine (Bauer *et al.*, 2011). Clissett *et al.*, (2013) observed that some carers coped with this loss of control through the development of strategies, which included: trying to protect the person with cognitive impairment; evaluating quality of care; and rationalising situations and supporting staff.

#### **1.6.3.6.4 Staff Attitudes and Style of Care Provision**

Carers were found to be dissatisfied when the care provided to PWD was task-orientated rather than person-centred (Jurgens *et al.*, 2012). Norman (2006) found that the style of the delivery of care was based on the staff attitudes and the way staff members construed individuals i.e. 'positive and acceptable patients' vs 'negative and unacceptable.' These judgements were often based on a patient's temperament and nurse experience. Interestingly, temperament was found to be an important factor in the ease with which a PWD settled on a ward (Digby *et al.*, 2011). However, it is unclear from the studies presented whether it was the temperament of the PWD or the staff attitudes towards PWD that led to individuals being more or less settled and affected the subsequent style of care provided.

Of note, Digby *et al.* (2011) found that PWD preferred the idea of wards that had a welcoming schedule, which promoted 'at home-ness.' This could provide an insight into how PWD consider their ward environment. For example, staff experienced the ward as a place to stay, whilst PWD viewed it as a place to explore or leave, as if they perceived it to be a place of home like living (Norman, 2006). These ideas were viewed as inappropriate by staff. Therefore, social constructions of how the ward environment should be used informs nurses concept of ward culture. Those who fail to adhere to these social expectations, might be at risk of being considered as behaving inappropriately by staff, this in turn may impact negatively on relationships between nurses and patients on the ward.

In addition to ward environment, Whittamore *et al.* (2014) found that carers were more satisfied with the overall provision of care on wards where more

staff were trained in person-centred care. These findings supported those of Norman (2006), who reported that nurse's actions were linked with experience and also, knowledge acquired through training.

#### **1.6.3.6.5 Carers Conceptualisation of the Quality of Care and Dissatisfaction**

Norman (2006) highlighted how in a focus group (which was alluded to, but not reported in full, in the study) nurses described the hospital setting as being un-conducive to providing good quality care to PWD; the nurses also highlighted how they lacked sufficient training to provide quality care for PWD. These observations were echoed by carers and PWD across studies, who construed poor quality care as task and 'care-speak' orientated in nature i.e. care which ignored personhood (Clissett *et al.*, 2013; Digby *et al.*, 2011; Norman *et al.*, 2006). Conceptions of poor quality care were also associated with nurses failing to maintain the PWD's hygiene (Jurgens *et al.*, 2012), psychological (Clissett *et al.*, 2013; Jurgens *et al.*, 2012) and physical health (including catheter interventions) (Jurgens *et al.*, 2012).

In contrast, good care was viewed by carers as care which demonstrated warmth, appropriate medical care, safety and reassurance (Clissett *et al.*, 2013; Jurgens *et al.*, 2012). Norman (2006) constructed and distinguished this form of care as involving 'emotional work.' Therefore, it is the manner in which care is delivered, along with the breadth of care (i.e. psychological and physical care) and standards of nursing (e.g. education and hygiene) that inform carer judgments' as to the quality of care being provided.

Carers were found to rationalise the occurrence of poor quality care (Norman, 2006). Clissett *et al.*, (2013) described how rationalisation was a coping response to try to control and cope with the disruption of the hospital admission. Carers tried to justify and explain failures of sufficient standards of care through staff inexperience (Bauer *et al.*, 2011; Jurgens *et al.*, 2012); age (Jurgens *et al.* 2012); poor training (Bauer *et al.*, 2011; Jurgens *et al.*, 2012); declining standards (Bauer *et al.*, 2011); poor communication (Jurgens *et al.*, 2012); ward busyness; systems (Clissett *et al.*, 2013); and the highly technical nature of health care (Bauer *et al.*, 2011). However, justification and

rationalisation did not work as a long-term coping strategy for all carers, with staff in some cases eventually being blamed for poor outcomes and future negative events (Jurgens *et al.*, 2012).

The process of making sense of poor quality care led people to respond in different ways. For example, some provided care to family members to alleviate the stress on nurses (Clissett *et al.*, 2013; Jurgens *et al.*, 2012) or empathised with the nurses (Clissett *et al.*, 2013) while others complained about the quality of care (Clissett *et al.*, 2013). However, those who tried to remedy deficits in care were sometimes prevented by staff without explanation as to why (Jurgens *et al.*, 2012). In contrast, those who were able to provide care reported that they did not always feel valued by staff, leaving carers feeling frustrated (Bloomer *et al.*, 2014). It is of note, however, that not all carers wanted to continue to provide emotional and physical care for the PWD, whilst in hospital (Jurgens *et al.*, 2012).

Furthermore, the focus of caregiver concern and dissatisfaction changed throughout the PWD stay. However, events which carers described as dissatisfying were reported to occur early in the admission process (Jurgens *et al.*, 2014). Initial concerns were: PWD symptoms; early discharge; frequency of bed moves; and lack of communication (Jurgens *et al.*, 2014). As the length of the hospital stay progressed, carers became concerned with the delivery of care, appropriateness of interventions and deterioration of health of the PWD (Jurgens *et al.*, 2014). There was also concern that there were not appropriate systems in place to manage challenging behaviour (Jurgens *et al.*, 2014).

Caregivers' dissatisfaction, however, was found to be associated with contextual factors at admission, such as: the PWD's symptoms, the PWD's behavioural and psychological wellbeing and presence of delirium and also the carer's own psychological wellbeing, levels of caregiver strain and relationship with the PWD (Whittamore *et al.*, 2014). These findings suggest that caregiver satisfaction may not be based on actual quality of care, but instead on perceived quality of care in the context of compounding variables (e.g. as identified by Whittamore *et al.*, 2014) and as constructed

retrospectively for specific audiences e.g. an interviewer (Jurgens *et al.*, 2012).

Finally, Jurgens *et al.* (2012) described how, when families felt concerned about the quality of care and loss of control, they became enmeshed in a cycle of discontent and dissatisfaction.

#### **1.6.3.6.6 Interaction Between Expectations and Experience**

The experience of the quality of care was associated with expectations, where carers judged care based on previous experiences, regardless of setting e.g. home care nursing (Jurgens *et al.*, 2012). These other experiences sometimes set a precedent for what was considered good care e.g. personalised style of care. These previous experiences not only impacted on the way carers viewed the care, but also affected their help seeking behaviours. For example, some carers delayed admitting family members to hospital because, based on previous experience, they thought it was more damaging than the illness itself (Jurgens *et al.*, 2012). Furthermore, previous knowledge made carers more aware of how certain aspects of care would make providing care more difficult in terms of caring for the PWD on discharge (Bauer *et al.*, 2011).

However, none of the studies reflected how previous experience of care impacted on the PWD's own expectations, hopes, fears and attitudes towards care.

#### **1.6.3.6.7 PWD and Carer Affect**

PWD described how family members were a 'great consolation'; carers' worry and attentiveness was perceived as comforting (Digby *et al.*, 2011). Carers were reported as often taking the role of advocacy, especially with regard to decision-making (Digby *et al.*, 2011) and care provision (Clissett *et al.*, 2013). This was also accompanied with the recognition that carers require a high level of support too. Carers' welfare and satisfaction was considered important for a number of reasons, including better outcomes for patients (Bloomer *et al.*, 2014).

However, overall, hospital stays appeared to be associated with emotional distress for both the PWD and their carers. PWD reported how transition was accompanied by distress, bewilderment, confusion, loneliness and anxiety (Digby *et al.*, 2011). Both carers and PWD reported feeling disempowered by the system (Bloomer *et al.*, 2014; Digby *et al.*, 2011). Carers described experiencing a range of strong emotions towards care providers at different points during the PWD hospital stay. Some described feeling angry, frustrated and disappointed with regard to deficits in staff knowledge and skill (Bauer *et al.*, 2011). Breakdown in communication was also a source of dissatisfaction and annoyance (Bauer *et al.*, 2011; Whittamore *et al.*, 2011). These ruptures in relationships with nursing staff left the carer feeling devalued, uninvolved and unsupported (Bauer *et al.*, 2011; Bloomer *et al.*, 2014). Carers who were not recognised for providing care for the PWD on the ward felt devalued, which contributed to the experience of tense and difficult relationships (Bauer *et al.*, 2011).

Bauer *et al.* (2011) found that family carers experienced a range of emotions, specifically in relation to the discharge process. These were associated with adapting to PWD needs on discharge (Jurgens *et al.*, 2012) and discharge to a place other than the one from which the PWD had been admitted (Bloomer *et al.*, 2014). Some carers also struggled with the pressures of the responsibility of having to make decisions about discharge to environments from which they were admitted (Bloomer *et al.*, 2014). Other carers reported how early discharge made them feel angry, an emotion which was at times accompanied with personal blame and a sense of injustice in the context of end of life care (Jurgens *et al.*, 2012).

Furthermore, it was found that PWD also expressed anxiety for the future, with people expressing awareness and concern about reduced ability leading to a new home environment, something which PWD found unsettling (Digby *et al.*, 2011).



#### **1.6.3.6.8 Recommendations for Practice**

All of the papers identified areas that, based on the research undertaken, could be improved. Through critical review it was identified that communication and transparent triadic partnership working was of value (Clissett *et al.*, 2013; Jurgens *et al.*, 2012). It was argued that employing triadic working would promote the recognition of the caregiver being a source of expertise (Clissett *et al.*, 2013), whilst also meeting the carers' needs (Bloomer *et al.*, 2014). Whittamore *et al.* (2014) suggested that this could be achieved through simple interventions, such as the availability of a PWD biography, involving family meetings and routine engagement with relevant and appropriate stakeholders. Based on this premise it could be assumed that system changes such as these would improve caregiver satisfaction with clinical practice (Jurgens *et al.*, 2012; Whittamore *et al.* 2014).

Furthermore, through critical review it was identified that a number of system changes could address issues in relation to pre-admission, planning discharge, discharge and post-discharge care regimes (e.g. Bauer, 2011). Along with wider system changes, Norman (2006) recommended a need for change in staff culture and attitude, with staff being supported to 'realise' rather than 'constrain' PWD, this could be argued to, therefore, promote the PWDs' sense of self and the recognition of the person as a whole. This could be achieved through changing staff culture and attitude through education would improve the care of PWD, along with addressing issues in relation to matters of orientation (Digby *et al.*, 2011). Failure to do so might contribute to difficulties in settling and also increased length of hospital stay.

#### **1.6.3.6.9 Implications for Future Research**

Through critical review it was identified that, regardless of the research context, there were many gaps in the literature with regard to understanding the experiences of both PWD and their carers. For example, five of the seven studies explicitly identified future areas of research including; adapting current nursing, family care and intervention models to fit with the needs of acute settings, including transitions e.g. discharge in the context of carers' expectations and austerity (Bauer *et al.*, 2011; Jurgens *et al.*, 2012;

Whittamore *et al.*, 2014) and; identifying aspects of care that need attention to improve carer satisfaction (Jurgens *et al.*, 2012).

In addition, through critical review, it has been identified that future research should aim to further develop our understandings of effective communication, interventions and systems to improve care for PWD and to empower their carers and relieve carer stress (e.g. Bauer *et al.*, 2011; Jurgens *et al.*, 2012; Whittamore *et al.*, 2014). It also emerged that research should seek to develop our awareness of PWDs' own definition of emotions in relation to constraint and realisation (Norman, 2006). Finally, it was noted that current research fails to significantly consider how care roles and care settings are constructed (Norman, 2006), thus future research should seek to explore the impact of social construction on care provision e.g. nurse attitudes and culture and physical construction to aid orientation (Digby *et al.*, 2011).

#### **1.6.3.6.10 Limitations**

The process of critical review led the author to identify a number of limitations of the studies presented here. For example, a number of the studies can not be generalised to other settings due to small sample sizes (Bauer *et al.*, 2011; Clissett *et al.*, 2013; Digby *et al.*, 2011; Jurgens *et al.*, 2012; Norman, 2006) and the use of site specific populations (w.g. Whittamore *et al.*, 2014).

Furthermore, the methodologies employed by the researchers meant that the data may have be biased due to i) social desirability factors (e.g. Whittamore *et al.*, 2014); ii) the PWD being present at a time of interview with carer (e.g. Whittamore *et al.*, 2014); iii) elite bias (e.g. Bauer *et al.*, 2011); iv) specific aspects of care or stay being focused on i.e. discharge, in-patient stay or transfer (e.g. Bauer *et al.*, 2011; Digby *et al.*, 2011; Norman, 2006).; and also through v) focusing on the interactional relationship rather than on the wider context (e.g. Norman, 2006) and on the subjective interpretation of experience (e.g. Clissett *et al.*, 2013).

#### **1.6.3.6.11 Summary of Systematic Review Synthesis**

The critical review and synthesis of findings, led the author to identify that PWD and carer experiences appeared to be linked to perceptions of the

quality of care observed to be provided to both parties. These were marked by; stages e.g. transitions and changes in patterns of care (Bloomer *et al.*, 2014; Clissett *et al.*, 2013; Jurgens *et al.*, 2012; Whittamore *et al.*, 2014); prior experience and carer stress levels at time of PWD admission (Whittamore *et al.*, 2014); and interactions and relationships with professionals and responses to the hospital stay as a whole and the events which occurred during the stay. Therefore, it was identified that the way in which the ward environment and culture was experienced by carers and PWD interacted with their sense of control and their emotional response. Some caregivers and PWD tried to regain control through communication and justifying the quality of care they observed (Digby *et al.*, 2011; Clissett *et al.*, 2013; Norman, 2006).

However, as already noted, the quality control framework highlighted how all of the studies had a number of shortcomings, some of which are addressed in Section 1.6.3.6.10. Findings should therefore be interpreted with caution and future research should aim to address these concerns in relation to the quality shortcomings, that have been identified in this review.

## **1.7 Study Rationale and Aims**

As already noted, dementia is a growing phenomenon and a large percentage of those with dementia come into contact with acute medical care settings. However, little is understood of the subjective experience of hospital admission. Research to date has largely focused on the carers' own experiences (Aggarwal *et al.*, 2003; Bauer *et al.*, 2011; Bloomer *et al.*, 2014; Clissett *et al.*, 2013; Jurgens *et al.*, 2012; Whittamore *et al.*, 2014) or the staff's experience of supporting those with dementia (e.g. Noolan, 2006).

In the context of the current climate, service user led research is becoming recognized as a necessary component of service development (Godfrey, 2013). However, there are many ethical and practical challenges in accessing PWD due to issues of capacity, consent and memory recall (see section 1.5). Therefore, through interviewing carers, the study will seek to understand the experience of PWD and hospital stays for physical health conditions. Thus, the data presented will reflect the carer's perspective and conceptualization of

the PWDs experience, rather than provide a first hand account of the PWDs lived experience. It is anticipated that through talking with carer's about their understanding of the PWD's experiences of their hospital stay, that the findings will contribute to our understanding of this population's experience of acute settings and thus contribute to a limited evidence base to consider how services can be tailored to improve care.

## **Chapter 2**

### **Methodology and Method**

#### **2. Overview of Chapter**

The chapter introduces the design of the study, the aim of which is to understand people with dementia's (PWD's) experience of staying in hospital for physical health conditions. A qualitative methodology, using constructivist grounded theory, was employed to analyse semi-structured interviews. The interviews were undertaken with carers of PWD, who had been, or were currently, in hospital for a physical health condition. Carers from England and Wales were recruited to the study through two third sector agencies, Social Services and word of mouth. An overview of the rationale for adopting a qualitative approach is provided, along with an account of the researcher's theoretical and professional stance. Procedures in relation to issues of ethics and governance and methodological process undertaken during data collection and analysis are considered.

#### **2.1 Qualitative Methodology**

##### **2.1.1 Philosophy**

Qualitative research methods encompass a broad range of philosophical assumptions, epistemological positions, methods and approaches (Denzin and Lincoln, 2011; Lyons, 2007; Ormston, Spencer, Barnard *et al.*, 2013). However, despite the diversity of qualitative methodologies, a number of authors have attempted to draw parallels between the various approaches. For example Barker, Pistrang and Elliot (2002) suggest that qualitative methods, on the whole, reject positivism, a paradigm which is positioned in objectivity and established truths, systematic approaches and utilizes unitary

methods, whilst minimizing the qualities of human experience (Charmaz, 2014; Gray, 2014). Although, GT does have positivism influences with systematic approaches being explicit in the method i.e. the process of coding (Charmaz, 2014).

GT methods are preoccupied with exploring context specific phenomenon, and also are naturalistic and interpretative in their nature (Ormston *et al.*, 2013). That is not to say, however, *any* process of interpretation is acceptable; interpretation of phenomena must be seen to demonstrate rigour, quality and usefulness, thus contributing to 'meaning-making' (Lyons, 2007; see Section 2.3). Awareness and understanding of the methodology employed is important, because it acts as the conduit between the method and the researcher's epistemological and ontological stance i.e. philosophical position (Nagy-Hesse-Biber and Lewy, 2011). The flexibility of the researcher's philosophic position is considered significant, because it impacts on openness to modify methodology, something, which can require revision throughout the research process, for example adjusting the study dimensions to capture the emerging data (Nagy-Hesse-Biber and Lewy, 2011). The flexibility and fluidity of a researcher, also links to reflexivity (see Section 2.2.4).

### **2.1.2 Rationale for Qualitative Methodology**

The decision to employ qualitative or quantitative research methods depends on the nature of the research question. For example, qualitative methods lend themselves to discovery-orientated frameworks, where the focus is to present a representation of an understanding of human experience and actions (Barker *et al.*, 2002; Elliot, Fischer and Rennie, 1999). In contrast, quantitative methods are suited to questions investigating causal relationships between variables (Barker *et al.*, 2002; Charmaz, 2014). Therefore, as the study presented here aimed to understand the experience of hospital stays for PWD, as told by a significant informal carer, a qualitative approach was considered appropriate.

## 2.2 Constructive Grounded Theory

### 2.2.1 An Overview of the Approach

Constructivist Grounded Theory (CGT) is influenced by traditions of grounded theory (GT) and holds a relativist epistemological position. CGT acknowledges that the researcher's own history and orientation contributes to their subjective interpretations of multiple realities, rather than discovering a truth, which is co-constructed with the participant (Charmaz, 2009; Wertz, Charmaz, McMullen *et al.*, 2011). It is acknowledged within CGT, therefore, that construction is produced in a number of ways:

1. The participant's construction of their reality, which informs the data;
2. The researcher's construction of their own reality, which influences the research;
3. Co-construction of multiple realities, which leads to the construction of interpretation i.e. results and findings (Higginbottom and Laurdisen, 2014).

Within this context, Charmaz (2009) suggests, it is the researcher's job to learn and understand how the participant constructs their world, and with this awareness, further interpret their reality. CG theorists contend that one way to do this is through the researcher immersing themselves in the data (Charmaz, 2014).

CG theorists draw on a number of *tools* to contribute to the process of constructing a GT. The tools give meaning and action to the data, whilst also reflecting the overall narrative of the participant(s) (Mills, Bonner and France, 2006; Charmaz, 2014). These tools include writing memos of emerging ideas and codes throughout the research process; these memos can act to add context and description to emerging categories, contributing to the researcher's cognitive capacity to reflect and make links between codes (Charmaz, 2014).

In addition, coding is a strategy that enables the researcher to 'interrogate, sort and synthesize ... interviews' (Charmaz, 2014, p.13). This process facilitates the examination of the data to further understand people's

reactions, beliefs in relation to experience and how the actions and attributed meanings develop. Therefore, the interactive and iterative process of coding acts as the link between data and theory. Codes are therefore 'transitional objects' that enable the researcher to understand the meaning within the data (Star, 2007).

There are two types of coding: *initial* and *focused coding*, which together contribute to *theoretical sensitivity*, enabling CGTs to 'understand and define phenomena in abstract terms ... [and] demonstrate abstract relationships between studied phenomena ... [enabling the theorist to] discern meanings in their emergent patterns and define the distinctive properties of their constructed categories concerning these patterns' (Charmaz, 2014, p.161). This process is illustrated through *theoretical sampling*, supported by *memo-writing* and facilitates the exploration of emerging categories. In the case of interview research, this is achieved through introducing new questions to aid the development of and distinguishing between categories (Charmaz, 2014), thus supporting the development of theory (Strauss and Corbin, 1998). These tools and strategies are discussed in Section 2.9.2.

### **2.2.2 Rationale for Using Constructivist Grounded Theory**

CGT was considered the most suitable approach for this study as it 'offers an interpretive portrayal of the studied world' (Charmaz, 2014, p.17) and also adds flexibility to the research process (Charmaz, 2014). The approach facilitates the acknowledgment of how reality is constructed and co-constructed in the context of past experiences, beliefs, social structures and discourse (Charmaz, 2009; Charmaz, 2014; Higginbottom and Laurdisen, 2014). These combined qualities of CGT were considered well suited to the phenomena under investigation.

In sum, CGT was identified as a suitable methodology to contribute to the development of theory, as it was thought to provide a transparent reflection of the constructed experience of the participant (and the person for whom they care), and the interaction between the participant and the researcher (Charmaz, 2006).



## 2.3 Ensuring Quality in Qualitative Research

The terms '*reliability*' and '*validity*' have developed from quantitative research. However, the translation of these concepts into qualitative research has produced much debate, with many challenging the reliability and validity of its methods (Mays and Pope, 2000; Morse, Barrett, Mayan *et al.*, 2002). Attempts to articulate the notion of '*quality*' have been associated with various quality frameworks e.g. 'trustworthiness' (Lincoln and Guba, 1985); 'interpretive accounts' (Packer and Addison, 1989); and 'standards of good practice' and 'standards of validity' (Stiles 1993). Furthermore, in recent years, guidelines have been developed to enhance methodological rigour (e.g. Elliot *et al.*, 1999; Henwood and Pidgeon, 1992; Mays and Pope, 2000; Pearson, Jordan, Lockwood *et al.*, 2014; Goldberg and Allen, 2015). These guidelines are considered to aid the assessment and enhancement of the work being communicated (Elliot *et al.*, 1999; Tracey, 2010). Based on this premise, guidelines were identified to enhance the quality and legitimacy of the qualitative research presented here.

Elliot *et al.* (1999) formulated a non-prescriptive model for assessing the quality of qualitative research. This model of quality assurance was selected over other models due to its consideration of a breadth of issues that are specific to qualitative research. The guidelines are described below in relation to how each point was addressed in the study presented here.

1. *Owning one's perspective*: Researchers are advised to explicitly identify their theoretical position and assumptions, both prior to the study and throughout the research process. In doing so, the researcher enables the reader to understand the context in which the findings emerged, allowing the reader to consider alternative interpretations to the one(s) presented. In this study, this is achieved through; identifying the theoretical stance adopted (see Section 2.4.2); outlining the personal and professional position, which conceptualises the researcher's own beliefs prior to the study (see Section 2.4.2); and through recording of emerging and developing beliefs in a research diary as the study progresses (see appendix 2.1).

2. *Situating the sample*: Descriptive statistics orientate the reader to the investigated population. In this study, it was not the carer per se who was the focus; instead it was the service user who had been hospitalised. Therefore, data was collected verbally from carers, identifying age, culture and place of residence e.g. home, care home etc. of the PWD and also the nature of their relationship e.g. spouse etc. (see Section 2.5).
3. *Grounding in examples*: Quotes provide a context to the researcher's interpretations and also support and illustrate the emerging themes. In this thesis, themes are supported by quotes from the interviews (see Chapter 3).
4. *Providing credibility checks*: Credibility of findings can be checked by: verifying emerging findings and interpretations with participants; utilizing other qualitative analysts to review findings, checking for errors and discrepancies; comparison with other qualitative perspectives; and employing the method of triangulation, whereby the researcher triangulates data from other sources. In the case of this study this was facilitated through conversations with supervisors and also, with two other trainee colleagues (see Section 2.7.1).
5. *Coherence*: The concept highlights the importance of presenting data in a coherent manner, which is sensitive to the subtle nuance between and within the data. In this thesis, coherence was demonstrated through the presentation of a narrative supported by relevant diagrams, tables and figures (see Chapter 3).
6. *Accomplishing general vs. special research tasks*: Within the quality framework, the researcher is required to identify the remit of the findings; that is, highlighting the extent to which the findings can be generalised to different contexts and populations. For example, it is the researcher's duty to outline findings as a *general* or a *specific* interpretation of the phenomena under investigation. In both circumstances, the researcher should endeavour to identify the limitations of the approach and caution against the interpretation of the data in other contexts, where appropriate.

In the case of the research presented here, the limitations are considered in Chapter 4.

7. *Resonating with readers*: According to the framework, the data presented should aim to resonate with the reader, bringing the interviewee's experience to life, through authenticity in the language used by the participants, rather than driven by complex jargon. The findings presented should also be written in a way that supports the reader's existing knowledge, whilst expanding their understanding of the phenomena. In the context of this thesis, this was achieved through both the academic and clinical supervisor reading chapters. Furthermore, the structure of the thesis provides a structure for the reader to gauge the theoretical resonance.

Further to the framework outlined above, Pearson *et al.* (2015) highlight the importance of ethical approval by an appropriate body (see Section 2.6); this aspect of the process of quality assurance begins at the earliest stage of research.

## **2.4 Personal and Professional Reflexivity**

### **2.4.1 Reflexivity**

The process of reflexivity promotes transparency and co-construction and thus acts as a conduit between the participant(s) and the researcher (Charmaz, 2014; Allen, 2015). Reflexivity is a method, which facilitates the communication of the research experience, both illustrating and tracking how decisions are made and interpretations arise. It offers the reader an understanding of what brings the researcher to a phenomenon and how presumptions interact with the inquiry (Charmaz, 2014). The process of reflexivity therefore, can be said to facilitate the acknowledgment and ownership of philosophical positioning, revealing the researcher's orientation and relationship to methodology and the phenomenon under investigation (Lingard, 2014; Nagy-Hesse-Biber and Lewy, 2011). (See Section 2.4.2 for a discussion of the researcher's position).

Reflexivity is pertinent to GT, as theorists argue it is not possible to 'bracket' ones presuppositions in their entirety, as is sometimes claimed for other methodologies. Instead, informed by a pragmatist philosophical tradition, grounded theorists acknowledge that data is co-produced through a dynamic process, which is central to three phases of the research process: preparation, post-analysis and feeding back (Ahern, 1999).

The process of reflexivity can be captured in a research diary and through other mechanisms associated with the approaches method (see appendix 2.1). This is understood to be an important feature for the preparation stage, demonstrating the researcher's ongoing awareness of self (Ahern, 1999). Elliot *et al.* (1999) emphasize the importance of the researcher sharing their own values, beliefs, interests and assumptions and also position (i.e. interests, theoretical alignment and experiences). This enhances transparency and illuminates the awareness of professional and personal bias of both the researcher and the gatekeeper i.e. the person/organisation who facilitates access to the participant(s) (Ahern, 1999). Within the context of this study, both third sector organisations and clinical supervisor acted as gatekeepers.

The preparation phase of reflexivity, according to Ahern (1999), highlights how problems with data collection may be indicative of methodological problems, which may therefore require a revision of the approach employed. The researcher who worked on this study utilised regular supervision, reflexive conversations with colleagues and a research diary in order to ease, aid and monitor the process of preparation. The awareness and use of the reflexive processes aided decision-making within this study, for example in relation to the revision of inclusion and exclusion criteria.

With regards to the post-analysis i.e. writing phase of the study, the GT researcher is directed to use careful inquiry with self-awareness, to attend to the balance of information presented (Ahern, 1999). Supervision was used within this study to reduce the risk of bias emerging. This process was further supported by the methodology employed, because the GT method directs the researcher to make memos i.e. research diary (appendix 2.1), to act as a

running record of the researcher's changing ideas and beliefs (Ahern, 1999; Payne, 2007). The purpose of this exercise is to facilitate self-awareness, thus freeing the researcher to engage extensively with the raw data (Glasser, 1998; Tufford and Newman, 2010).

However, the risk of bias is not limited to the interpretation of data. Bias can also affect the literature review. This can be managed through undertaking a systematic review (British Medical Journal, 1994) (see Chapter 1). Bias can also be addressed through the post-analysis phase, whereby researchers work with colleagues to examine the data (Ahern, 1999). In this respect bias within this study was monitored through examining coding with supervisors and consulting with other trainees, who were considered neutral to the study i.e. had no direct involvement. However, it was acknowledged that despite apparent neutrality, those who examined the data may also have been affected by some bias.

#### **2.4.2 Researcher's Position**

The researcher positioned herself as a 30 year old, white British female who, although identifying herself as English, had lived in South Wales for eight years. She is in her third year of Clinical Psychology Doctorate training and lives in England.

During the writing of the thesis the researcher was a trainee clinical psychologist in a service for looked after children. Previously she had completed core placements, including working with older adults and carers of PWD (including young carers of people with early onset dementia). During her training the researcher took a break from employment and worked with adults across the life span in a domiciliary care role. The care role inspired the researcher's interest in working with those with dementia. The researcher was in the position of observing and supporting the day-to-day living of people (and their families) with significant memory problems and co-morbid physical health difficulties. This interim role may have influenced the researcher's understanding and curiosity in exploring the experience of hospital i.e. greater curiosity about different aspects of personal care. This may have been further influenced by the researcher's personal experience of one of her parents

having frequent and regular hospital stays (non-dementia related) during the writing of the thesis. Her experience may have added to over identification with certain hospital experiences, as described by the carers who were recruited to the study.

Furthermore, prior to training the researcher had worked as a Health Care Assistant on an acute psychiatric ward and had, therefore, some working experience of non-physical health wards. Here she developed a familiarity with the short-hand and medical language used on wards and also with the processes of sudden admission and discharge in an English context and mental health context. It is acknowledged that this role influenced her awareness of how ward environments can be experienced by both workers and service users.

With regards to epistemological positioning, the researcher situated herself in a social constructionist paradigm, understanding meaning to be co-constructed between individuals. In addition to this, the researcher recognized that through the course of training, biopsychosocial and systemic models strongly influenced her thinking.

## **2.5 Design**

### **2.5.1 Overview**

Constructivist grounded theory, a qualitative method, was employed to explore the experience of a PWD being in hospital for a physical health problem. The experience under investigation was that of the patient, as told by the carer. The study was advertised through third sector organizations and word of mouth. Using semi-structured interviews, conducted by the author, data were collected from 8 carers.

Participation in the research project involved a one-off semi-structured interview, which explored a number of areas of the experience of being in hospital (appendix 2.2 for semi-structured interview and revised questions, see below for explanation). The process of semi-structured interview meant participants contributed to the process of *meaning-making*, through co-creation of experience with the interviewer (DiCicco, Bloom and Crabtree,

2006). The inductive nature of CGT meant that co-creation of experience emerged across interviews, i.e. questions evolved between interviews, as new areas for potential exploration with the next participant emerged. The interviews were recorded using a Dictaphone and then transcribed. The data were then analyzed using CGT (see Section 2.2.1).

## **2.5.2 Context**

The research was conducted across England and Wales. Participants were recruited through word of mouth, third sector organizations (the Alzheimer's Society and The Lewy Body Society) and South Wales Social Services. The author interviewed participants at times convenient to both parties, either in their home, place of work or by telephone, depending on the participant's preference and geographical area. Where interviews were conducted in participants' homes, necessary precautions were taken (see appendix 2.3 for risk assessment).

## **2.6 Research Governance**

### **2.6.1 Ethics and Risk Assessment**

The Cardiff University School of Psychology Research Ethics Committee approved the study (date 22/09/2014; reference no: EC.14.09.09.3844R; see appendix 2.4), ensuring that the project conformed to good practice in terms of respect, competence, responsibility and integrity, as outlined by the British Psychology Society Code of Ethics and Conduct (2006). Due to difficulties in recruiting participants to the study, the inclusion criteria were revised and approval for this was granted in January 2015 (date: 7/01/2015; see appendix 2.5).

The project was also submitted to and approved, on both occasions, by the Alzheimer's Society Research with Service Users pathway, allowing the researcher to recruit participants through the Society from a number of carer groups and service activities in both England and Wales.

## 2.6.2 Inclusion and Exclusion Criteria

Carers were invited to take part in the study. Within the context of the research presented here, the term carer was defined using Clause 10 (3) of the Care Act (2014) which states people are considered carers if they are ‘an adult who provides or intends to provide care for another adult (an “adult needing care”)’ (p.10, HM Government, 2014). This broad legal definition accounts for unpaid people who care, look after or support a friend, relative or neighbour who due to their dementia, can not manage without their help (DirectGov, 2011).

As already noted, due to problems with recruiting participants to the study, the inclusion criteria were revised (Table 2.1); a process consistent with CGT (see Ahern, 1999 in Section 2.4.1).

Table 2.1 Revised Study Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
<p>The person being cared for has a diagnosis of a dementia or a significant memory difficulty.</p> <p>The person for whom the carer cares must have been in hospital for a physical health difficulty/condition.</p> <p>The admission must have been in the last 18 months (including current admissions).</p> <p>The admission must have been for at least one day.</p> <p>Participants are to be 18 years of age or older.</p>	<p>The cared for person being admitted to a ward for mental health difficulties.</p>



Individuals were considered eligible to participate in the study, if they were a carer (as defined above) and if they met the inclusion criteria, outlined in the table above.

### **2.6.3 Consent, Confidentiality and Debriefing**

All participants were provided with an information sheet (see appendix 2.6), detailing: an overview of the study; inclusion criteria; what participation involved; information on withdrawing; confidentiality; intention to publish results; and contact details of both the researcher and academic supervisor. The sheet enabled the participant to make an informed decision as to whether or not to take part. Participants were then asked to read and, if happy, to sign a consent form (see appendix 2.7) to confirm that they were willing to take part in the study.

On completion of the interview, participants were given a debrief sheet (see appendix 2.8) which provided information detailing information of relevant third sector organizations e.g. dementia and carer specific charities.

To protect the confidentiality and identity of those taking part in the study, the people for whom they care and the hospitals to which the PWD were admitted, identifiable information i.e. names of hospitals and people, were omitted and/or altered in the final transcription. In addition, pseudonyms chosen by a person naive to the study were assigned at random to participants (see Table 8, Section 2.5.5). Audio data was kept securely, as were the transcripts.

## **2.7 Participant Information**

### **2.7.1 Sample**

The sample consisted of carers from across England and South Wales who all described themselves as significant carers and had been involved with the PWD's care before, during and after the PWD's hospital admission. Carers were either adult children or spouses. A total of 8 participants were recruited to take part in a semi-structured interview.

## **2.7.2 Description of the Participants**

The demographic information relating to the participants is presented in Table 2.2. The Table details the relationship of the carer to the PWD and also specific information about the PWD including their age, ethnicity and hospital status at the time of the interview i.e. admitted or discharged and where, the PWD was discharged too.

Furthermore, using carer report, severity of dementia was estimated and determined using the Clinical Dementia Rating (CDR) grid (Morris, 1993) (see Table 2.2). The CDR consists of a number of measures to help clinicians determine the severity of dementia; however, in the absence of utilising the measures with the PWD, the descriptive summary, which provides a conceptual narrative of the stage of dementia, was employed. The decision as to the stage of the PWD's dementia was determined through interview descriptions of the PWD and decided in consultation with the Clinical Supervisor (a Clinical Psychologist, who specialises in working with older adults). It is however, recognised that the stages are descriptors rather than diagnosis of the stage of illness; thus CDR scores, should be used to orientate the reader to the nature of the PWD's difficulties, rather than as a formal clinical diagnosis.

In terms of hospital stays, these varied in length, with some cares describing repeated admissions in the last 18 months. Length of hospital admissions varied from four days, to three months in duration; the frequency of repeated admissions are discussed in the context of the findings in the chapter that follows.

## **2.8 Procedure**

### **2.8.1 Recruitment Procedure**

Initially, participants were recruited through the Alzheimer's Society alone. However, due to difficulties with recruitment, the parameters of the study were revised (see Section 2.6.2); this was done in consultation with both academic and clinical supervisors. The revision enabled the researcher to approach a

Table 2.2 Carer and PWD Demographics

Participant Pseudo-nym	PWD's Pseudo-nym	Interview Format	Carer Relationship to PWD	PWD Demographics				Hospital Status at Time of Interview		Last Discharge Location
				Age	Gender	Ethnicity	Stage of Dementia (CDR)	Inpatient	Discharged	
Andrea	Anita	Face-to-face.	Daughter	83	Female	White British	Mild	x		N/A.
Boris	Bernice	Face-to-face.	Husband	62	Female	White British	Severe		x	Nursing Home.
Clive	Chrissie	Face-to-face.	Husband	63	Female	White British	Severe		x	New Nursing Home.
Diana	Debra	Telephone interview.	Daughter	90	Female	Polish	Severe		x	Home.
Edward	Eve	Face-to-face.	Son	89	Female	White British	Moderate		x	Nursing Home.
Fredrick	Francis	Face-to-face.	Husband	69	Female	White British	Severe		x	Nursing Home.
George	Gina	Face-to-face.	Husband	65	Female	White British	Severe		x	Nursing Home.
Hugh	Harold	Face-to-face.	Son	86	Male	White British	Moderate		x	Nursing Home.

number of third sector organizations, care organizations and Local Authorities, and to employ a snowball strategy to recruit participants to the study.

Based on the revised recruitment parameters, the Lewy Body Society advertised the study on a social media platform (Facebook) and also on their website. In addition, Social Services in South Wales identified potential participants through their working experience of their client group, through which one person was recruited. The broad recruitment process outlined above led to 11 people expressing interest in participating in the study, of whom 8 participated. Reasons for deciding not to take part were associated with not meeting study criteria and significant life events preventing availability to participate.

### **2.8.2 Construction of the Interview Schedule**

A semi-structured interview framework was used, to capture caregiver accounts of the PWD's experience of hospital stays. The semi-structured interview schedule provides a guide for the researcher, whilst freeing them to enquire about areas of interest (Smith and Eatough, 2007). The flexibility in the interview schedule allows the researcher to be led by the participant; thus reducing risk of interviewers pursuing their own agenda (Pope, Van Royen and Baker, 2002). Furthermore, the process of the semi-structured interview enables the participant to guide and shape the interview, promoting the participant's sense of agency in the way the story is co-constructed with the interviewer (Smith and Eatough, 2007). This approach to interviewing allows the researcher to revise questions in the interview so that key points to the interviewee are addressed and explored.

Prior to the interview the researcher explored the nature of the relationship between the carer and the person with dementia i.e. gaining relevant informational background to the study (Charmaz, 2014). The semi-structured questions were constructed in consultation with both academic and clinical supervisors (see appendix 2.2 for interview schedule and schedules that subsequently developed through the interview process).

Overall, the questions were structured chronologically with a timeline spanning pre-hospital admission to discharge. Intermediate questions were developed within this framework, allowing the researcher to better understand the participant's views and experience. The interview concluded using tapering, a method outlined by Charmaz's (2014), focusing on the interviewee's overall reflections. In line with the inductive nature of CGT, following each interview questions were revised in consultation with supervisors, to facilitate emerging themes (Charmaz, 2014).

### **2.8.3 Interview Procedure**

Prior to the recording of the interview, the participants were provided with the information sheet (appendix 2.6) and a verbal explanation of the aims were discussed, along with key points including confidentiality and anonymity. Participants were asked to sign a consent form, the person who was interviewed by telephone provided the forms via email.

Prior to the interview being recorded, the interviewer spoke with the participants to put them at ease and reduce sense of power imbalance, so that the participant felt able to tell their story freely. The interviews ranged between 38 minutes and 84 minutes, with an average time of 58 minutes. A majority of the interviews were conducted in the participant's home, but one participant was interviewed via the telephone. It is of note that on one occasion a PWD was present at the time of interview; the PWD actively contributed towards the interview. The Cardiff School of Psychology Research Ethics Committee ruled that due to ethical constraints the PWD contribution could not be analyzed although permission was given to analyze the carer's contribution.

Out of courtesy, the interviewees were informed that the researcher would be guided by an interview schedule. The interviewer utilized skills developed through clinical training, and similarly to Charmaz and Belgrave (2012), drew on Rogerian (1951) approaches rooted in non-directive client-centred therapy. The researcher therefore acknowledged and drew upon the concerns and words of the participant to inform the questioning. It was anticipated that this approach would aid alignment between interviewer and interviewee,

enhancing both the richness and authenticity of the data collected (Coyle and Wright, 1996).

The interviewer maintained an awareness of the potential tension and blurring of the dual interviewer/researcher and trainee clinician roles. Literature suggests clinical psychologists are vulnerable to unwittingly using therapeutic skills to elicit information, over and above the agreed researcher-researched contract (Thompson and Russo, 2012). In line with Yanos and Ziedonis's (2006) recommendations, the interviewer utilized supervision opportunities to reduce this risk.

#### **2.8.4 Data Recording and Management**

The interviews were recorded using a digital Dictaphone and then transcribed verbatim by the researcher or a third party. The researcher listened to the audio and read the transcription, checking for accuracy whilst also removing/altering identifiable information, including names and details of third parties i.e. hospital names, nurses, doctors and family members.

### **2.9 Analysis of Data**

As already noted, writing a reflective and methodological journal is a process central to both GT and CGT (Charmaz, 2014); within this study a diary was maintained to record both decisions and dilemmas. The reflective component of the diary was written after each interview and acted as a running record of emerging themes, observations and ideas concerning future avenues of investigation with following participants. These reflections and observations were shared and discussed with the clinical and academic supervisors. The diary also contributed to quality assurance (Elliot *et al.*, 1999; see section 2.3).

#### **2.9.1 Analysis of Interview Data**

Analysis began with the researcher listening to each interview immediately after it had been completed and using a research diary to make notes of emergent themes. Particular attention was paid to the meaning participants conveyed i.e. the meaning (or possible meaning) they ascribed to the PWDs experience. These initial ideas were used to inform the interviews that followed, in line with CGT methodology (Charmaz, 2014).

The researcher immersed herself in the data by reading each transcript a number of times. This enabled her to sense an overall picture of the data (Barker, Pistrang and Elliot, 2002). The data was analysed by hand, this decision being influenced by literature suggesting that computer aided software can constrain analysis and contribute to the loss of context (e.g. Coffey and Atkinson, 1996; Dey, 1999).

A line-by-line analysis of each transcript was undertaken i.e. annotating each line of the data. Throughout this initial coding process, the researcher coded for possibilities of implied meaning using gerunds i.e. action focused language, a heuristic tool which enables the researcher to focus on the implicit meanings and actions of the participants (Charmaz, 2014). In addition to the initial coding process explained here, other core concepts of GT were utilised and adhered to as outlined below.

1. *Coding and Memos*: Code construction comprised of two phases: initial coding (see Section 2.7.2) and focused coding, both of which are central to the ongoing repetitive comparative process that occurs throughout CGT analysis, across data sources (Payne, 2007).

The process of focused coding involved the researcher identifying the most significant and frequent codes (Charmaz, 2014). This process was supported through memo writing, which facilitates the ongoing analysis of data and coding whilst also enabling the researcher to identify gaps in the data (Charmaz, 2014).

2. *Conceptual Category Formation*: Emerging concepts were categorized to form sub-groups, based on both frequency and significance. Through further analysis, higher level-analytical categories were created.
3. *Constant Comparative Methods*: The process of constant comparison was used at all stages of the research. It is an iterative technique whereby the researcher continually compared data, codes and

categories, moving back and forth between the data sets and the properties i.e. memos, codes and categories of the emerging analysis. This process helped the researcher to identify gaps in the data, whilst also enhancing the quality of the data (Elliot *et al.*, 1999) and offering some clarification as to the theoretical centrality of emerging ideas. Furthermore, the technique enabled the researcher to account for variation in the data, such as negative cases i.e. data that appears to contrast with the rest of the data (Charmaz, 2014).

4. *Triangulation*: In line with Elliot *et al.*'s (1999) guidelines on quality of qualitative research, the researcher in this study utilized the method of triangulation; this was achieved through discussing emerging codes with the supervisors overseeing the project. The researcher also coded a transcript in the presence of a supervisor to ensure credibility of coding.

## **2.10 Summary**

Data were collected through a number of sources. Using the CGT approaches outlined within this chapter, the interview data was analyzed and themes developed. The following chapter presents the findings of this study.



## Chapter 3

### Results

### 3. Overview of Chapter

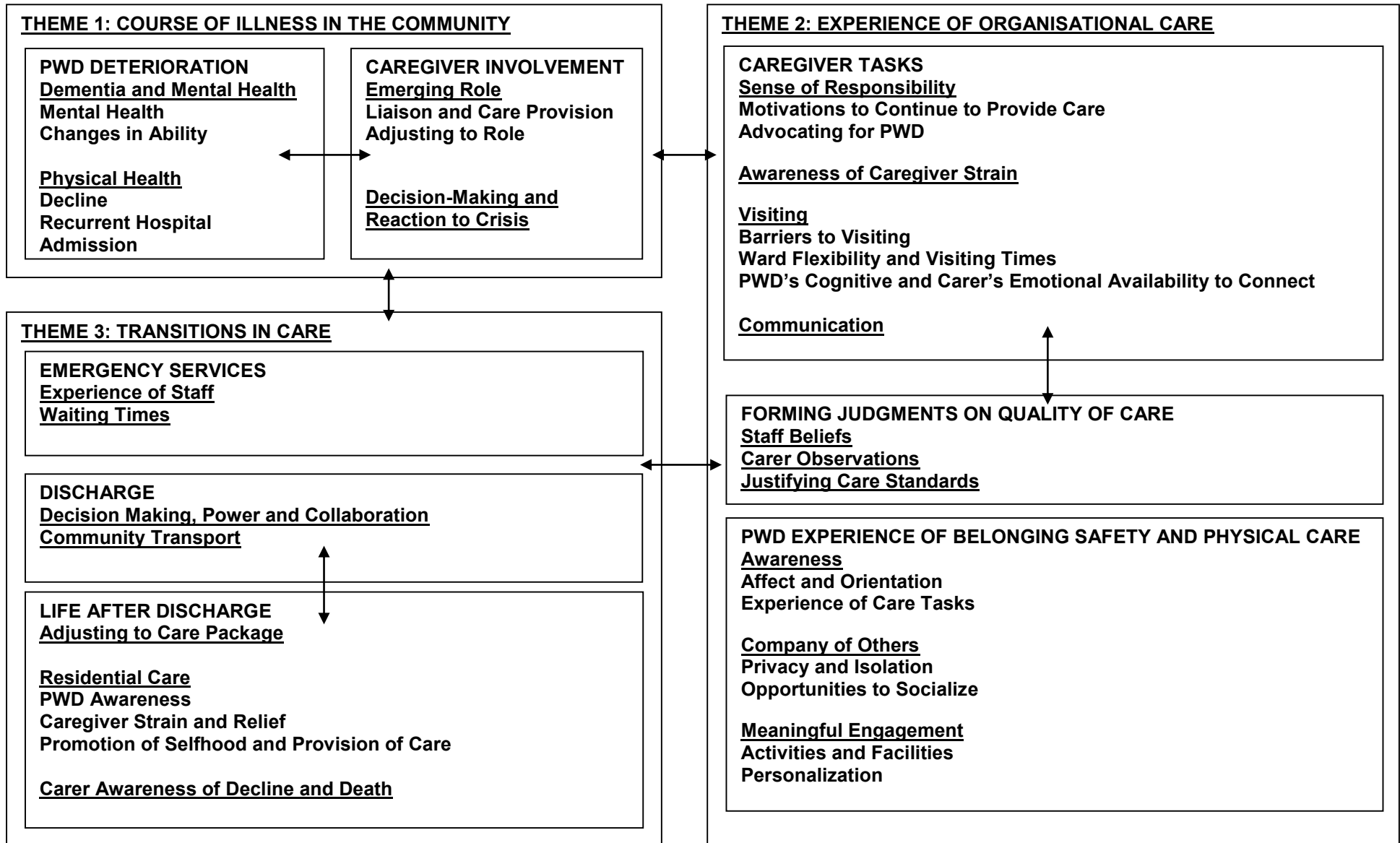
Interviews with eight caregivers were analyzed using constructivist grounded theory (CGT) and the findings are presented here. In the following account the titles of **THEMES** are presented in bold capital underlined letters; **CORE CATEGORIES** are written in capitals and presented in bold; **categories** are underlined and written in lower case with bold font; and **sub-categories** are in lower case, with bold lettering.

Three key themes emerged: **COURSE OF ILLNESS IN THE COMMUNITY**, **EXPERIENCE OF ORGANISATIONAL CARE** and **TRANSITIONS IN CARE**, along with eight **CORE CATEGORIES**, twenty-one **categories** and twenty **sub-categories**. A diagrammatic summary of the findings is presented in Figure 3.1. Further figures (3.2, 3.3 and 3.4), along with an in depth narrative account of the themes and of categories along with illustrative quotes from the interviews, are presented in the sections that follow.

### 3.1 Analysis

In line with qualitative report writing guidelines, quotes have been edited to aide comprehension (Brinkmann, 2013). Also, to protect the identity of the participants and PWD, names of people, work places, hospitals and all other identifiable information has been removed. Finally, throughout this chapter the terms 'participant', 'carer' and 'caregiver' are used interchangeably.

Figure 3.1 A Diagrammatic Summary of Constructivist Grounded Theory



### **3.1.1 Theme One: COURSE OF ILLNESS IN THE COMMUNITY**

Participants described the **COURSE OF ILLNESS IN THE COMMUNITY** in the context of **PWD DETERIORATION**, in relation to the PWD's **dementia and mental health** and **physical health**. The reported timeline of decline varied between people, with some participants describing the PWD's decline as occurring over a long period of time, whilst others described a more rapid decline before admission.

Changes in **physical health** were sometimes associated with the PWD's ability to maintain self-care, which was often a result of **dementia and mental health**. This latter category was associated with the deterioration of, and changes in, ability to successfully complete day-to-day tasks and, also, changes in mobility and personality. Some of the participants disclosed that the PWD had a history of mental health problems, whilst others commented on increasing distress associated with confusion as the dementia progressed.

**Decline** in the PWD's **physical health** was linked to **re-current hospital admission**. Some participants recalled a number of hospital assessments and/or admissions over the past 18 months or longer. It is of note, however, that participants were asked to only describe experiences of hospitals within the last eighteen months.

Accounts of **PWD DETERIORATION** in the community were often associated with aspects of **CAREGIVER INVOLVEMENT**. This core-category includes participant descriptions of their **emerging role** and was found to include **liaison and care provision**. The nature of the **care provision and liaison** depended on the carers' availability in terms of other competing demands, such as employment and, also, their distance from the PWD. For example, some participants described themselves as long distant caregivers. Participants spoke of managing long distance caring through either telephone contact with relevant services and/or commuting to and from the PWD. Furthermore, the nature and type of care provision provided appeared to be associated with where the participant lived in relation to the PWD e.g. sharing the same home or residing at a different address.

The nature of the caregiver's **emerging role** was associated with a change in the relationship contributing to **caregiver strain**. For some participants the **emerging role** meant a change in the relationship dynamic e.g. a daughter providing care for her mother or a spouse for their partner. The new role was found to cause strain on relationships, on work and on the participant's personal life.

The **decision-making and reaction to crisis** category offers a framework through which to understand carers' responses to crisis and their need for support at this time. Some carers described how professionals such as G.Ps made the decision for the carers with regard to appropriate action and admission. Some participants described their feeling of worry and shock at this time, and how this impacted on their ability to take appropriate action e.g. contacting a non-medical professional before contacting emergency services.

A narrative account will now follow, exploring the various categories with supporting quotes. A diagrammatic overview, illustrating the interaction between, and within, the various levels of categories is presented in Figure 3.2.

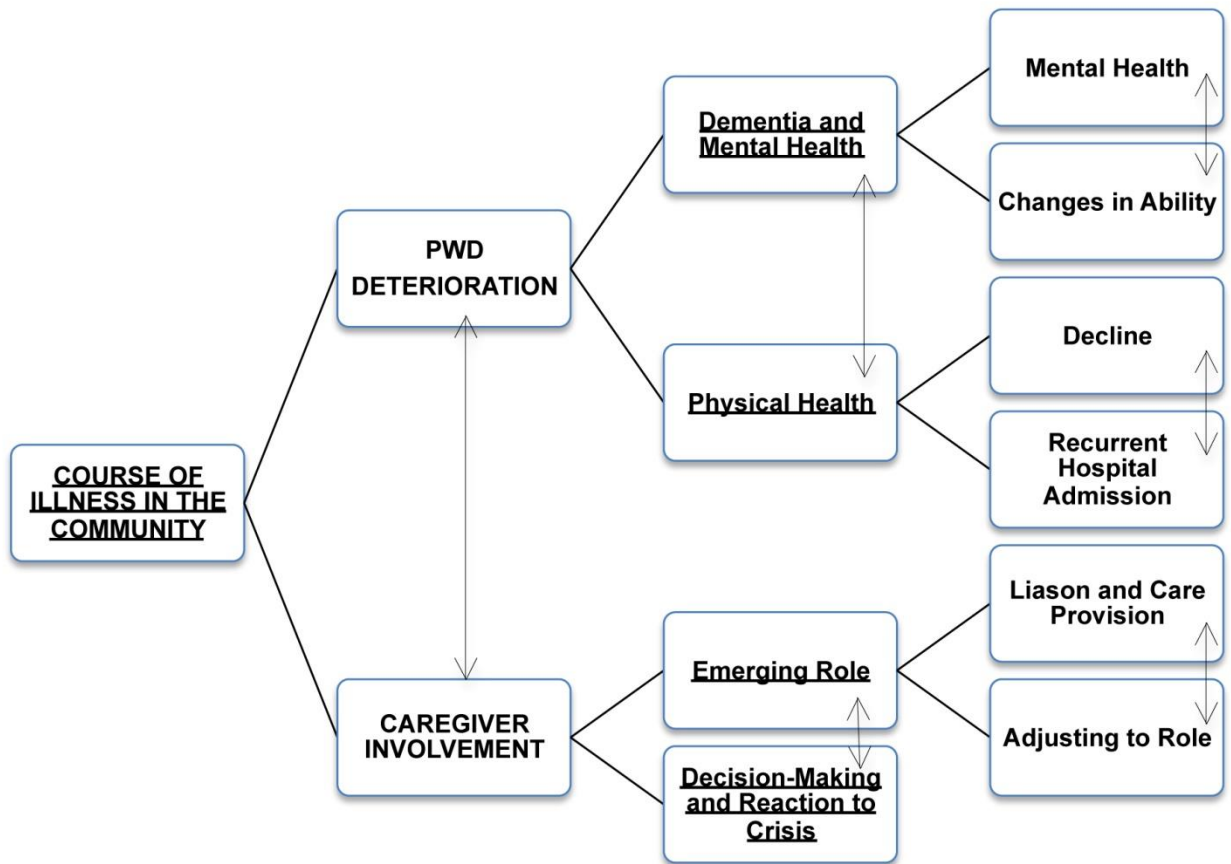
### **CORE CATEGORY: PWD DETERIORATION**

An overview of the categories and sub-categories identified in this core category is presented below. The core category consists of two inter-relational categories: **dementia and mental** and **physical health**, each with two sub-categories.

#### **Category: Dementia and Mental Health**

The category encompasses aspects of deterioration associated with mental health and dementia; these were conceptualized as being interlinked, whilst also being separate, and they were therefore explored through two separate sub-categories: **mental health** and **changes in ability** due to deterioration associated with the progressive nature of dementia.

Figure 3.2 A Diagrammatic Overview of Theme One: **COURSE OF ILLNESS IN THE COMMUNITY**



**Sub-category: Mental Health**

Three participants reported that the person they cared for had a long-standing mental health difficulty. Participants conceptualized these difficulties as being associated with (i) early trauma, (ii) late onset depression and (iii) life long difficulties. For example, Andrea described her mother, Anita, in terms of her long-term mental health, but did not relate Anita’s mental health to her dementia;

*ANDREA: My mum ... [has] ... vascular dementia ... But she's also got mental health problems, which she's had all [of] her life ... She's ... [been] diagnosed with ... borderline personality disorder ... And she suffers from extreme anxiety.*

In contrast, Diana, whose mother, Debra, had experienced early trauma, focused on how, as Debra’s dementia progressed, her mental health deteriorated:

DIANA: *For the last year ... she has been crying for her mother, she is unsettled in her mind [and] she's crying at night ... it's just like having a child.*

Other participants noted changes in the PWD's mood, describing uncharacteristic aggressive behavior which, at times, was confusing to the participant:

HUGH: *[Harrold's] aggressive side has come out a lot more, which I've never seen ... over the last five months [he's] rapidly declined.*

BORIS: *... [Bernice] was starting to get a bit aggressive ... [I was] not quite sure what was bringing [the] aggression on ... perhaps she wasn't sure what was going on, and... She thought I was talking about her or whatever, I dunno ...*

### **Sub-category: Changes in Ability**

Some participants reported decline in relation to the PWD's ability to successfully complete previously accomplishable tasks. These examples appeared to be related to decline in the context of dementia and were associated with such aspects as dressing, confusion, eating and mobility:

HUGH: *... [Harold's] friends were texting ... [saying] 'Oh, your dad's with me. He's looking a bit confused, he's wearing his pyjama top.'*

BORIS: *... And [Bernice is] getting a bit more of a problem in the car, she's trying to escape...*

FREDRICK: *[Francis has] now started to eat with her fingers because she couldn't use a knife and fork.*

FREDRICK: *... [Francis'] walking was getting worse and worse and worse. Um, and I used to have to ... literally drag her to a sitting position in bed. Uh, because she couldn't get herself up any more ...*

Diana highlighted how, for her mother, the dementia and associated changes in ability and mobility led her to withdraw:

DIANA: *... she [was] gradually progressing, she [was] still gradually getting worse and worse, her horizons narrow[ed]. She no longer goes to the garden, she stops going to the outside toilet. She goes up the stairs very, very slowly. Um, so, eventually she ends up upstairs with her own sitting room and bedroom.*

### **Category: Physical Health**

The category **dementia and mental health** was also associated with **PWD DETERIORATION** in **physical health**, for which two sub-categories were identified: **decline** and **recurrent hospital admission**.

### **Sub-Category: Decline**

This sub-category captures the difficulty in disentangling the interaction between physical and mental health and dementia. For example, Andrea described how Anita's lack of self-care, appeared to link to her decline in physical health. However, it was not clear whether her mother's lack of self-care was a cause or a consequence of the physical health problem:

*ANDREA: ... [my Mum, Anita] doesn't eat very well. And she smokes. So she's not really looking after herself that well... [I went down to her home] ... Before Christmas [and] ... I went down just after Christmas, and I don't think she'd eaten anything ... for those days I wasn't there ... she was very poorly and frail... I then went back again after the New Year and I was really worried about her, she looked even worse... um, she could hardly walk between her bed and the toilet, which isn't a very great distance at all ... She was very frail and ... hunched ... [the G.P] found out that Mum had a urinal infection ... so she prescribed her some antibiotics...*

This case highlights the difficulties in differentiating between symptoms and cause and effect relationships between physical health, dementia and mental health difficulties. However, some health changes were more clearly associated with the dementia:

*BORIS: ... [Bernice] was having seizures, but they were changing, they weren't so violent, seizures. Where she can sort of look blankly at a wall ... just blanked out.*

Edward reported how his mother's deterioration in physical health led to an increase in a community care package:

*EDWARD: ... me and my sister ... thought 'The care visiting isn't enough. We need to have somebody stay overnight.' So we got somebody to stay overnight ...*

### **Sub-Category: Re-current Hospital Admission**

Associated with the PWD's **decline** in physical health, was a pattern of **re-current hospital admission**. Some participants reported the experience of frequent Accident and Emergency (A&E) assessment, admission and re-admission:

*BORIS: ... we'd been there to A and E a number of times.*

*HUGH: ... [my Dad] was in back and forth, one-week home, one-weekend home, one-week in, one-weekend home.*

Others described a variety of physical health problems and triggering events, which led to a number of recurrent admissions including stroke, urinary tract infections (UTIs), seizures, falls and constipation:

CLIVE: *[Chrissie] had a ... slight stroke. ... And, er, the[n a] water infection. And then, a few months later she had another water infection...*

EDWARD: *[Mum] had a fall, erm, in the town, and was admitted to hospital for a couple of days. And then, erm, then she was allowed back home ... Um, she had another fall ... in the summer [which led to an admission] ... she [then] had the infection that resulted in the third hospital visit...*

In contrast, George described how a crisis admission led to a planned admission:

GEORGE: *[My wife has] had various illnesses [over] the last [year, the] major one was gallstones, which I called an ambulance out for... Then, in September this year she had she had her operation for gallstones in hospital.*

Therefore, changes in physical health were found to lead to recurrent admissions, both planned and unplanned.

## **CORE CATEGORY: CAREGIVER INVOLVEMENT**

The core category **CAREGIVER INVOLVEMENT** reflects the position of the carer in relation to the PWD, in the context of the **COURSE OF ILLNESS IN THE COMMUNITY**. Two categories were identified: **emerging role** and **decision-making and reaction to crisis**.

### **Category: Emerging Role**

Participants described how their role as a carer emerged over time; the **emerging role** was conceptualized through two sub-categories: **adjusting to role**; and **liaison and care provision**.

### **Sub-category: Adjusting to Role**

The **emerging role** of care-giver was associated with the participants having to make adjustments in their own lives to accommodate their new role:

BORIS: *[Due to the progressive nature of her illness, Bernice] finished work and ... so I had to start taking on more ... Then she couldn't cook, so I had to cook, never cooked before in my life.... then four years ago I had finished work to look after her.*

FREDRICK: *Back in 2011 ... I decided that I couldn't go on [working] any more. It was too much for me to leave [Francis] on her own ... and to go back, because I*



*was working twelve-hour shifts ... [so] I decided ... I'd call it a day... and [that] enough's enough ... so I embarked on [becoming a] full [time] carer...*

The **emerging role** of becoming a carer for the PWD also meant that families had to adjust through working together to manage respite:

*DIANA: ... so [Mum is] now cared for by myself, basically, with the help of my sisters, who come in and give me some respite in the week...*

Others described how the **emerging role** led to changes in the use of their personal time:

*GEORGE: It was a case of going up in the evenings, weekends, um, and sometimes being called out of work, being called out late at night, when the dementia had started to set in.*

*HUGH: I'd be ringing twice a day at the hospital where he was. And I'd be going up there three times a week, from here, from [work]. So it was a lot of, y'know?*

Adjustments in relationships were also observed, for example Hugh explained how the **emerging role** of caring for his father in the community placed additional strain on his relationship with his partner:

*HUGH: It was a strain for us as well ... because ... [my partner] he'd be here very often on weekends, and I'd have to stay with Dad on the weekend. So we wouldn't see much of each other, and it was quite a hard time.*

In contrast, Andrea reflected how her relationship with her mother had improved since her mother's decline in health:

*ANDREA: We hadn't always got on well... [but now] we sort of quite enjoy our time together, really... We get on quite well, really.*

Diana explored the changing quality and intensity of the relationship:

*DIANA: ... When you have ... a one-to-one relationship as a carer [with] ... your mother, it is such an intense relationship.*

Some participants described how adjusting to becoming a carer had involved a learning curve:

*CLIVE: Well, it's certainly been a learning curve for me. Well, all of us really. Something you wouldn't have done by choice, but you're just thrown into it!*

Participants' experience of the emerging care role, therefore, involved a period of adjustment which was associated with learning and changes in their relationships with both the PWD and significant others.

### **Sub-category: Liaison and Care Provision**

As noted above, participants described varied experiences of the **emerging role** as a carer. Some managed their care role in the context of long distance. Andrea explained how she managed the long distance through commuting:

ANDREA: *I go down and stay with [Anita] er, two nights, three days, a week.*

In contrast, Edward managed long distance care through liaising with Primary Care services via the telephone:

EDWARD: *... we're ... two-and-a- two-and-a-half hours' drive away ... [so] I had been phoning up the doctor ...*

Hugh described how he had to balance his care role in the context of work and the associated challenges of trying to liaise with Primary Care services whilst being in full time employment:

HUGH: *For me, to organize a doctor to go to Dad's flat, while I'm in work, is impossible. They won't go ... all day, until maybe the evening, if you're lucky.*

Andrea, George and Hugh also described how they liaised with paid carers and 'meals on wheels' to provide and maintain levels care:

ANDREA: *I sort of spoke to the carers, and said, oh, you know, "We need to keep an eye on [Anita], she's not eating."*

Participants who lived with the PWD described providing high levels of personal care:

FREDRICK: *I had to get [Francis up], in the morning then ... sit her up [and] because she was incontinent by this time, ... I was having to ... take pads ... clean her all up and ... I couldn't get her in the shower, so I used to have to strip-wash her down.*

These accounts appeared to significantly contrast with those who did not live with the PWD:

ANDREA: *I clean the house, do her shopping ... help her out, I walk the dog.*

Some of the participants who did not live with the PWD described the PWD's reluctance to receive care provision in the community:

HUGH: *... I put ... in place, that he'd have carers ... So the carers then were put in place, to control his medication. Because I couldn't be there because I'm working full-time. So the carers did the medication, plus also they would call me if there was a problem. But he was aggressive to them sometimes.*

The **emerging role** of **liaison and care provision**, therefore, appeared to be dependent on: (i) the participant's geographical location in relation to the PWD; (ii) the PWD's stage of decline; (iii) whether the PWD was living at home or in residential care; and (iv) the PWD's receptiveness to help from paid carers in the community.

### **Category: Decision-Making and Reaction to Crisis**

The participants' **emerging role** as caregivers affected their decision-making and actions taken at times of physical crisis. Some of the participants described how the decision to admit the PWD to hospital was decided by supportive and authoritative others. It was as if some participants needed a professional to make the decision for them:

*FREDRICK: [The G.P.] was a bit concerned why [Francis'] legs wouldn't [work]... He sat there [and] said '[Fredrick] ... 'I can't have her ... [stay home] tonight. [Francis has to] be in hospital.' So I said 'Okay then.'... [The] Doctor ... rang an ambulance for me ... The [company] owner [of the care agency] ... [also] happened to come in ... that ... particular morning ... and she said to me '[Fredrick] ... You can't have her [home] tonight.'*

Some participants described experiencing shock at the abruptness of the crisis, even in the context of significant decline. However, for Clive, it was the care home, where Chrissie resided, who initiated the admission:

*CLIVE: They notified me that, um, they were taking her to hospital, so I had to go over to [x hospital] to find her there ... [It was] a bit of a shock! ... quite frightening...*

Similar experiences happened to other carers who did not live with the PWD. In contrast, Boris, who lived with the PWD, sought help from someone else, before contacting the emergency services for help:

*BORIS: ... I didn't phone the ambulance, I phoned [a third sector organization and] said 'What shall I do?' And ... she said 'I think you'd better phone the ambulance.'*

Therefore, the decision to seek emergency services and hospital care was often made in the context of support and advice from professionals.

### **3.1.2 Theme Two: EXPERIENCE OF ORGANISATIONAL CARE**

The **EXPERIENCE OF ORGANISATIONAL CARE** emerged as a theme linked to **THE COURSE OF ILLNESS IN THE COMMUNITY** and

encapsulates three core categories: the **CAREGIVER TASKS, FORMING JUDGMENTS ON THE QUALITY OF CARE** and the **PWD EXPERIENCE OF BELONGING, SAFETY AND CARE** in hospital.

Participants described themselves as having a continued **SENSE OF RESPONSIBILITY** to the PWD whilst they were in hospital. This took the form of **advocating for the PWD** and continuing to provide care. The care provision involved provision of personal care and company, and these types of involvement were associated with staff requests and also stimulated by witnessing deficits in the care of other patients (**motivations to continue to provide care**). However, some participants described how providing care had an emotional impact on them, with one participant implying she had been traumatized by her experience of providing care in hospital.

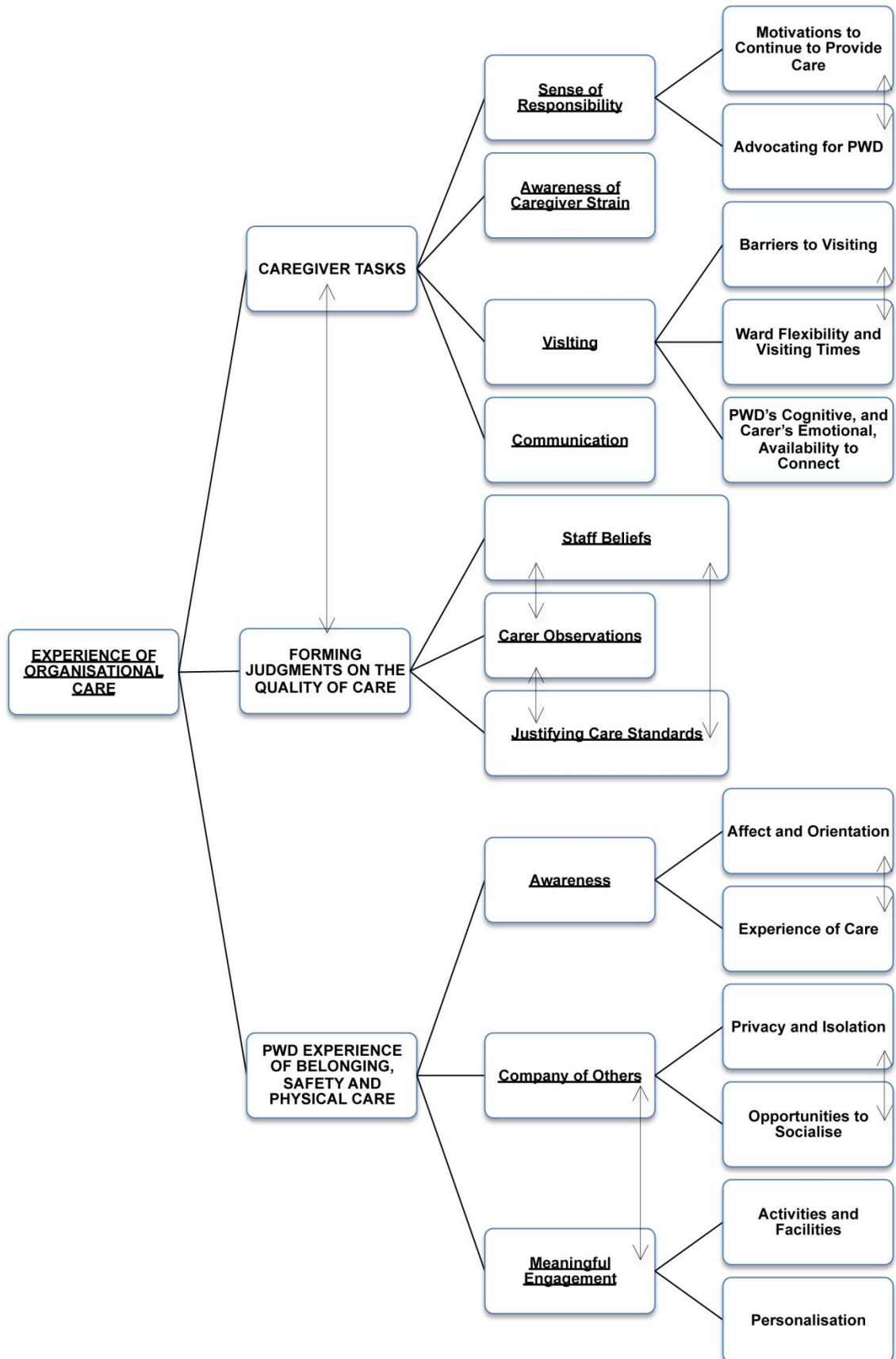
**Advocating for the PWD** was associated with the caregivers' perceptions of whether the PWD's personhood and care needs were being met in hospital. Furthermore, other participants described experiencing their own emotional task associated with awareness of their own needs and **caregiver strain**. This experience emerged in the context of their own declining health associated with their caring role and other competing demands.

In addition, the theme encapsulates the task of **visiting** and reflects accounts in relation to **barriers to visiting, ward flexibility of visiting times** and both carers' and PWD's **availability to connect**.

**Visiting** provided a platform from which carers began **FORMING JUDGMENTS ON THE QUALITY OF CARE**; these judgments were informed through feedback from staff (**staff beliefs**) and their observations (**carer observations**). Where quality of care was insufficient, carers would attempt to make sense of the deficits through **justifying care standards**.

The categories of the core category: **PWD EXPERIENCE OF BELONGING, SAFETY AND PHYSICAL CARE** were identified as the PWD's **awareness**, the availability of the **company of others** and opportunities for **meaningful engagement**. The various levels of the theme are discussed below. A

Figure 3.3. A Diagrammatic Overview of Theme Two: **EXPERIENCE OF ORGANISATIONAL CARE**



diagrammatic overview illustrating the link between the categories can be seen in Figure 3.3.

### **CORE CATEGORY: CAREGIVER TASKS**

This core category focused on the tasks associated with the caregiver experience of organizational care. These were conceptualized as (i) a **sense of responsibility** (i) **awareness of caregiver strain** (iii) **visiting** and (iv) **communication**.

#### **Category: Sense of Responsibility**

Even though the PWD were no longer in the community, participants described how they continued to provide care whilst the PWD was in hospital (**motivations to continue to provide care**). They also described their role of continuing to provide a voice for the PWD whilst in hospital, conceptualized here as **advocating for the PWD**. This appeared to be an extension and transition of a caring role from the community to the hospital organization.

#### **Sub-category: Motivations to Continue to Provide Care**

This sub-category illustrates the motivations of participants to continue to maintain a caring role and the nature of the care tasks they provided. Andrea described how staff requests motivated her to feed Anita at meal times:

*ANDREA: ... they [the staff] actually ... ask[ed] me if I'd go in at mealtimes. ... Because I think that they are short-staffed ... And ... it is quite time-consuming sitting with somebody and trying to get them to eat [and] ... I can sort of encourage her...*

Similarly, Diana described how staff requests led her to assist with Debra's personal care. This was something Diana found distressing:

*DIANA: ... I had to come in, they said - 'Oh, do you think you can give us a hand with your mum?' ... 'Can you..?' And I would have to hold her hands down, and the whole experience of ... watching my mum screaming and ... trying to get ... the nurses, and scratch ... [the nurses] eyes out was just... It was just so horrible.*

In contrast, Andrea described how they had chosen to provide hands-on-care for her Mum, for example attending to personal care:

*ANDREA: I'll ... help her wash ... it was my choice, I wasn't asked to do it.*

Other participants described how it was their observation of staff failing to provide basic nutritional care that motivated them to provide food and drinks for the PWD:

DIANA: ... *It just seemed a bit ... haphazard ... sometimes ... if the patient was dozing [staff would] ... leave her food in front of her. And then whip it away ... two hours later ... [and because of] health and safety [they] weren't allowed to keep it, or reheat it or anything. So ... I observe[d] what was happening to other people [and so] ... we used to bring food in as well. I used to make my own soup, and I used to bring in fresh fruit. Which [Mum] ... loved ...*

Another way of providing care was to provide company to the PWD:

CLIVE: *I used to make sure I went in every day, or somebody went in every day, just to spend a few hours there... And take [Chrissie] walking up and down the corridor.*

Some participants described how providing such care made them feel better; Fredrick spoke of how continuing to provide care also acted as a form of gratitude to the staff:

FREDRICK: ... *it made me happier that I was there, knowing that she was eating... And at the same time ... [me being there and feeding Francis] gave them [the staff] that time back...*

Despite some participants describing their experience of continuing to provide care as reassuring and rewarding, others reported that it had a negative emotional impact on them:

CLIVE: *[it was] a bit distressing. But now, I've got used to it now, because... prior to her going into hospital I'd care for [Chrissie] anyway.*

Therefore, motivations to **continue to provide care** were associated with; (i) compassion for nursing staff; (ii) observations and concern about insufficient care; (iii) response to nurse requests; and also, (iv) meeting the basic needs of PWD in the form of company, nutrition and clothing.

### **Sub-category: Advocating for PWD**

Throughout the interviews participants described advocating for both the PWD's care needs and also their personhood, whilst in hospital. Some participants described advocating on behalf of the PWD in relation to preferences around care provision. A theme which emerged across several interviews related to participants giving staff permission to not complete care tasks e.g. to not change a PWD's clothes or to not shower the PWD. Staff

often sought such permission from the carer, despite the PWD trying to communicate their reluctance to receive certain aspects of care:

HUGH: *I said 'Well, I know my Dad.' So ... [if] my Dad doesn't shower for a week, I'm not gonna be upset by that, because I know my Dad.*

Participants described how, even when there were recurrent admissions, staff would not necessarily know about the PWD, beyond their medical needs. In this context, the carer would often try to advocate for the PWD's preference for care and their personality and interests:

ANDREA: *... it's the same hospital that she's been in and out of ... but they don't really know much about my mum ... I suppose all they know is that I'm her daughter, and I don't live nearby... I try to talk to them ... about her little dog and everything. Because she likes ... to talk about her dog ... but it is... not unpleasantness, it's... [that] they do a difficult job... [so] they've got a medical history, but they don't know my mum.*

Several participants noted that staff regularly failed to seek out biographical information, and they understood this to be a consequence of the staffs' primary role of providing medical care:

HUGH: *... the only thing they're concerned about is [his medical history] They don't ask 'What is he like?', 'What does he like to do?' 'What's his personality like?' ... they don't think that's really relevant. They just need to know 'What has he had?', 'Is he allergic to anything?'...I don't think ... they regard the personality side of things.*

Diana described how she found hope when a member of staff did appear interested in Debra as a person and as a consequence proactively sought out information to share with staff and advocate for her mother's history:

DIANA: *... I went in, and there was ... a one-to-one nurse ... allocated to my mother... And I said 'Oh, that's great. Because ... I can sit down and I can talk to you about my mother, I can tell you who she is. I can tell you all about her.' And the nurse said 'That's great.' ... So I thought 'That's great, that's the first time I have ever come across somebody who might be interested in her as a person, rather than a patient or ... a medical body. ... and I said 'I'll bring [in] ... things about my mum. I'll bring in the photograph albums ... some history about her. I'll bring it in tomorrow.' ... Then I noticed that ... as soon as I was in the ... room ... [the nurse] decided that she wasn't needed any more, so she went off, and she had to do something else somewhere else in the ward, in another bay.*

Therefore, participants' experience suggests that staff demonstrated a greater focus on the medical presentation rather than on the PWD personhood. In some cases this motivated the carers to pro-actively advocate for the PWD



and also, to provide company and personal care that was not being provided by the medical staff.

### **Category: Awareness of Caregiver Strain**

This category illustrates how it was often only at the time of the PWD's admission to hospital that participants became fully aware of the strain and toll that caring for the PWD in the community had taken on them. Therefore, this category was seen to link with the **CAREGIVER ROLE** in theme one: **COURSE OF ILLNESS IN THE COMMUNITY**. Boris described how this realization happened at a professionals' meeting:

*BORIS: ... we had a big meeting about her... I didn't realise how bad [Bernice] was, really... Because when you're caring you just tend to go through the rough bits, and take on a bit more again ...*

Some of the participants described how caring had taken a physical strain on them:

*HUGH: I didn't realise it affected me so much. Didn't think [it had] at all, I thought I was invincible. There we go. I've lost two stone in the process! On the bright side!*

Andrea, Diana, Edward and Hugh also described how competing demands, such as relationships, children, work, ill spouses and bereavement within the family, had contributed to the sense of caregiver strain. This perhaps goes some way to explaining why some participants noticed a sense of relief when the PWD was admitted to hospital:

*CLIVE: Prior to her going into hospital I'd care for her ... So I was a bit relieved, because I didn't have to do everything. ...Someone else was doing it...*

The experience of caregiver strain, therefore, appeared to be only noticed by participants, once the PWD had been admitted to hospital, rather than when they were actively providing care in the community.

### **Category: Visiting**

Another aspect discussed by all of the participants was the experience of **visiting** the PWD in hospital. These experiences have been conceptualized here into three sub-categories: **barriers to visiting, ward flexibility and visiting times** and the **PWD's cognitive, and carer's emotional, availability to connect** with one another.

### **Sub-category: Barriers to Visiting**

Participants described a number of barriers to visiting, some of which were associated with the distance between the hospital and their home. It is of note that the distance from home to hospital sometimes reflected the location of the nearest hospital in relation to where the PWD and the carer lived, rather than reflecting the geographical distance between the PWD's home and the participant. This was highlighted by several participants:

*BORIS: Trouble is [with] the [hospital] ... [it would] take me one-and-a-half, two hours getting back home.*

Edward, George and Hugh described barriers to visiting in terms of a decline in their own physical health. For example, although Edward was still able to visit the length of his visit was limited by his own health needs:

*EDWARD: I did visit her. Unfortunately, I had a streaming cold. So I didn't really wanna stay. For all kinds of reasons, I was in a really bad state at the time. So I didn't stay very long. I stayed for about half an hour ...*

The barriers to visiting were even greater for George, because he was no longer able to drive:

*GEORGE: ... [it was] difficult to visit because visiting times were not really long enough ... [and] 'cos I can't drive. The DVLA [has] taken my license away, because I had a stroke a few years ago... [this was] one of the biggest bugbears really, just couldn't get there. I looked into various ways of doing it. I could've got a taxi but that's £70 a time and then there was the trains...*

For some participants, failure to visit was associated with guilt and worry:

*ANDREA: At the moment I'm feeling like I should be down there, I'm sort of feeling guilty...*

Therefore, **barriers to visiting** were associated with geographical factors, as well as constraints due to poor carer health. Emotions that arose as a consequence of not visiting were often guilt and worry.

### **Sub-category: Ward Flexibility and Visiting Times**

Participants described differences in the flexibility of different wards with regard to visiting times, with rigidity of times sometimes cited as a **barrier to visiting**. Thus, this sub-category was seen to be associated with the sub-category: **barriers to visiting**, as outlined above. Some participants

understood the rigidity of the ward rules as reflecting the need for ward routines:

CLIVE: *They ... had certain times, but uh... Because of bathing and all that sort of stuff.*

Andrea and Clive, however, found that some wards were more flexible than others, depending on how busy the ward was:

CLIVE: *... they had ... visiting times, but depending on the circumstances, if they were very busy and stressed then the bell would go at that time and everybody had to clear ... And if it wasn't such a busy day then, and depending on the staff, they might, y'know, forget it for an half an hour.*

This reflected George's experience, whereby the flexibility of visiting hours was largely dependent on the needs of ward staff:

GEORGE: *[I] got to [the hospital] one day before visiting time and they let us in for half an hour and then kicked us out for an hour or so while the doctor did his round and then they let us back in again. That was about the only time.*

However, on the whole participants generally adhered to the visiting times:

DIANA: *... the visiting times were from two 'til eight. So we fell into respecting those times.*

Participants often felt that the length of visiting times was not always sufficient for their needs and they often felt that the flexibility of visiting times reflected staff needs, rather than the carers' needs.

### **Sub-category: PWD's Cognitive, and Carer's Emotional, Availability to Connect**

Participants described challenges in relation to their own emotional availability and PWD's cognitive ability to connect with one and another. For example, some difficulties in connecting were found to be associated with the extent of the PWD's physical illness and their ability to communicate:

ANDREA: *... I don't know whether she's able ... to have a conversation... She's not really making a lot of sense. I think she's so anxious, and ... poorly...*

Others described limitations in the PWD's availability to connect with the carer in terms of the progressive nature of dementia:

FREDRICK: *... I'll go in and say 'Are you alright, darling?' 'Yes, I'm fine.' she'll say. Erm, and- and that's about as much conversation as you'll get out of her.*

Participants also described how their desire to protect the PWD from their own emotional response impacted on the authenticity with which they could connect with the PWD:

CLIVE: *Because when you visit, you mustn't let anything slip ... you've got to be [acting] normal[ly], when you go there ...*

In contrast, Andrea described how her availability to connect with the PWD was affected by the stress of visiting:

ANDREA: *I stayed, well, I stay I think between an hour-and-a-half and two hours is about as much as I can take! Sorry, I know that sounds awful really. But she's quite hard work to be with...*

Therefore, availability to connect was a two way process and difficulties were compounded by a number of variables.

### **Category: Communication**

Participants described a recurring theme of **communication** difficulties in the context of their caregiver **EXPERIENCE OF ORGANISATIONAL CARE**. A majority of the participants described difficulties in relation to communication with staff groups. Some reported varying success with regard to communicating via telephone with the ward for updates:

GEORGE: *No [the staff would not initiate phone calls to keep me updated] I used to ring them up and ask them what the situation was ... They were pretty good [when I spoke with them].*

ANDREA: *... When I ring up, they always say 'Oh, you want an update? I'll get the nurse that's caring for your mum.' ... But today I haven't managed to speak to her, I've rung twice. And... once she was on her break, and once she was busy.*

Hugh described how the quality of communication depended on how well the staff member knew the PWD and, also, on their approach to confidentiality:

HUGH: *... you feel, in the hospital ... [that] they were never answering phones. ... Sometimes I'd be ringing eight, nine, ten, twelve times a day. No answer. Because ... I know they're not stuck to a phone... I know they have a job to do. But the communication's not there. And sometimes they can't say too much over the phone either [they'd say] 'Yeah, he's fine.' I'd say 'Well, has he eaten his food?' 'Yeah, he's had some food.' I said 'So, is he- he's sleeping now?' 'Yeah, he's comfortable.' That's all I get... I think there's a confidentiality issue ... if I talked to [one] woman who I knew, that would be fine. But if it was somebody who was, y'know, just a voice at the end, they wouldn't say very much. And [one hospital] was just as bad. 'And we can't discuss that over the phone.' I'd say 'Look, y'know, I'd say 'Look, I live in [a distance away]. I can't get there. I need to know how he...' 'Sorry, we can't.' I'd say 'Look, I'm next-of-kin...' [and they would*

say] ... 'No, sorry, can't tell you anything about that.' So ... it's a really horrible thing...

Others found it difficult to communicate with staff even when they were on the ward. Such difficulties were linked to both staff busyness and lack of staff continuity, so that the staff on duty did not have an in depth knowledge of the PWD:

CLIVE: *In the hospital because [there are] ... different nurses all the time ... [and] they're so busy and stressed they haven't got time [to talk with you].*

GEORGE: *Yeah, it was very difficult to find somebody to talk to. You could ask them a question and they would look at the notes and say she's progressing well and that would be it. And they'd be gone off somewhere else ... It's all a matter they just haven't got the time...*

Some participants did describe times when they were able to speak with staff, but staff availability due to the demands of the job remained a prominent theme:

DIANA: *There were some nurses you could talk to because they were not, like, being occupied by somebody...you could have a bit of a chat ...*

Staff were described as being more likely to respond to a request for task orientated care:

CLIVE: *I mean, they're very good if you call ... wanting a change or something like that, then ... they come over, but they were really stressed ...*

Participants described how they developed strategies to overcome the challenges associated with deficits in communication with staff, for example reading the PWD notes. However, this was sometimes unsatisfactory, as the notes kept at the end of the bed only described behavioural and medical observations and were not helpful in informing the participants' understanding of the provision of care and changes or improvements in the PWD's health:

DIANA: *... the notes that she'd written about my mother were literally that she was crying out, or she was aggressive with this nurse and that nurse.*

GEORGE: *I used to read her notes when I went there ... whether I should look at them I don't know. Yes, to see what her blood pressure was. I don't know if that was good or bad. I wouldn't have a clue, but at least I looked through the notes. It was the only way I could find out what they were doing that day or what they had done that day.*

Participants described how they realized that they had to develop strategies to elicit the information they wanted:

GEORGE: ... *I found you needed to ask the right questions. And they only gave you one answer to the question. They wouldn't [add] anything additional to it.*

However, it is important to note that participants did report examples of good communication:

FREDRICK: *I chatted to the doctor [at the hospital] ... He was bloody brilliant, [we talked] for about an hour.*

Others reported effective communication, although this was in the context of informing the participants of the difficulties the staff had experienced with the PWD's behaviour and other events, such as falls:

DIANA: ... *the matron called me in one day, she said 'Do you realise that your mum ... had a pair of scissors in her hand, and she tried to ... [and] I thought 'Oh my God.' She said 'She cut the nurse's hair.'*

HUGH: *I got the feeling they knew him well, and, if I rung the hospital, they would know me. I'd be ringing twice daily for an update [and ask] 'How's he today? What's happened today?' And they would be quite honest, 'Oh, he's had a fall today ... he's fallen down.' 'He wouldn't change his clothes.' They'd tell me everything. Because he'd be quite stubborn on quite a few things, he had a shower today...*

Therefore, carers' experience of communication with staff varied enormously in terms of quality and availability of information.

## **FORMING JUDGMENTS ON QUALITY OF CARE**

This core category captures the mechanisms which informed participants' **judgment on the quality of care**; these were identified as **staff beliefs** and **carer observations**. Participants provided various accounts, reflecting their opinion on the quality of care they observed; where care was thought of as substandard, the participants would make sense or justify the level of care through rationalization, thus giving rise to the category: **justifying care standards**.

### **Category: Staff Beliefs**

Some participants described how staff shared their professional judgments on the possible negative impact of the hospital environment on the PWD's safety during admission:

ANDREA: ... *when Mum was in hospital ... I saw the consultant. And he said to me ... "If you want your mother to live, you should take her home." He said "If you leave her in here, she's gonna pick up a bug or something, and die." He actually*

*said that to me. ... And uh, I couldn't believe it! ... so I said "Okay. Well I'll take her home then. I'm not gonna leave her here... If that's what you think." ...*

Participants also described how staff spoke with them about their own personal experiences and beliefs, with regard to the ward environment:

*BORIS: I said '[I want her to go to] x hospital please, [I] don't wanna go to the [other hospital].' ... He [the paramedic] said '[I] don't blame you, [the other hospital] it's like the third world war.'*

*DIANA: One of the nurses ... came in one day said 'I'm not coming back here again.' I said 'Whoa, you can choose, can you?' She said 'Yeah, I'm not coming back here, it's awful.'*

### **Category: Carer Observations**

Participants described how, coupled with staff feedback, their own observations of care provision informed their opinion as to the quality of care. Some reported observing how the busyness of staff and their associated competing demands impacted on delivery of care:

*DIANA: ...they always ... seem to be sitting at a computer, or writing notes or writing stuff down. There was a lot of that... every time they did something ... they had to scurry back to a desk to write things in these huge folders that they always ... kept misplacing.*

Others observed how staff sometimes failed to recognize and appreciate that the PWD had dementia:

*CLIVE: I mean, they look at the notes, and they say 'Yes, Mrs so-and-so's had a stroke.' or 'She's broken her leg.' or whatnot. And then probably, just as a by the way, she's got Alzheimer's, y'know, when that's quite a big feature... Because they may not speak to you, they may just stare at you or something like that, you know.*

Furthermore, George felt that the hospital to which his wife was admitted failed to utilize existing schemes to prompt staff to attend to his wife's dementia:

*GEORGE: Yeah, it's the first thing I told them, she's got dementia. They should have put a forget-me-not on the wall but they didn't.*

Interestingly, however, some participants were keen to describe the good care they observed:

*ANDREA: ... they are looking after her.*

*HUGH: ... [Dad was distressed, so the staff] sat on the bed for about forty-five minutes, chatting to him. Diverting his thought processes. And they ... were there for ages. Sitting there, on the edge of the bed, and I could see through the window what they were doing, they were lovely.*

### **Category: Justifying Care Standards**

Participants regularly justified unsatisfactory levels of care through describing how organizational pressures impacted on the quality of care provision at various stages, for example admission:

CLIVE: ... *the[re was a] long wait ... for the ambulance. But then that's, again, that's pressure, isn't it?*

HUGH: ... *there was no space in the wards, either. So there was a complete backlog of people. Just in trolleys. Just awful. Um, but there we go. It's the reality of the thing we're in.*

And also during inpatient stay:

DIANA: ... *[the nurse] hasn't even got the time to sit down and talk about my mum, she's always somewhere else ... so there was always another patient to ... care for ... There was always something else to be done, and even... the times my mum wanted to sit on a commode, I used to go and ... chase for it, and find another nurse, and they were always busy. 'Oh sorry, I've got to just give...' so there was always ... 'Just give it a minute.' or 'Just this.'*

Participants also described the quality and level of care provision in terms of both staff skill and experience. For example, Clive described how staff's personal and professional experience of dementia positively influenced care:

CLIVE: *Well, they were very caring...And er, I found that er, there's always somebody there, a nurse or a doctor or someone, who's got someone with Alzheimer's ... So they're a bit more understanding, because there's so many people with Alzheimer's ... someone will [say] 'Oh yeah, my sister's got it.' or 'My mother's got it' ... so... then you get a bit more understanding come through ...*

In the same vein, Fredrick and Diana described how a lack of experience and training with PWD negatively influenced care:

DIANA: ... *either they haven't had the training, or they don't ... they haven't up 'til now had [that] ... many dementia people [on the ward] but I don't believe that, actually, they must get a lot of dementia people.*

DIANA: *they ... didn't understand what people with dementia [nor] ... [what] the best way to approach it was.*

FREDRICK: ... *A lot of the staff didn't know what was going on, I mean ... if ... you've got a person with Alzheimer's ... in a stroke ward...Half of them don't know what's going on, half of them don't know what the ailment is or how it operates and what it's about. Because they're not trained in that- in that field, you see.*

George summed up care as being driven more by the demands of the organizational care system, rather than person centered care per se:

GEORGE: *I think ... everything is done for statistics. It's not about patient care as such. I mean they care the best they can but it's about as far as it goes, I think.*



Therefore, participants **justified care standards** through lack of staff experience and also through deficits in training and constraints of the system, meaning that some staff were thought to be too unskilled and/or too busy to provide adequate care.

## **CORE CATEGORY: PWD EXPERIENCE OF BELONGING, SAFETY AND PHYSICAL CARE**

The core category illustrates the PWD's experience of the hospital stay. The participants frequently alluded to several areas of the PWD's experience in terms of their sense of belonging, safety and physical care; these were conceptualized in to three categories: **awareness**, **company of others** and **meaningful engagement**.

### **Category: Awareness**

Participants described how the PWD had fluctuating and differing levels of orientation, which interacted with their mood and awareness and understanding of what was happening. Thus, their sense of orientation was thought to make a significant difference to how they experienced care.

### **Sub-Category: Affect and Orientation**

Participants described how the PWD would often express strong emotions which the participant understood, on some occasions, to be associated with a lack of orientation and confusion. Andrea described how she believed the hospital affected her mother's mood and confusion:

*ANDREA: She does really go mentally downhill ... she gets very confused and agitated in the hospital.*

George associated Gina's disorientation with increased levels of tiredness:

*GEORGE: ... she was getting herself quite disorientated ... when she's tired things go downhill.*

In contrast, Andrea described how, in part, her mother's confusion was due to problems associated with poor memory recall and her sense of orientation to the ward:

*ANDREA: I tried talking to [my mother] about it (admission)... And she has no recollection of it. She doesn't even know where she is at the moment. She ... says 'Where am I? Where am I?', and, 'Am I at home? ... She hasn't got much awareness of where she is at the moment.*

Similarly, other participants discussed how, due to the symptoms of dementia, the PWD were unable to recall or process the hospital experience and lacked awareness:

*FREDRICK: I don't think [my wife] ... has experienced anything, if you know what I mean? Uh, I don't think her mind would- I mean, she certainly wouldn't remember ... one day to the next.*

Hugh described how his father's fluctuating awareness of his illness meant that his father would often want to leave the hospital. The participant described how his father would demonstrate his dissatisfaction and lack of awareness of his ill health through contacting the police, packing his bags and leaving notes around the ward:

*HUGH: ... he'd pack up his clothes quite often ... [and say] 'I'm going home now. You can't keep me yer against my will.' He'd write notes, and he'd ... once, quite humorously ... written a big note in the hospital to say that the hospital was under new management ... And he said to the nurses that they were all sacked! Because [in his previous job] he used to hire and fire [people]. So, he'd reverted back to that. So...So in his head, he wasn't happy there, and he was sacking people... [he] hated it, I'd say ... because one of the comments he made was um, 'I should've never let you bring me yer in the first place.', is one of them. And, 'How did ... I get in yer? I don't wanna be here' ... 'I want my papers, I haven't signed anything, you can't keep me yer against my will.' [He] rang the police, the police turned up ... to the hospital. So, there was distress signs ... To tell me that he wasn't happy there. He knew where he was. Sometimes he didn't, but sometimes he did.*

George described how his wife's confusion and disorientation impacted on her ability to leave the ward area and engage in activities which she enjoyed:

*GEORGE: ... at [the hospital, the layout] was just too complicated from the ward [to go out for coffee].*

Therefore, awareness of place and general orientation was seen as impacting on PWD and their day-to-day experience of the ward and the hospital environment.

### **Sub-category: Experience of Care Tasks**

Participants recounted stories of how PWD were confused by the care interventions given and thus this sub-category was associated with the sub-category **affect and orientation**. Confusion was thought to contribute to the PWD's failure to adhere to treatment plans and to resist personal care.

Andrea described how her mother was reluctant to use a commode and was unable to understand nursing staff's concern about her walking herself to and from the toilet:

*ANDREA: She won't use a commode ... And so she's sort of... And they're really worried about her falling again. And ... she gets quite cross if you try and tell her that she can't go.*

Others described how the PWD's lack of awareness led to them to become distressed at times of personal care:

*BORIS: [Bernice] did get a bit distressed when she was ... being dressed and washed [and she tried] ... to push them off and... She just doesn't know what's going on, really.*

Some participants spoke of how staff tried to comfort the PWD. However, pressures of the organizational care system meant that they were unable to do this for long periods of time:

*CLIVE: [the staff would comfort her] as much as they could...[but] it might be one nurse perhaps in charge of six or eight people. ...[and] the beds [need] changing, and somebody soils the bed, that's got to be changed, and then call in some help, and then the doctor wants to see somebody ...*

One spoke of how staff failed to understand her mother's needs, utilizing 'care speak' and infantilizing language to address the PWD. The participant described how this contributed to her mother's expression of aggression and reluctance to receive care:

*DIANA: ... she was like, hating it all, and she was ... so aggressive in the hospital, the nurses [would say] 'Do you know, your mother's pinched me today, and she's trying to scratch me. And she's punching me.' ... they would speak really loudly to her, like she ... was deaf, but she wasn't. And they'd treat her like a baby, which she hated, they would try and comb her hair, which she hated, I mean, there was all sorts of things ...*

Participants explained how care provision for the PWD was often medically orientated, rather than person centered in nature:

*FREDRICK: ... there isn't that, um, closeness. There isn't that, um... although the hospital is doing what they should be doing.... They're uh, they're coming in and checking them every couple of hours, they check their bloods, and they check...*

Food was also discussed by a number of participants. Most of those who mentioned this described the food as being poor, repetitive and as lacking in nutrition:

GEORGE: ... *It wasn't very healthy food. You knew from one day to another what was on the following day ... So if you had something on a Monday you'd probably get it on the same day or on the Wednesday. [It was] processed stuff ... powdered mashed potatoes that sort of thing.*

DIANA: *I can say the food wasn't very good. The food would be ... over-microwaved, and it would end up looking like a jellyfish, you could pick the whole lot of glob off the plate ... [it] sort of look like it had come off a mould ... sometimes the food was cooked good. And then sometimes it was... it seemed to be quite salty ... It ... never looked fantastic. A bit sort of gloopy.*

Participants suggested that the PWD was equally as dissatisfied with the catering:

HUGH: *The hospital food was ugly ... where he was ... he was ... complaining he didn't want it.*

Only one carer described the food as satisfactory:

FREDRICK: *I found the food was ... as good as you'd get ... anywhere ...*

Therefore, the quality of communication, nutrition, and also staff understanding of PWD's reluctance to receive care, collectively impacted on the PWD's experience of care. Although, there were varying accounts as to the extent to which care organizations had good awareness of the PWDs' needs.

### **Category: Company of Others**

Participants described how the PWD's had varying opportunities to have the **company of others**. This was conceptualized here into two sub-categories: **privacy and isolation** and **opportunities to socialize**.

#### **Sub-category: Privacy and Isolation**

Participants described a mixed experience of privacy. Some spoke of not having enough privacy, whereas others spoke of the PWD having too much privacy and as being isolated from other people. A lack of privacy was associated with the PWD staying on a shared ward, contributing to a sense of reduced confidentiality for the PWD:

HUGH: *There was no privacy ... That's the bit I don't like... everybody else hears everything. There's ... no privacy at all, and if there's any treatments got to be administered, you see and hear everything. So there's no ... confidentiality either.*

Some described how the PWD were given a separate room from other patients, because their expressions of distress disturbed others. Fredrick

described how, despite the perceived isolation, he preferred this privacy for his wife:

FREDRICK: ... *she was put in a room [because] there was a lot of complaints, because ... she used to shout and bawl ... and she was disturbing everybody ... of course in the end they er, they decided ... [to] put her into a side ward ... [which] more or less... isolated her from everybody else, really... I was quite happy about that because it gave me a little bit more privacy with her than [when] ... she was ... in a six-bed ward.*

In contrast, Hugh recounted a stay where his father was in a separate room because of the fabric of the building rather than being separated from others due to distress. He described this isolation as detrimental for his father:

HUGH: ...*They've got single rooms ... they're on their own in a room. ... [it was] terrible [for him, like] prison.*

He described his father as happier, when he was on a shared hospital ward:

HUGH: *[when] he was in a room with others ... I think he preferred it. Because there was other people around him, and that ... he could chat to ... Because when I went to visit, they were telling me 'Ah, he's been up and down like...', 'Ah, he's given that man a help there, that man fell out of bed.', or something, and 'he picked his pen up for him.'* So, there was some interaction.

However, one participant observed that when his wife was placed in a ward in which several people had communication difficulties due to their condition, socializing was difficult. Therefore, the nature of inpatient illness was also found to contribute to isolation:

CLIVE: ... *had they all been able to talk to each other they would have been company, but of course most of the people [were] recovering from strokes or dementia [so] they weren't able to talk to each other anyway.*

This was also reported to be the case where people were too physically ill to converse. The experience of privacy and isolation is also closely associated with the other sub-category: **opportunities to socialize**.

### **Sub-category: Opportunities to Socialize**

Participants described how a number of factors interacted with PWD's opportunities to socialize. As highlighted above, whether people were on a shared ward or in a single room impacted their **opportunities to socialize**. Some participants considered a single room as both boring and lonely for the PWD:

CLIVE: *The only thing [was] that they were in ... separate rooms, so it was a bit lonely, I thought.*

GEORGE: *It was definitely quieter [in the private ward] and gave you time to think. Yes, it was lovely because there was no-one around you. ... Although [the PWD] got bored quicker because you couldn't people watch.*

HUGH: *it was a solitary time, for him.*

In contrast, a number of participants spoke of how physical illness reduced the PWD's desire and availability to socialize:

EDWARD: *... I don't think she really talked to ... other people ... [they] were physically quite a lot ill-er than her, I think.*

The PWD's ability to communicate was also reported to impact on socializing, although, one participant described how his wife still sought out the company of others who responded well to her:

BORIS: *[My wife] she can't communicate now ... [but] she seeks out company ... [she] touches them ... all the patients were very good with her.*

Therefore, opportunities to socialize were dependent on whether or not a PWD was in a shared ward and also on their own, and others', ability to communicate.

### **Category: Meaningful Engagement**

This category is associated with the category **company of others**. However, it differs in that it illustrates the **provision of activities and facilities** that were available to the PWD and also how **meaningful engagement** was addressed in terms of the **personalization** of care in the ward environment.

### **Sub-category: Provision of Activities and Facilities**

Some of the participants talked about the provision of a personal television, although, several noted how expensive this facility was and also how inaccessible television was for the PWD:

ANDREA: *There is a television by her bed. But I think it's one of those ones that you have to put money in ... She wouldn't know how to use it ... I'll put the money in, but it's- it's just that I know she wouldn't know how to turn it on and off.*

Televisions were not available on every ward:

CLIVE: *... sometimes there was televisions. But on the ward, she was in the acute ward, they didn't have the televisions.*

One person spoke of how the facilities available were not appropriate in the context of the PWD's ability:

*CLIVE: ... with Alzheimer's, she couldn't really tune into the television, or read a book, or anything like that.*

In line with the lack of appropriate activities, one participant spoke of how a nurse tried to settle a PWD with inappropriate reading materials:

*ANDREA: she had a nurse sitting with her... Trying to read the paper with her... to stop her getting up and down ... and.... it's really unfortunate, the headline ... was about ... elderly people not being cared for properly.*

Some participants said that the only thing available to the PWD was a window with a view. Other wards were reported to have day rooms; but, they varied in terms of how well used they were:

*HUGH: Because all of the people were too elderly or infirm ... [the room was] empty ... with chairs and one TV that's never on ...*

*BORIS: they've got a day room, ... it's quite comfortable. ... Got a seating area, and a sort of recreation area. ... you all go into the day room. All the families [meet] in the day room. ... So ... I just used to meet their families, help people's families as well. It was quite a family atmosphere.*

All of the participants reported a lack of adequate provision for activity for the PWD. Diana described how the staff would provide medical care, however, all forms of entertainment had to be provided by the families:

*DIANA: I mean, the ... gestures, doing things for your mum, were done for them by the family, the things done to my mum were done by the medical profession.*

This took the form of providing magazines and company. Boris described how they were able to take the PWD out for a walk within the grounds of the hospital:

*BORIS: I'd take her out into the gardens because it was nice weather then.*

Therefore, from the perspective of the participants, there was little, if any, meaningful provision of activities or facilities for the PWD whilst they were in hospital.

### **Sub-category: Personalisation**

Participants described the varying degrees to which the ward staff were able to personalize care. Participants described how the PWD's emotional needs and personal interests were rarely attended to:

GEORGE: ... *they didn't ask about Gina's social side or anything like that. No, it wasn't 1-1 or personal ... you was just a number. Seems the same in all the places.*

HUGH: *I don't think they ... regard the personality side of things.*

Several of the participants described how they themselves tried to provide meaningful stimuli such as photographs for the PWD. However, those who did this reported that staff would move the photographs as they were unable to accommodate these items due to the demands of care provision, infection control and hospital rules:

DIANA: ... *the next day the picture was always ... propped up somewhere where she couldn't see it. So it was like [the photos were] a bit of ... a nuisance to ... the nurses, which I imagine it was ... because they had to change her and everything.*

However, some nurses did personalize care, although this was reported by one participant as short lived:

DIANA: ... *she had her ninetieth birthday... in the hospital ... they brought a cake at tea time, which I was so touched by, actually ... [and] just in front of the curtains where they put the cards out ... but then the next day they were folded up out of the way.*

Participants, therefore, reported how they tried to encourage staff to personalize the care for the PWD, but in many cases organizational care constraints restricted their attempts.

### **3.1.3 Theme Three: TRANSITIONS IN CARE**

The theme **TRANSITIONS IN CARE** links with both themes one and two, because it captures the experience of times of change throughout the PWD's and the participant's journey through the hospitalisation from the initial contact with **EMERGENCY SERVICES** through to **DISCHARGE** and beyond. Participants shared accounts in relation to **EMERGENCY SERVICES**. The participants' awareness of the PWD experience of **EMERGENCY SERVICES** was dependent on whether or not they were present at the time of the crisis. Those who were present provided accounts of their **experience of staff** and also of **waiting times**.

In contrast, **DISCHARGE** was largely described from the experience of the carer and focused on the processes which were influenced by **power, collaboration and decision-making** by professionals. Another category to



emerge in relation to **DISCHARGE** was community transport, which highlighted some of the difficulties that both the PWD and the participant experienced at this time, namely in relation to communication, waiting time and PWD anxiety.

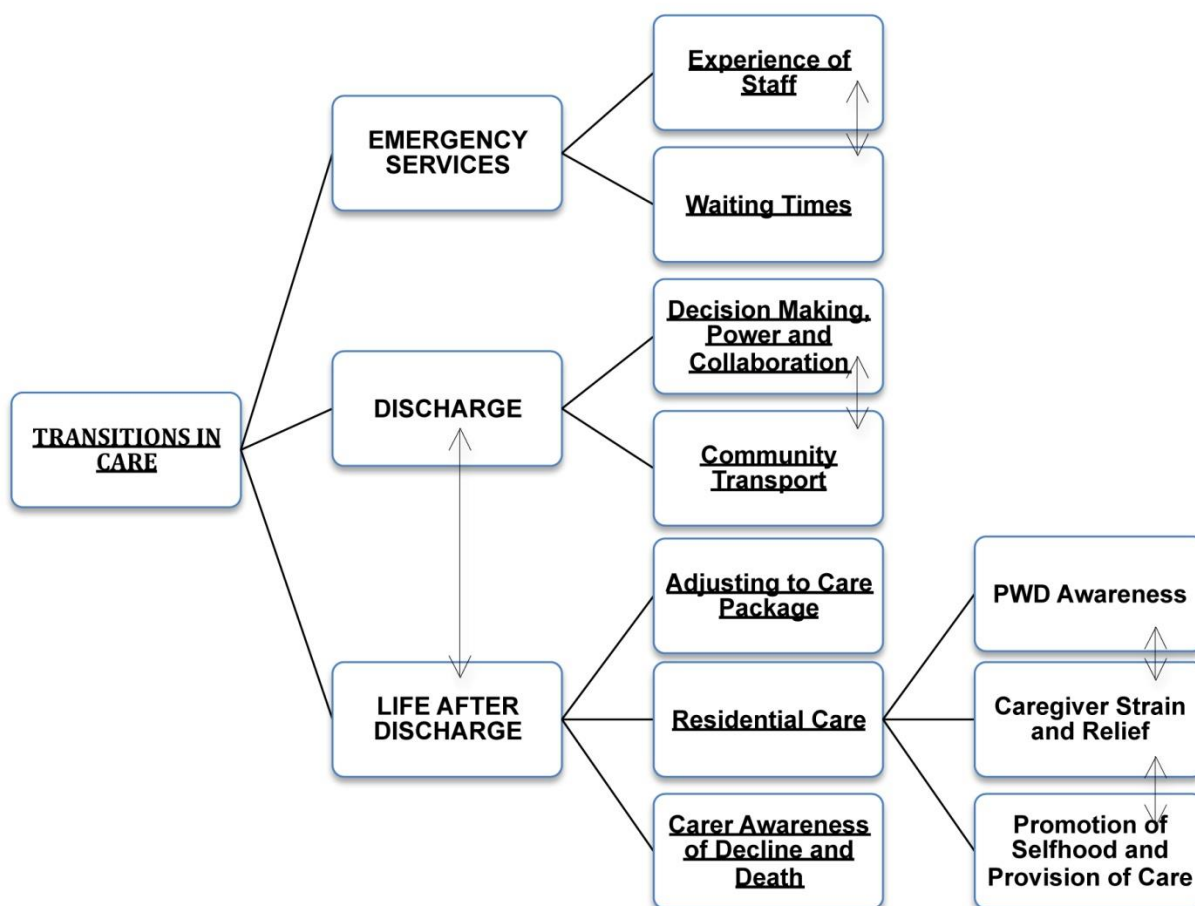
Participants reported how decisions made at **DISCHARGE** interacted with **LIFE AFTER DISCHARGE**. For example, some described how both the carer and the PWD experienced having to adjust to the care package which was put in to place prior to discharge being approved. Some experienced the discharge care package home as either intrusive or helpful. Participants also noted how some PWD found the new community care regime confusing. Thus, the experiences here, were associated with PWD COURSE OF ILLNESS IN THE COMMUNITY. However, discharge did not always lead to the PWD returning home, with some being discharged to **residential care** or to a different care home from which they had been admitted.

Residential care was associated with **caregiver strain and relief**. Participants described how the PWD was not always aware that they were now living in residential care (i.e. **PWD awareness**) and many described being impressed with how the staff managed to maintain and promote the PWD's individuality through **promotion of selfhood and provision of care**.

Some participants also described the PWD's future in terms of their ongoing decline, whilst others spoke of how the dementia will led to the PWD's death (**awareness of decline and death**).

The narrative account that follows explores the various levels emerging as core categories. A diagrammatic overview, illustrating the interaction between the categories, can be seen in Figure 3.4.

Figure 3.4 A Diagrammatic Overview of Theme Three: **TRANSITIONS IN CARE**



### **CORE CATEGORY: EMERGENCY SERVICES**

The two categories associated with **EMERGENCY SERVICES** illustrate the experiences of both PWD and their carers of emergency service staff, as reported by participants. Participants also described their experience of **waiting times** at accident and emergency (A&E) departments.

#### **Category: Experience of Staff**

Participants described their **experience of staff** specifically in the context of **EMERGENCY SERVICES** i.e. paramedics and A&E staff. Participants reflected on their experience of the ambulance service. Some carers

described having a choice of which hospital the PWD would be taken to, others said that they were not given a choice by paramedics. The latter situation appeared to be associated with clinical judgment and strategic management of service provision:

GEORGE: ... *they said [they could only take my wife to] only one [hospital] because they came from [x hospital].*

Participants spoke of paramedics' relationship with the PWD, describing them as reassuring:

BORIS: *she was very confused ... [but the paramedics] they were very good, very patient and very professional.*

Similarly the staff in A&E, were described as being able to calm the PWD:

BORIS: *I don't think she was too bad at that occasion, but we'd been ... to A and E a number of times, and sometimes she hasn't reacted very well ... [she] tried to escape from the ... profile bed ... [but] they've managed to calm her down.*

Some participants described how staff asked them to help settle the PWD. Boris described how the paramedics asked him to travel in the ambulance with his wife:

BORIS: *I was gonna drive behind the ambulance, but they said 'No, it's best to stay [with her] here [in the ambulance] to calm her down.'*

Others described how they stayed with the PWD in A&E to help settle them, and this experience appeared to be related to **waiting times**.

### **Category: Waiting Times**

Participants had varying experiences of waiting times in A&E departments. Boris described how his wife was fast tracked due to her dementia diagnosis:

BORIS: *[Bernice] went in [to] A&E, but she was put to the front of the queue... Well, because she's got dementia... They seem to prioritize dementia.*

Others described waiting between 3 to 19 hours before they were seen. Delays were attributed to various factors, including the time of year, staffing levels, hospital crisis and lack of beds:

DIANA: *So we go to hospital, it's very busy, it's pre-Christmas, when it's a very busy time, I'm told, that 'Oh gosh, it's the time when everybody dumps their old people on us. We are so busy.' But um, my mum is eventually washed, taken up to a ward.*

GEORGE: *It wasn't so good when she was left on a trolley there [for] 3 hours, something like that before they decided to move her [to a different hospital] ... [because] ... they were at crisis level.*

FREDRICK: *... she was put in assessment for eight, ten hours, and then they took her up into the stroke unit. They didn't have anywhere else for her to go at the time, so...*

One participant described how waiting times were experienced as chaotic:

FREDRICK: *In the x. It's like a cattle market in there. It's bloody dreadful....*

Therefore, people had varying experiences of waiting times, due to issues associated with organizational care management systems.

### **CORE CATEGORY: DISCHARGE**

The core category reflects the process of **DISCHARGE**. The participants described a sense of powerlessness in relation to decision-making and felt that at times they were unheard. Some described how neither they, as a carer, nor the PWD were involved with the decision-making. They also described difficulties with practicalities at discharge. These accounts gave rise to the categories: **power, collaboration and decision-making** and **community transport**.

#### **Category: Decision-Making, Power and Collaboration**

Participants described variations in the time frame within which discharge was made. For example, Andrea described how, not long after admission, the nurses were considering her mother's discharge. This was anxiety provoking for the participant:

ANDREA: *... she'd only been on the ward a few hours... And they were trying to talk about her situation ... [and] sending her home. ... And I thought 'Well,, she's got to get better before she can get home!'... I'm presuming that they'll be professional, and they won't send her home unless she's safe to go home ... and I think that that's probably their responsibility at the moment, not mine.*

Edward associated rapid discharge, with staff lacking concern about his mother's health:

EDWARD: *... she was off the critical list, so I don't think they were bothered with her, really. She wanted to go, they said she could go.*

Edward went on to discuss how, at a later admission, his mother was kept in hospital so that appropriate care plans could be developed:

EDWARD: *She was declared fit to leave hospital after about five days ... But it then took a total of thirteen days before the care plan was in place.*

Other participants, who also described how the decision to discharge lacked collaboration, shared this experience. Delays in discharge were associated with professionals and family members expressing concern about the participant's ability to cope with continuing to care for the PWD:

EDWARD: *They [said they] would not release [Eve] back home until they'd done a proper assessment, put in a care plan.*

DIANA: *... they have kept [Debra] in the hospital because there was a problem with the siblings. ... Everybody, my two sisters, think that I can't cope, and neither can the children at home.*

BORIS: *Well, they said that care had to be put in place before [Bernice] was released ... they ... dictated it to [me]... They knew ... [I] needed that care [package].*

There were also doubts about the PWD's ability to continue living independently in the community:

HUGH: *... social services said 'Look, yeah, it's out of your hands anyway. We couldn't let [Harold] go back home like this.' And I knew in my heart that no, he can't. We can't let him go home, y'know. Because he doesn't have the capacity to look after himself.*

Professionals, therefore, were described as authoritative, key decision makers in relation to discharge. However, participants did report experiencing greater collaboration in relation to negotiating discharge care packages and also choice of care home:

DIANA: *Well, the care package, it was discussed ... and they said 'the best thing is to take ... on as much as is offered you. And then you can just pare it down.'*

HUGH: *I was recommended by the panel, which consisted of the doctors, social services, and the nurses and the sisters who looked after him ... They said ... that 'You need to start looking for care homes.' And they gave me a list of three possible ones that were suitable for ... So, I trawled through those ...*

However, participants reported that the PWD was rarely consulted:

DIANA: *the discharge nurse was nice, but she didn't have much ... to do with the patients...*

And even where the PWD was consulted, they did not have much choice:

EDWARD: *Well, she kind of understood that it was necessary [for her to have home care] in order for her to be at home. But she didn't really like it ... 'Well, I suppose I'd better have them, otherwise I can't stay here [at home]'...*

Therefore, participants discussed having little choice and there being collaborative little working with professionals in relation to clinical decisions

regardless care packages and location of discharge. Decisions were often made in isolation and without the PWD being consulted or involved.

### **Category: Community Transport**

Participants spoke of the transition from hospital to home or residential home. Some participants described how miscommunication with community transport providers made transition difficult:

*FREDRICK: ... found the ambulance service pretty abysmal, because you ... were ... told that an ambulance was gonna arrive at eleven o'clock, and it'd be four o'clock in the afternoon before it came.*

The wait for transport contributed to a sense of frustration and distress for both PWD and carer:

*FREDRICK: Of course, she was getting distressed. I was getting angry.*

*CLIVE: [It was a] bit stressful, because [we were] waiting a long time for an ambulance ... we waited nearly the whole day for her [my wife] to arrive.*

Another participant described how journey from the hospital contributed to the PWD's distress:

*BORIS: Yeah, she was panicking in ... the ambulance bus. So I had to leave the car at the hospital and go down with her. Yeah, oh, they asked me to. Well, actually, [they] were ... delivering ... other patients round other care homes ... so it took about two hours getting down there ... I was holding her hand.*

This experience of waiting for and using community transport was described as distressing for both the PWD and the participant.

### **CORE CATEGORY: LIFE AFTER DISCHARGE**

All but one of the PWD that the participants were describing had been discharged from hospital at the time of interview. However, all were able to provide an account of what life had been like following discharge (the one PWD who was in hospital at time of the interview had experienced repeated admissions and discharges). The participants described how both they and the PWD had experienced and coped with **adjusting to care packages** that were developed as part of the discharge care plan.

Participants of PWD who had been discharged to a care home, whether returning or for the first time, described a period of adjustment in the context of

**residential care.** Finally, a category was identified, which captures **carer awareness of decline and death.**

### **Category: Adjustment to Care Package**

Participants described how both they and the PWD adjusted to the care package. Some described how they, the participant, and the PWD, experienced the care package as helpful:

DIANA: ... *now, I feel ... in a way it's a bit easier. I've got people coming in to care ... to ... do the cleaning as well.*

In contrast, some described the care packages as intrusive, disruptive and distressing:

EDWARD: ... *it's quite intrusive [for my Mum].*

DIANA: ... *it is very intrusive, and it's very intrusive for her as well ... I would tend to wash her when she was ready, or I'd tend to sit her on the commode when she was ready, and then change the bed at that time. But, because people are coming in, they have to do it. So now ... I come into the kitchen, and I can just hear the screaming.*

Similarly, Edward spoke of how the new care plan disrupted his mother's life long routines:

EDWARD: *One of the things that she really didn't like about ... the care plan, was that these people were given the job of coming in four times a day... there was an afternoon visit around tea time... [but], five o'clock isn't the time [she eats] ... [but] she's had [eaten later in the evening] all her life. And now she's being told to... this visitor will put food on the table for her at five o'clock. Um... she didn't adjust. She protested... we'd tell [the carers] 'She wouldn't mind a chat...' 'Come round for a chat.' But they couldn't do that. Because that's not in the care plan ...*

Also, Edward described how the new regime confused his mother:

EDWARD: *The blister pack system just completely confused her... And, she never did get the idea that, actually, you don't need to write it down, because ... it says that it's Sunday!... But she would be writing down 'Sunday the twenty, taken that tablet. Taken that tablet.' Of course, we never knew that that was the truth.*

Some described how, when the PWD returned home, they observed loss of confidence and also incontinence, with PWD now wearing pads when they hadn't done so prior to admission:

BORIS: ... *from that visit in hospital, she's started wearing pads then. [Bernice] didn't previously.*

DIANA: *I think her continence has got much worse. I think she's now ... I think her confidence has gone down a lot, um...*

Diana spoke of how Debra was adjusting to returning home:

DIANA: *... it's nearly a week she's been at home now, but she's slowly settling down.*

Others described how they, too, as carers, had to emotionally adjust to the new care plan:

DIANA: *... I now feel in control. I was- I felt so out of control in the hospital.*

### **Category: Residential Care**

Some of the participants spoke of the transition from hospital to residential care and EMI homes. (The term 'residential care' is used here to describe all types of care homes). Participants described their own experience of **caregiver strain and relief** and also of the **PWD's awareness** of the transition. Participants tended to describe the PWD's experience of care at this time and their accounts are coded in terms of the sub-category: **promotion of selfhood and provision of care.**

### **Sub-category: PWD Awareness**

Participants spoke of the PWD's awareness in terms of the insight that they had when they moved to a care home or a new care home environment from hospital. Some spoke of how the PWD did not have any awareness of the transition:

BORIS: *I thought if she'd realised it was a care home, she was ... going in, but she was very calm about it. They all- they sat her down, and... All the nurses came around, one by one, and made a fuss of her, and she was smiling and I was very relieved.*

CLIVE: *... she didn't have any awareness at all, no, we- we just called her an ambulance, and we waited in the new care home for her. ...But then, she came in, and she was fine.*

However, this was not true for every PWD:

HUGH: *Um, the transition, literally going from hospital to the place, seemed smooth. He didn't wanna come out of the ambulance, apparently... But, the nurse ... who was his nurse-in-charge .. she went into the ambulance, had a chat to him and took him in. And he was fine then. I think a bit of reassurance...*



Participants also suggested that the PWD's awareness of where they were fluctuated and in some cases strongly reduced. The level of awareness was also associated with whether or not they were described as settled:

EDWARD: *She thinks she's in a hospital now. Well, actually, it's rather funny. She's in a nursing home, but sometimes she thinks she's in a hospital. Er, the last time she thought she was in a school. Erm, which I didn't understand!*

CLIVE: *... the care home, it's like a like a new home. I'm sure she's accepted it as her new home.*

HUGH: *I took him back to the home [and] ... that's when the aggression started, because he realised where he was ... he said 'Oh, I'm here, am I? I didn't wanna go back here, I told you.', and he said 'You- if your mother knew what you've done to-...'; and then he started throwing chairs around in the [care home]. Then he started tipping drinks. Then he started shouting at the residents ... it was quite horrible...*

PWD's awareness and response to the transition was also seen to be related to some degree to **caregiver strain and relief**.

### **Sub-category: Caregiver Strain and Relief**

Participants described their own feelings in relation to the PWD's transition to a residential home. As suggested in discussing the previous sub-category, participants described experiencing relief when they thought that the PWD had accepted and settled into their new place of residence. Participants also spoke of the sense of relief they experienced, as they themselves adjusted to changes in their care responsibilities:

BORIS: *It's like a pressure relief er, coming off my shoulders then.... I haven't really accepted it yet, mind, she was gone. That'll probably take a while to ... get through that.*

HUGH: *... And I haven't got to worry tonight what's gonna happen to him. I haven't got to worry like I- I had to ring- to ring him, about six, seven o'clock, 'You off out tonight then?'... constantly trying to track him ...*

However, Clive did speak of the ongoing care role:

CLIVE: *you never stop caring, even when your other half's gone into a care home. Because you're- you don't just say 'Right.' Because you're still caring, you still go and visit, you still have to provide the clothes, and arrange for the hairdressing and the chiropodist, and the opticians and all that sort of stuff. You're still caring, but you haven't got the physical care where you've got to bath and wash and dress. You- you always care, you're- you're a carer forever ....*

Hugh described how he was still adjusting in terms of learning how to be with his Dad in the context of emerging behaviours associated with continuing decline. This was a source of on-going strain:

HUGH: ... *this is all new for me ... I'm learning as well, and I've tried to learn not to get angry when he's aggressive to me ... I see my dad, I don't see dementia. I just see that this- this man is behaving out of order, he's wrong. He needs to be told. But, y'know, I- I don't know if that was right or wrong.*

Clive described how the whole period of change and decline had been experienced as a strain:

CLIVE: *It's all been a shock, still- we're still in shock really, I think, now... I think I'm still in shock, and getting over it. Um, but you've just got to adapt.*

However, even with the sudden and unexpected decline, Hugh described how his father moving into a care home was more bearable than his death, as it allowed him to adjust to these life changes with greater ease:

HUGH: *So this [the move in to a home] is a relief all round. And to clear the family home away, in a circumstance that's not tragic, because he's not died, where it would have been terrible.*

However, some participants described how the emotional adjustment to the PWD's deterioration was an ongoing source of caregiver strain:

HUGH: ... *when I realised that he wasn't going back home again ... I broke down in [my place of work] crying, and I don't cry very often. I just couldn't stop myself thinking that I wouldn't be going back home again. And, y'know, that hit me in [work]. I broke down completely. But I thought I was okay. And then I became ill. And now he's back, now he's safe and sound. There's a clear future for him. A clear path. I have become better again. So...*

Therefore, transition to **residential care** was described as a relief for carers, with ongoing strain being associated with the continuing care role and adjustment to the PWD's decline. However, carers did find the level of personalized care provided in the homes as both comforting and reassuring. The experience of the provision of care was, not surprisingly closely associated with **caregiver strain and relief**.

### **Sub-category: Promotion of Selfhood and Provision of Care**

Participants spoke of the residential homes with warmth. They described staffing levels and intensity of care provision as preferable to those that had been experienced in the hospital setting.

BORIS: *Well, she's getting a lot of extra care there as well because I think there's about one nurse for every three patients.*

Participants described how they experienced staff as interested in the PWD:

HUGH: *They've also asked me ... to create ... a memory box [I put in] photographs, that he'd had in a shoebox for years, all of me, all of him, me and him. Me and my mum. The three of us together, his family, my- my mum's family.*

Participants also described how the residential homes collected biographical information to ensure that those working with PWD, knew how to meaningfully engage with them:

HUGH: *... they've got a little profile in his room, by the door ... and I had to write an A4 pen portrait about his life...As if he's speaking. 'My name is...', 'I live...' 'My wife was called...' Things like that. So, as if people want to visit, or do visit, or nurses, doctors, and they need to engage in conversation with him about something. They can sort of read a couple of things about that, and then have a chat to him about it. 'Oh, I see you still like cars then.' ...*

Others spoke of how rooms were personalized with the PWD's belongings:

FREDRICK: *... [Francis has] got everything, she's got TV, she's got a radio, she's got all her ornaments ... she's got flowers and ... pictures there, and we put a thing on the wall, and.... you can take furniture in if you want.*

Participants described how they thought the PWD was happy, describing a range of available activities and noting how the environment was sociable and accommodated to the PWD's communication needs:

BORIS: *... [Bernice] hasn't been in the care home for long, but she seems to be very happy with all the people there .... She can't talk with them, but... She's happy ... in their company ... She's got another friend who likes wandering as well, and they hold hands and go walk...*

HUGH: *... they do activities, they [the staff] engage them in very very good things like, for instance they had, for an international rugby game they had a big screen, burgers, hot dogs, ice cream.*

One reflected how the care home had familiar memorabilia from his mother's earlier years:

EDWARD: *They have these ... mementos ... from the nineteen fifties stroke sixties ... That kind of era, which I guess ... the people in there will have come through the fifties and the sixties.*

Participants spoke positively about the care that the PWD was receiving, reflecting on how well they were looked after:

CLIVE: *... [Chrissie is] healthy, and well-looked after, well-dressed. Girls make her up every day, and she likes her clothes and her jewellery and that sort of thing, so she's always got costume jewellery on... Sometimes I feel as if I'm intruding when I go there ... it's like another little family.*

Fredrick thought the level of care was, in part, a reflection of the training the care workers received:

*FREDRICK: [Francis] is in an EMI home ... therefore, [only] people with dementia [are in] this home she's in ... [the care workers] they're trained... To deal with people with dementia, so, it ... [makes] a tremendous difference.*

The residential home experience appeared to facilitate and encourage the expression of individual difference through providing high levels of individualized and personalised care.

### **Category: Carer Awareness of Decline and Death**

Although few participants explicitly discussed the person's trajectory in terms of dying, there was an awareness of ongoing decline after discharge. One participant considered the PWD's ongoing decline in the community and changes in independence:

*ANDREA: Even with an increased care package [I'm not] ... sure that Mum [is] gonna cope on her own any more...*

For PWDs who were already in a care home, participants focused less on changes in independence and more on continuing cognitive decline in terms of orientation, awareness and communication skills:

*FREDRICK: it's very strange ... I think I am losing her ... I think her mind's going a bit more now, she's er, er, where I could have a little bit of conversation with her, it's gone now, absolutely. Um, she still knows me.*

*HUGH: I'm very well aware that things might, sort of, get- well, they will get worse, I know that. Um, and it might come a point where he might not know who I am ... and he might just- he might think I'm his father or something, or... You don't know ... I'm prepared for- I've heard of people saying that.*

In contrast, Diana was able to see the trajectory of her mother's dementia in terms of death:

*DIANA: I know it's going to end in death, I mean, she's going to die of dementia. Because I know it's a disease, and it kills old people, especially women.*

Although, Fredrick demonstrated similar awareness of his ongoing loss when discussing his wife's decline, he was unable to continue with the conversation:

*FREDRICK: It's like I've lost my arm, really. Y'know. Anyway, she erm... [talking about it] it'll start me off [crying] in a minute.*

### 3.2 Summary of Results

The aim of the study was to explore the experience of PWD's hospital stay, for physical health conditions. As noted in the introduction, there is a dearth of literature exploring the PWD's experience of hospital stays, with existing studies examining staff (e.g. Noolan, 2006) and carer experiences (e.g. Aggarwal *et al.*, 2003; Bauer *et al.*, 2011; Bloomer *et al.*, 2014; Clissert *et al.*, 2013; Jurgens *et al.*, 2012; Whittamore *et al.*, 2014) of care provision. Therefore, the existing study aimed to expand the literature base, by beginning to explore the PWD's experience of hospital stays, as described by a carer.

A constructivist grounded theory of PWD's experience of hospital stays was developed from interview data with eight carers of PWD. Three key themes emerged: **COURSE OF ILLNESS IN THE COMMUNITY** (which described (i) the PWD's deterioration in the community and associated (ii) caregiver involvement); **EXPERIENCE OF ORGANISATIONAL CARE** (which explored (i) caregivers ongoing tasks whilst the PWD was in hospital (ii) how caregivers formed judgments on quality of care and (iii) the PWD experience of belonging, safety and physical care); and **TRANSITIONS IN CARE** (which included participants' accounts of the emergency services, discharge and life after discharge). The experiences of PWDs' hospital stays for physical health conditions were found to cover a context wider than the hospital experience alone. Furthermore, the three key themes were found to be loosely related to one another, as might be expected given the complex nature of care provision and service delivery, both preceding admission and following discharge.

The key themes will be further discussed in the following chapter, in the context of existing research and the, clinical and service implications of the findings.

## **Chapter 4**

### **Discussion**

#### **4. Overview of Chapter**

The chapter summarizes and synthesizes the findings in the context of the existing relevant research, drawing comparisons and identifying gaps in the literature that this study addresses. Arising clinical implications for services are considered and followed with a discussion of the methodological strengths and limitations of the study. The chapter concludes with recommendations for future research and a concluding summary.

#### **4.1 Research Findings and Existing Research**

The main purpose of the study was to understand the experiences of PWD during hospital stays for physical health conditions. Three key themes were identified: course of illness in the community, experience of organization care and transitions in care. The main findings are discussed below, in relation to the existing literature and psychological theory.

##### **4.1.1 Theme 1: Course of Illness in the Community**

This theme captured the experience of the PWD's course of illness in the community, highlighting the trajectory of PWDs' declining physical and mental health in the community, which preceded hospital admission and co-occurred alongside recurrent hospital admissions. Thus a key and implicit feature of this core category was transition; Meleis' (2000) asserts that transitions are precipitated by significant events, which require new patterns of response. Schumacher, Jones and Meleis (1999, p.2) argues that transitions are 'a passage between two relatively stable periods of time' during which, individuals move from 'one life phase, situation, or status to another.' Based on this middle-range psychological theory of transitions, it is recognized that

with regards to dementia that transitions are an ongoing theme for people. Transitions in relation to the course of the illness in the community, were conceptualized here through two core categories: PWD deterioration and caregiver involvement.

#### **4.1.1.1 Core Category: PWD Deterioration**

Carer reports of the PWD deterioration in the community were associated with dementia and mental health and also physical health, this supported existing findings, which show that PWD are at greater risk than people without a long-term health condition, of developing an affective disorder (Naylor, Parsonage, McDaid, Knapp, Fossey and Galea, 2012). The participants appeared to differentiate between long standing mental health difficulties and the exaggeration of these symptoms in the context of dementia. Others described how the experience of labile mood was new and the difficulties they had in adjusting to the new presentation, something the Alzheimer's Society says is not an uncommon experience (Alzheimer's Society, 2013).

Interestingly decline in relation to dementia was conceptualized as changes in ability leading to increased dependency, with few focusing on the impact this had on the PWD in terms of socialization and personhood. Instead, carers discussed changes in ability, which required greater task based care. This appeared to be at odds with their role of advocacy in the theme that follows, whereby carers wanted staff to consider the PWD as a person, rather than a medical body, which required care tasks (see Section 4.1.2). However, the focus on care tasks may reflect how when providing care, carers' focus on the task at hand due to their sense of responsibility, fear of criticism from services and family members and also, due to being under pressure to provide good enough care.

The Stress Process Model of caregiving, provides a framework through which to understand these findings (Pearlin, Mullan, Semple and Skaff, 1990). The model illustrates four domains of multiple components across time, which influence the way the carer perceives their own stress. The psychological model provides an overview of the: (i) background and context of stress; (ii)

stressors; (iii) mediators of stress; and (iv) outcomes or manifestations of stress for carers. Pearlin *et al.* (1990) argue that the mix of circumstance, combined with experience, response and social resource, significantly impact on caregiver's behaviour, health and also, the way in which they perceive other's judgments i.e. as threat (criticism) or support. Therefore, in this context, carers own biography, might act to influence their sense of responsibility and duty to provide care and also, the quality of care that they provide.

The conceptualization of PWD deterioration also included decline of physical health. Some reports of decline were more clearly attributable to dementia than others e.g. stroke versus urinary tract infection. The generalized deterioration reported by participants, therefore, mapped on to psychological theories of dementia staging and medical conceptualization of dementia as a progressive syndrome (see Chapter 1, Section 1). NICE (2006) note that deterioration can be exacerbated by psychological distress; however, within this study, the causes and the experience of distress for the PWD were not ascertained. Instead, the study highlighted the intricate nature of mental health, physical health and dementia, with carers describing how it was not clear as the causes declined were not clear e.g. was a lack of self care a consequence or a causal factor in the worsening of dementia, and mental and physical health. This perhaps can be understood through psychological theory, which would suggest that there is an independent association between emotional distress and physical illness (Delahanty, Grant, Wittenberg, Bosch, Wexler, Cagliero *et al*, 2007).

It was perhaps no surprise that participants reported a cycle of recurrent hospital admission; statistics within one English Health Board demonstrate 8.2% of PWD are admitted following an elective procedure, increasing to 25% after a non-elective admission (Dementia Action Alliance, 2012). However, the impact on the PWD of repeat admissions was unclear from this study, although it was highlighted how declining health increases the risk of hospital admission for PWD.



In line national with statistics (e.g. Alzheimer's Society, 2009), seven out of the eight PWDs were admitted to hospital from a place of residence in the community, compared to one person who was admitted to hospital from a care home. This reflects the estimated PWD residential split within the UK, with two thirds of PWD living in their own home and one third living in a care home (Alzheimer's Society, 2007).

#### **4.1.1.2 Core Category: Caregiver Involvement**

Participants spoke of their caregiver involvement and described how they experienced an emerging care role, which involved liaison and care provision; this was accompanied by a process of adjusting to the care role; this supports interactionism and structural role theory, which suggests that the role-making processes inherent in caregiver role acquisition occur through situated interaction. Hence, transition, and adjustment, to becoming a carer is known as role-acquisition and can be understood to a process, which is developed through interactions between the carer PWD and others (Schumacher, 1995).

The liaison and care provision role reflected the nuances of the practical aspects of caring. In line with Roy and Gillespie (2011), findings here suggested that carers would assume the role of liaising with relevant care professionals to maintain care, thus enabling the PWD to keep their independence in the community. Furthermore, it was found participants who shared a home with the PWD were more likely to provide hands-on care, such as personal care. In contrast, those who commuted to visit the PWD in the community provided less invasive personal care based tasks e.g. dog walking, providing meals and company. Both groups of carers reported significant caregiver strain; however, in some cases the extent of the strain had not been realized whilst caring for the PWD in the community (see Section 4.1.2 for more discussion of the carers awareness of caregiver strain). This supported the findings of Spencer Grey (2011), who found that carers did not seek help early on, because it took carers time to realize that they were not coping. In line with the Stress Process Model (Pearlin *et al.*, 1990), the study presented here found that the intensity of the relationships and the perceived sense of responsibility to provide care for relatives with dementia, meant that carers

prioritized the needs of the PWD over their own. This was thought to be a consequence of their values and thus, might in part explain why carer distress in this population is significantly under reported (Neil and Bowie, 2008).

Furthermore, theories of learned helplessness posit that high levels of stress, impact on subjective wellbeing, physical health and self-efficacy, which are collectively related to depression (Martin, Gilbert, McEwan and Irons, 2006). It maybe that given the context, carers' attribute the stress that they are experiencing to the ongoing demands, rather than recognizing an emerging depressive type episode. Depression is commonly associated with self-neglect, social isolation and apathy; these aspects of depression, may further contribute to them neglecting themselves and failing to utilize support networks appropriately, whilst also using their remaining energy to support the PWD, which is reinforced by their value base. This maybe specifically true in populations, who have learned helplessness and associated depression (Pinquart and Sorensen, 2003).

The sub-category 'adjusting to role' reflected changing relationships. The findings supported existing research, with carers balancing the emerging role with personal relationships and also the demands of their job (Dolan and Thien, 2008; Pinquart and Sorensen, 2006; and Scharlach, Gustavson, and Dal Santo, 2007). Skaff and Pearlin (1992) theorised these changes in the carers (re)-organization of their lives, as a reshaping in self-concept, leading to shrinking or loss of self due to 'role engulfment.' Similarly to Skaff and Pearlin (1992), carers within this study reported both loss and gain with the adjustment to the care role. The gain was often seems in terms of closer relationships with the PWD and increased family support e.g. sharing the caring role between siblings.

Caregivers described varying levels of involvement at the time of the physical crisis which immediately preceded admission. It is unclear whether this was a consequence of some carers not being present at the time of crisis or whether it was a reflection of the extent of the physical illness and the PWDs' dementia impacting on their ability to articulate their distress. The dearth of information as to the PWDs experience at this time was also considered to possibly reflect

reduced empathy due to caregiver stress. Such a response might protect the carer from the emotional burden of understanding their loved one's experience. This may have been particularly true of the six male participants. Research shows that male caregivers are more likely to process their emotions privately and are also less likely to admit their negative feelings, compared to females (Baker, Robertson and Connelly, 2010; Sanders and Power, 2009). These concepts offer a framework through which to understand the lack of information that participants volunteered with regards to the PWDs' own emotional response at the time of the physical crisis.

Therefore, carers' responses to crisis are contextual and may depend on their own capacity to cope with the shock of an acute physical crisis. The findings contrast with those of Clissett, Porock, Harwood and Gladman (2013), who suggested that family members of PWD experience less shock in response to an acute physical crisis, compared to family members of people who experience stroke and traumatic coma. But the findings here are in line with previous research (e.g. Bloomer, Digby, Tan, Crawford and Williams, 2014) which suggests that carers may need additional support from others, not only with the practicalities at the point of crisis, but also in the decision to admit a person to hospital. This maybe particularly true where carers experience anxieties based on previous negative experiences of hospital admission (Jurgens, Clissett, Gladman and Harwood, 2012). The issue of seeking help at time of crisis, warrants further research in areas over and above theories of coping styles.

#### **4.1.2 Theme 2: Experience of Organizational Care**

The second theme to emerge from the analysis was 'experience of organizational care'; this captured both the carers' and PWD's perceptions of care and also the subjective and self-defined role of the carer within this setting. The experiences of the PWD and carers, in this context, were classified in terms of three core categories: caregiver tasks; forming judgments on quality of care; and PWD experience of belonging, safety and physical care. These are discussed on the pages that follow.

#### **4.1.2.1 Core Category: Caregiver Tasks**

Carers described experiencing a sense of responsibility, which was reflected by carers engaging with a series of practical and emotional tasks. These findings supported those of Bauer, Fitzgerald and Koch (2011), who also found that carers' motivations to continue to provide care tasks included compassion for nursing staff, observations and concern about insufficient care, response to nursing requests and also difficulties in nursing staff meeting the basic needs i.e. nutritional and personal care needs, of the PWD.

Carer need to help and provide support on the ward may have also reflected their level of sympathy that they had for the PWD, when admitted to hospital. Psychological theories of sympathy and empathy, suggest people who have high levels of sympathy and low levels of empathy seek to do tasks for others, rather than trying to sustain the care-receiver's emotional involvement with regards to their abilities and hospital admission (Paris Stephens, 1990). Caregivers may experience reduced empathy at time of crisis due to feelings of distress and anxiety (Batson, Fultz and Shoenrade, 1987).

Clissett *et al.* (2013) described how participants sought to protect the PWD through advocating on their behalf. It was reported that carers would advocate to try to influence care and treatment plans. Similarly, the findings from this study highlighted how carers adopted an advocating role for the PWD. However, the focus here was largely on carer attempts to share with staff details of the person's preferences of care and also, aspects of their personality and interests (see Section 4.2 for Implications for Practice).

Interestingly, however, staff at times placed the carer in the advocating position through seeking permission from participants to not provide aspects of care or to reduce the frequency of care. Permission was sought when the PWD was resistant to adhering to the care plan, for example with regard to washing and dressing. It appeared that staff used carer feedback rather than feedback from the PWD to inform care provision; this mirrors psychological theories of advocacy, whereby staff direct information seeking away from the patient and more toward the advocate and also, how patients position responsibility on the advocate to assist them in the decision-making about

health issues (Petronion, Sargent, Andea, Reganis and Cichocki, 2004); this maybe more prevalent in dementia populations, by virtue of the illness.

Furthermore, it could also be hypothesized that had staff gathered biographical information, they may have been able to develop a more person centred care plan which fitted with the PWD's preferences. Staff reluctance to follow PWD feedback highlights the need for carers to advocate on the PWD's behalf. It also raises questions with regard to how staff view the PWD and the PWD's ability to accurately convey their own needs and preferences (see Section 4.2 for Implications for Practice).

Participants reported a delayed awareness of caregiver strain, with many being unaware of the toll that caring in the community had taken on them until the PWD had been admitted to hospital. The delay in awareness of caregiver strain may in part reflect the disproportionate number of males to females (male to female ratio 3:1) who participated in the study. For example, psychological theories of coping styles have illustrated that there are differences between male and female coping styles, with women using more emotion-orientated methods, compared to men who are more independent in their approach and are less likely to seek help from formal services (Baker and Robertson, 2008; Cahill, 2000; Zodikoff, 2007).

However, it is of note that a number of male participants in this study had sought support from third sector organisations which led to them to develop informal networks with other male carers. However, support from third sector organisations was sought in order to help the PWD, rather than the carer themselves. Therefore, third sector organisations may be well positioned to engage male carers when they bring the PWD to groups. Such indirect involvement may feel less threatening to their masculinity (see section 4.2 Implications for Practice).

Experiences between participants not only reflected gender, but also differing kinships, and both of these variables have been found previously to affect carers' levels of worry and sense of burden (Sparks, Farran Edward and

Keane-Hagerty, 1998). The age variable is therefore, also of interest here, as some of the participants were adult children and others were spouses.

Psychological theories of coping suggest that spouses and adult child carer's experience different stressors due to the nature of their relationship to the PWD (Parris-Stephens, 1990). For example, spouses experience a loss of a life long partner and confidant. In contrast, adult children may, for the first time, become aware of their own and their children's frailty, they also might develop concerns about hereditary factors of the disease and are likely to have additional stressors due to the need to manage multiple roles (Broody and Schoonover, 1986). Thus psychological theories of coping, offer us a framework to understand carers experiences in the context of age, gender and biography e.g. Process Stress Model (Pearlin *et al.*, 1990). Regardless of aetiology of stress, however, dementia carers do appear to experience the intensification of loss and demands on them, as the PWD's illness progresses (Mace and Rabbins, 1981).

Another sub-category to emerge from the research was visiting, where participants reported barriers to visiting including geographical distance. This was an issue for both long distance carers and home carers where, for the latter, the nearest hospital was often a considerable distance. Another barrier to emerge for one carer was associated with no longer being able to drive. Although this was a problem for only one participant, the impact of not visiting is a worthwhile avenue of research, specifically looking at the impact on the PWD and also the carer's psychological welfare. Not visiting was associated with feelings of guilt and worry for the carer. Although, the research findings here did not address the PWDs' experience of not having visitors, research suggests that PWD find visits both comforting and reassuring (Digby, Moss and Bloomer, 2011).

Barriers to visiting were associated with ward flexibility and visiting times, with some wards being more flexible in their approach in allowing carers to visit the wards outside of the allotted times. Interestingly, since this research was undertaken steps have been taken by political leaders to further promote dementia-friendly hospital environments, with the Minister of State for Care

and Support and the National Clinical Director for Dementia calling for hospitals to consider 'carers of people with dementia who are in hospital, to be allowed the option to stay with that person outside of normal visiting hours or even overnight ... They [carers] are requesting that they also be allowed to visit, care and stay with the person with dementia that they care for outside of normal visiting hours' (Department of Health, p.1., 2015b).

Similarly to Clissett *et al*'s. (2013) study, participants described how at visiting times they experienced difficulties in interacting with the PWD. This was attributed to worsening symptoms of dementia in the context of poor physical health i.e. the health condition exaggerated difficulties that were a product of the dementia. In addition to Clissett *et al*'s. (2013) findings, this study found that some carers reported themselves as being unable to authentically connect with the PWD. This was a consequence of the carer wanting to appear to the PWD as if they were coping, in order not to impact negatively on the PWD. This was conceptualized within this study as PWD's cognitive and carer's emotional availability to connect, because of the carer's limited emotional availability due to coping style and also, the PWD's reduced ability to effectively communicate. The latter experience is inline with communication and linguistic theories, which highlight the increasing communication barrier as dementia diseases progress and also, how communication breaks down at different stages of the disease (Small, Geldart and Gutman, 2000). Future research therefore, should endeavor to focus on ways to support PWD and carers with communication, in order to promote interconnectivity and thus, reduce the risk of social isolation. This is important, as psychological theory would suggest that social isolation exacerbates poor mood states, reduces quality of life and has also been reported to contribute to worsening of the expression of dementia symptoms.

Participants described various experiences of the quality of communication with ward staff. Carers reported that a combination of a lack of staff continuity and high demands placed on staff by the organization meant that staff were too busy to effectively communicate with carers and lacked in-depth knowledge on the PWD. The findings here echoed those of Clissett *et al*.

(2013) where participants reported similar difficulties. Participants in both studies described developing strategies to breach the communication gap e.g. using a specific line of questioning and speaking with any member of staff available. It emerged that in line with existing research, the participants felt that they had to initiate communication with staff teams themselves, in order to gain a better understanding of care provision and the PWD's physical health status (e.g. Bauer *et al.*, 2011; Clissett *et al.*, 2013), rather than staff seeking out carers to share information. Staff would often employ modes of dyadic working with either the carer or the PWD, rather than triadic working, with both the PWD and their carer. This is a potentially problematic way of working, because PWD are not always able to communicate to carers the necessary information needed with regards to treatment and associated care plans (Clissett *et al.*, 2013) and also, PWD are at risk of being excluded from contributing to aspects of their care. Quinn, Clare, McGuinness and Woods (2013) emphasis, therefore, that it is important that the perspectives of each person is explored and considered carefully, helping the members of the triad to balance the views of others, against their own needs. Woods theorises that in negotiating the balance of needs and views, the care becomes relationship centred, which is beneficial to all of those involved with the care of the PWD and the PWD.

Some participants described ways of remedying the dearth of patient information, for example by reading the PWD's notes. However, this was described by some as unsatisfactory, as they lacked information beyond medical recordings and displays of disruptive behaviours and/or incidents. Interestingly, the findings here differed from those of Jurgens *et al.* (2012) who reported that carers would often read notes when they were in a phase of discontent and experiencing a loss of control and concern for the quality of care that the PWD was receiving.

Furthermore, the findings here expanded upon how issues of confidentiality impacted on the perceived quality of communication. For example, some staff were reported as inconsistent in sharing the PWDs' information over the telephone to family members and this was cited as a source of frustration



for carers. Also, carers reported that staff members demonstrated limited efforts to maintain confidentiality when communicating and relaying information on open wards. The environment of shared wards, where curtains separated people, exacerbated this.

In addition, it was found that some staff initiated feedback when the PWD was presenting with difficult behaviours, and that the purpose of this appeared to be to complain to carers rather than information sharing or acting as a way of gaining information on how to settle and support the PWD. From the perspective of Norman (2006), this could be argued to be an example of staff failing to give meaning to the expressed 'self' and this contributing to the objectification of PWD.

#### **4.1.2.2 Core Category: Forming Judgments on the Quality of Care**

The findings in this study support existing research (e.g. Bauer *et al.*, 2011; Clissett *et al.*, 2013) and reflects how carers used staff feedback and their own observations of care provision for both the PWD and others, to inform their judgments on the quality of care.

Carers shared accounts of staff telling them the dangers of the PWD remaining in hospital and advising that the PWD would be better off at home. Participants described how these staff beliefs were both frightening and shocking. It was not always clear as to the staffs' rationale, although one participant thought it was because of the increased risk of infection whilst in hospital. Regardless of the motivation, the way in which the staff shared their beliefs with participants was at times surprising. However, it is of note that such staff beliefs might reflect sound evidence: 'the longer people with dementia are in hospital, the worse the effect on the symptoms of dementia and physical health' that are not a direct by-product of the physical health complaint (Alzheimer's Society, p.xi, 2009). Therefore, it is not the message that is perhaps not the problem here, but rather the way staff articulate and share their beliefs with PWD and their families.

Participants reported observed deficits in care which were similar to those reported by Jurgens *et al.* (2012). Participants described how they tried to

fulfill these deficits themselves, for example through providing food, company and personal care to the PWD. Those who did, understood themselves to be helping and supporting staff in the context of a difficult job. In line with other studies, participants rarely criticized the staff's failure to meet the PWD's needs and instead, justified care standards through conceptualizing the deficits in care through the lens of austerity and the climate of the NHS i.e. target driven, understaffed and undertrained (e.g. Bauer *et al.*, 2011; Clissett *et al.*, 2013). Bauer *et al.* (2011) found that family carers' judgments of care and staff capability impacted on how families construed the quality and efficiency of discharge; however, this was not the case here.

The category justifying care standards, therefore, may offer a framework with which to understand why a number of carers report satisfaction with care (e.g. Whittamore *et al.*, 2014) even when care could be perceived as sub-standard. Justifying care standards may lead to carers and PWD not complaining about their experience of service provision, thus leading to under-reporting of the difficulties that PWD and their families face when admitted to a ward (see section 4.2 Implications for Practice).

#### **4.1.2.3 Core Category: PWD Experience of Belonging, Safety and Physical Care**

Another core category to emerge from the study was the PWD experience of belonging, safety and physical care; a category which linked to Maslow's (1987) humanistic and holistic psychological theory of motivation and human's basic need. Maslow's theoretical model suggests that there is a hierarchy of needs. Only when basic needs are met do higher needs motivate the individual. According to Maslow (1987), physiological needs are the foundation of all needs; once homeostasis is reached then needs for affection and belonging-ness appear, followed by self-esteem and self-actualization needs.

Within this study, physiological needs (physical care) were conceptualised as being met by the nursing staff, giving rise to the sub-category experience of care tasks, which interlinked with the PWD's affect and orientation (safety) and company of others (belonging) and meaningful engagement (associated

with self-esteem and self-actualisation). It is of note that each of these tiers of needs were met to a varying extent, with higher levels of the hierarchy seldom being met. These findings support those of Nyden, Peterson and Nystrom (2003), who found that older patients in emergency care environments often had higher needs, such as the desire to know and understand, neglected, although, some lower needs were also met with varying degrees, with participants reporting poor quality of food and lack of staff availability to provide meal support.

Similarly to other studies, participants reported that the PWD experienced confusion and disorientation (Bloomer *et al.*, 2014) with regard to where they were and the necessity to receive care. The reluctance to receive task orientated care was often demonstrated through the expression of strong emotions such as anger. It is of note that it is not uncommon for PWD to refuse personal care, this is often a tension for nursing staff; the need for personal care is often driven by nursing's staffs concerns about infection control and also, for reasons associated with social desirability (Sloan, Rader, Barrick, Hoeffler, Dwyer, McKenzie *et al.*, 1995). Interestingly, PWD who were described as having high expressed negative emotion and problematic behaviour were sometimes described as being subject to infantilizing language and care speak.

According to Norman (2006), nurses provided different types of care depending on whether they viewed a PWD as being either 'positive and acceptable patients' or 'negative and unacceptable patients'. Norman (2006) theorises that positive acceptable patients were treated holistically and experienced as compliant and independent. In contrast, those who were viewed as negative were depersonalised. Participants in this study reported that the PWD had similar experiences but they tended to justify the depersonalisation by conceptualising the wards as medical rather than social environments. However, it would be of value to further research PWD's experience of care in relation to their orientation and affect and how this interlinks with their sense of feeling safe.

The Alzheimer's Society (2009) reported that 62% of staff and carers were dissatisfied with PWDs' opportunities to engage in social interaction. Similarly, participants in the current study reported limited opportunities for the PWD to socialize and have benefitted from the company of others. Participants described how some PWD were isolated from others, as their behaviours were experienced as disruptive. Others were separated from other people because the ward was laid out as a series of private rooms, rather than a shared ward. A number of participants reported how this was experienced by the PWD as isolating.

The concern here was not only the lack of opportunities to socialize in terms of occupancy, but also the detrimental affects of social isolation on PWD. Research demonstrates that a lack of company from others and meaningful engagement can exacerbate dementia symptoms of agitation and distress (Gilster, Accorinti and Dalessandro, 2002; Perrin, 1997). This perhaps explains why PWD in this study continued to display symptoms of stress when isolated, although, not all participants construed single rooms as bad, with some preferring the privacy it offered the PWD in terms of confidentiality and treatment provision and the privacy it provided when they visited the PWD.

Psychological literature recognizes that there is a tension between over-stimulating and under-stimulating a PWD, with busy wards also being overwhelming; Gilster *et al.* (2002) recommend that PWD should be placed in small shared rooms with consideration to room-mates in terms of communication skills and sensitivity to PWD. Despite Gilster *et al's.* (2002) recommendations, there is little research into the role of socialization and meaningful engagement in acute physical health settings. Research conducted in care homes suggests that occupation and pleasure can significantly improve outcomes for residents (Alzheimer's Society, 2008) and quality of life (Kitwood, Buckland and Petre, 1995).

Participants described how care lacked personalisation with few, if any, staff seeking out biographical information or information as to how they could settle, sooth and effectively communicate with the PWD. These comments

echoed the findings of the National Audit of Dementia Care in General Hospitals (Royal College of Physicians, 2013), which found that of ‘the information ... recorded in the notes, less than half contained information about details which aid communication with the person; support or actions that can calm the person if they become agitated; and recurring factors that may cause or exacerbate distress’ (p.6). That is, the notes lacked person-centred information.

### **4.1.3 Theme 3: Transitions in Care**

Conceptualizations within the third key theme: ‘transitions in care’ captured experiences of transitions between community services and emergency services and also, transitions as a consequence of decline and increased need i.e. transition to residential care and the impact this had upon the carer and PWD. The theme therefore focuses our attention on organizational and personal processes of change and how this was experienced, perceived and adjusted to by both the PWD and their carer. The core themes identified were: ‘emergency services,’ ‘discharge’ and ‘life after discharge,’ all of which are discussed below.

#### **4.1.3.1 Core Category: Emergency Services**

Participants in the study discussed waiting times in the context of emergency services, specifically within Accident and Emergency (A&E) Departments. The length of wait varied between participants and was associated with whether or not fast track systems were in place for people with dementia. This suggested, therefore, that hospitals had differing systems in place to support PWD, with significant delays being reported at hospitals who were at capacity and/or did not have sufficient systems in place to support this population.

Similarly to Clissett *et al.*'s. (2013) findings, participants within this study reported A&E as a busy and chaotic environment, with some PWD being described as unsettled at this time. The study presented here elaborated on that of Clissett *et al.* (2013), with participants reporting the experience of staff in A&E and their abilities to soothe and settle the PWD. Furthermore, participants expanded their narrative to include their experience of those who helped with the decision making process to admit and, also, of hospital and

emergency services staff such as paramedics. Similarly to the findings of Jurgens *et al.* (2012), the participants spoke positively of this sub-group of professionals.

However, this study failed to ascertain the nature of the experience of A&E beyond symptoms of distress. The lack of explorative data in relation to this point may be a reflection of not all participants being present at the time of the PWD's admission to A&E (see Section 4.3 Strengths and Limitations of the Study).

#### **4.1.3.2 Core Category: Discharge**

With regard to discharge, participants described a power imbalance in decision-making in relation to the provision of care that was to be provided post discharge, including the setting i.e. community vs residential care. Similarly to other studies, carers described feelings of frustration, reporting a lack of involvement, poor communication and sometimes a sense of distrust (Almborg Ulander, Thulin and Berg (2009); Bauer, Fitzgerald, Haesler, and Manfrin, 2009). Some described experiencing discharge plans as dictated. This was especially the case for the PWD, who were rarely consulted. This is thought to have been because the PWD had often deteriorated to the extent that they no longer had capacity to make decisions for their own day-to-day care. However, participants were unable to elaborate on this from the perspective of the PWD.

Furthermore, the consolidation of the care plan was found to be time consuming and contributed to extended stays in hospital. This may have contributed to increased care needs post discharge due to the hospital care leading to the PWD being institutionalised and deskilled. For example, some participants described the PWD as becoming incontinent due to nursing practices which encouraged the use of pads rather than a commode, thus increasing post-discharge dependency. Research suggests that this is a common consequence of prolonged hospital stays (Alzheimer's Society, 2009), although it is also argued that longer stays can increase the chances of correct assessments being completed and also allows the PWD more time to

recover from their acute physical illness (Victor, Healy, Thomas, and Sargeant, 2000).

Similarly to Bauer *et al.* (2011), findings here demonstrated carers' dissatisfaction with coordination at discharge, with concerns being expressed in relation to the timing of discharge and provision of community transport. However, the findings differed from those of Bauer *et al.* (2011) in that families were generally aware of the timing of discharge, although some still experienced the PWD being discharged home or to a new care setting with minimum warning.

#### **4.1.3.3 Core Category: Life After Discharge**

Participants described both their life, and also the PWDs' life after discharge, one aspect of which was adjusting to care package. Carers described care packages as being helpful as well as invasive for both the caregiver and the PWD. This conceptualization may have reflected the experience of little opportunity to input into the decision-making process in relation to the care plan at the time of discharge. It may also reflect the participants' reluctance to receive care in the community, something that is common among spouses of PWD (Seltzer & Li, 2000).

A high proportion of the PWD within this study, lived at home prior to their physical illness, but 6 of the 8 were discharged to residential care of some form. This trend reflects national statistics, which show that 'over a third of people with dementia who go into hospital from living in their own homes are discharged to a care home setting' (Alzheimer's Society, 2009). Despite these high statistics, there are few studies on PWD's adjustment to care homes from hospital (Sheehan, Stinton and Mitchell, 2009). Sheehan, Thein, D'Souza and O'Malley (2007) however, found that PWD were discontented with their lack of involvement in the decision-making associated with transition to residential care and were often anxious about the transition, with fears of loss of dependency. In addition, the study here reflected the carers' anxiety concerning the PWD's awareness of what was happening to them. This suggests that the carer may have experienced some guilt with the decision to

admit the PWD to a care home, although this was not explored in great depth within this study (see Section 4.4 Implications for Future Research).

Carers were less able to articulate the PWD's experience, attributing it to their lack of awareness as a consequence of the dementia. However, carers did describe some symptoms of anxiety and distress. The PWDs experience of this major life transition would therefore warrant further research.

At the time of transition to residential care, carers began to experience a form of caregiver strain and relief, which differed from the realisation and awareness of caregiver strain reported earlier in their experience of organisational care. Instead, caregiver strain and relief emerged in relation to the transition in care, whereby carers were emotionally adjusting to the ongoing decline of the PWD and the associated symptoms e.g. emerging aggressive behaviours; this adjustment was perceived as stressful, but also as a part of the carers' continuum of learning. However, the transition itself was also associated with relief, as the carer felt less need to worry about the PWD's safety and needs. A residential home's attentiveness to the PWD's promotion of selfhood and provision of care appeared to contribute to the carer's sense of relief.

Residential care homes were described with much warmth, with participants describing how they felt that their family member was receiving specialist and attentive care, which appeared to reflect all elements of Kitwood's (1997) model of personhood, focusing on the PWD's values, independence and wellbeing (Mitchell, 1999). The care given in the residential homes appeared to be experienced as both positive to the carer and the PWD. However, due to the focus of the present research, this study did not explore this experience in much depth. Therefore, this area would warrant further research.

Finally, carers discussed and alluded to an awareness of the PWD's ongoing decline and death. There appeared to be different conceptualisations and concerns of decline, depending on the PWD's stage of dementia. Where the PWD was in the earlier stages of dementia, carers appeared to be concerned with reducing independence. In contrast, carers of those who were in the



later stages were more concerned with decline in terms of remembering who the carer was, increased behaviours indicating distress and reduced communication skills.

Interestingly, and perhaps not surprisingly, carers found that discussions of decline (with or without death being the focus) were experienced as difficult by the carer. This perhaps reflects the sensitive nature of death in a culture where death and dying are not openly discussed (Alzheimer's Society, 2012). Psychological theory also suggests that cultural factors may have been further compounded as many of the carers were male, which could have impacted on their ability to talk freely about their emotions (Baker et al., 2010; Bookwala and Schulz, 2000; Fromme, Drach, Tolle, Ebert, Miller, Perrin and Tilden, 2005).

## **4.2 Implications for Practice**

The research findings highlighted many areas of cause for concern with regard to PWD's experience of care in physical health settings. Some of these concerns are linked to the lack of personalised care. Research has shown how care that fails to attend to selfhood is associated with the risk of being objectified, leading to the PWD being depersonalised and invalidated (Clarke, Hanson and Ross, 2003; Clissett *et al*, 2013). This was exemplified in this study through reports of nursing staffs' (i) use of infantilizing language and care speak, (ii) medicalisation of the PWD over personalization, and (iii) provision of care orientated tasks, rather than person-centered care. Some of these difficulties could be remedied through clinical psychologists delivering psycho-educational workshops on dementia and person-centre care to all ward staff. Although training would be important for all hospital staff, it would be of particular pertinence to nursing staff, as dementia training is not a mandatory pre-registration module (Alzheimer's Society, 2009).

However, the extent to which the staff implement their learning would have to be monitored. This is because reports such as the Andrews Report (Andrews and Butler, 2014) showed that a number of hospitals failed to effectively utilize schemes such as the Butterfly Scheme which helps staff to identify patients with dementia with a view to attending to their needs in a way that is sensitive

to their condition. Therefore, given clinical psychologists' core skills in working with and evaluating systems, the profession would be well placed to both develop training packages and evaluate their effectiveness.

Furthermore, it was hypothesized that due to carers tending to justify standards of care, to poor care may be under-reported. Psychology, therefore, is well positioned to develop service evaluation tools to engage with this population and promote their voice and needs to bring about organizational change.

In terms of improving working relations with carers, organizational care systems might also be improved through the movement towards triadic instead of dyadic working, with care staff actively involving carers in understanding the PWD's selfhood to inform care routines and to help settle the PWD. This may also act to help develop discharge plans that are person centered, thus increasing the likelihood of the PWD engaging in community care.

Finally, it is of note that there were a significant number of male carers in this study, a percentage of whom engaged with third sector organizations. Therefore, third sector organizations may be well positioned to engage male carers when they bring the PWD to groups, with it feeling less threatening to their conceptualization of masculinity and relationship to accept support and help. This would be of benefit to both the PWD and their carer.

### **4.3 Strengths and Limitations of the Current Study**

The current study aimed to explore the experience of the PWD during hospital stays for physical health conditions. Research shows that a great many people with dementia use hospital beds (Alzheimer's Society, 2009). But there is little research to date explicitly exploring the experience of hospital stays for the PWD (Sheehan, Stinton and Mitchell, 2009).

The study here interviewed carers of PWD and thus, ascertained the experience of hospital stays by proxy. This method was necessary because of ethical concerns in relation to issues of gaining consent from PWD in the context of capacity and also because the study required people to recall

retrospective experiences and it was unclear how accurate the PWD's memories would be. The use of carers to inform researchers about experience is not uncommon, with end of life studies (e.g. Addington-Hall, Hunt, Shlomo and Richardson, 2011) and studies of PWD (Alzheimer's Society, 2012) utilizing carers to further understand experience. The approach is generally seen as a robust way to begin to understand another person's experience.

However, it was found that utilizing carers meant it was not always possible to get a complete version of events, as carers were not present for the whole stay. Also, carers at times found it difficult to adopt the position of the PWD i.e. they were unable to describe in-depth emotional experiences from the position of the PWD.

There were substantial difficulties in recruiting carers to this study, despite the fact that a high percentage of people with dementia occupy hospital beds (e.g. Alzheimer's Society, 2009). One explanation for this could relate to how family members or significant others conceptualize their role of caring. For example, a person might not identify himself or herself as a carer if the PWD is residing in a care home or if they are not providing personal care. It may also reflect how family members perceive their role, for example some carers do not view themselves as being a 'carer', rather they view their role 'as a natural consequence of their relationship with the person with dementia' (Spencer Grey, p.2, 2011). Furthermore, family members may not define themselves as a significant carer once the PWD has been admitted to a care home. Clarification of how people define their new role could be achieved through future research.

On completion of the interview some participants discussed their motivation for taking part in the study. Their motives included the desire to help others and to speak about the matter. Thus, within this sample set, there may have been an element of 'elite bias' (Sandelowski, 1986), whereby the views expressed were those of the people who are the most passionate about the topic (Bauer *et al.*, 2011).

The sample represented a small number of carers from across the U.K, a strength being that the study captured a broad range of experiences across hospitals, rather than the experience of care in one hospital alone. However, some of the PWDs described here had attended the same hospitals and care home as other PWDs in the study.

Within the study diversity was captured to a varying degree e.g. Welsh and English contexts; but, the experience was largely that of white British people, with many carers also being male. This may reflect the increasing rates of male carers for PWD (Robinson, Bottorff, Pesut, Oliffe, and Tomlinson, 2014). However, the study did not examine gender differences in the caring role and this would be worthy of future of research.

Furthermore, when the interviews were conducted, the PWD were at various points in their recovery from physical illness. Some were still in hospital, whilst others had not long been discharged or had been discharged a long time ago. These variations may have impacted on the participants' ability to provide an overview of the whole experience. Variations in accounts could have been dependent on how much time the carer had to reflect since the hospital admission, on the emotional strain associated with inpatient stays and on the adjustment to new care packages (Clissett *et al.*, 2013).

Rigorous research guidelines on ensuring quality in qualitative research were followed (see Chapter 2; Elliot *et al.*, 1999). Interviews continued until saturation occurred. This was achieved through the researcher utilizing reflective dairies and engaging in reflective conversations with supervisors and through the process of triangulation with those who were naive to the study.

Finally, this study included a systematic review of the literature to explore the evidence base for the experience of physical health inpatient care for the PWD. The review, however, was kept broad because few papers addressed this research question. All but one of the research papers were qualitative and this, meant that the existing research papers focused on the richness of the PWD experience rather than on outcomes for PWD.

#### **4.4 Recommendations for Future Research**

As noted above, research has seldom been undertaken with this vulnerable group. This is largely due to concerns of consent and PWDs' ability to contribute to such research, because of recall and communication difficulties. However, these concerns should not prevent researchers from attempting to engage with this population. Researchers should instead work creatively to involve PWD to inform our understanding of how they experience hospital wards, through tailoring the method of research to suit the PWD and their stage of dementia. For example, Toms, Quinn, Anderson and Clare (2015) employed direct methods of data collection to involve people with early stage dementia in their research. In contrast, Norman (2006) employed a hybrid of methods, including observation, to glean information as to the PWDs' experiences of hospital (e.g. Norman, 2006). Therefore, through creative working, future research should aim to include PWD to better understand their experience of hospital stays, because PWD are best positioned to describe their experiences (Godfrey, 2013).

Therefore, with PWD inclusivity and the findings of this study in mind, further research might consider different areas of the PWD's experience of hospital stays, including but not limited to: pre-hospital admission, admission, inpatient stay, discharge and life after discharge. As this study found, it is hard to separate these experiences into these individual stages.

Points worthy of further investigation include the experience of repeat admission and the impact on the PWD, the implications for the PWD of being isolated on a physical health ward, experiences of acute physical illness, discharge and PWD care planning involvement and the experience of admission to a residential setting.

In addition, carer-focused themes which emerged in this study would merit further investigation. These include motivations for continuing to care; coping with quality of hospital care and complaints procedures; carer guilt and the PWDs transition to residential care; and the awareness of loss and death. Furthermore, it would be interesting to examine gender differences, different kinship roles and coping styles (Baker, Robertson and Connelly, 2010). The

latter topic may be of special relevance given the increasing number of male carers for PWD (Robinson *et al.*, 2014).

## **4.5 Conclusions**

Limited research has examined the experience of those with dementia, with existing evidence focusing on carers' own experiences (Aggarwal *et al.*, 2003; Bauer *et al.*, 2011; Bloomer *et al.*, 2013; Jurgens *et al.*, 2012; Whittamore *et al.*, 2014) or the staff's experiences of supporting those with dementia (e.g. Noolan, 2006). This study therefore, adds a considerable contribution to beginning to explore PWD's experience.

The current study explored carer's accounts of PWD's hospital inpatient stay. What emerged were not only stories of PWD hospital inpatient stay but also the events that led up to admission (including repeated admissions) and the events that followed discharge. This highlights how hospital experiences form only part of a very complex picture and how the hospital experience is central to what happens next in terms of discharge location and any associated care package. The breadth of hospital related experience was captured through three key themes: course of illness in the community, experience of organizational care and transitions in care.

The study provided a novel and comprehensive overview of the experience of PWD's during hospital stays for physical health conditions. It is hoped that the findings presented here will contribute to our understanding of this population's experience of acute settings and prompt further research exploring how services can be further tailored to improve care, using the voice of people with dementia.

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## **Appendix 1**

1.5 Summary Table of Welsh Policies

1.6 Summary Table of English Policies

1.7 Flow Chart of Systematic Review Process

1.8 Summary Table of Studies Included in the Systematic Review



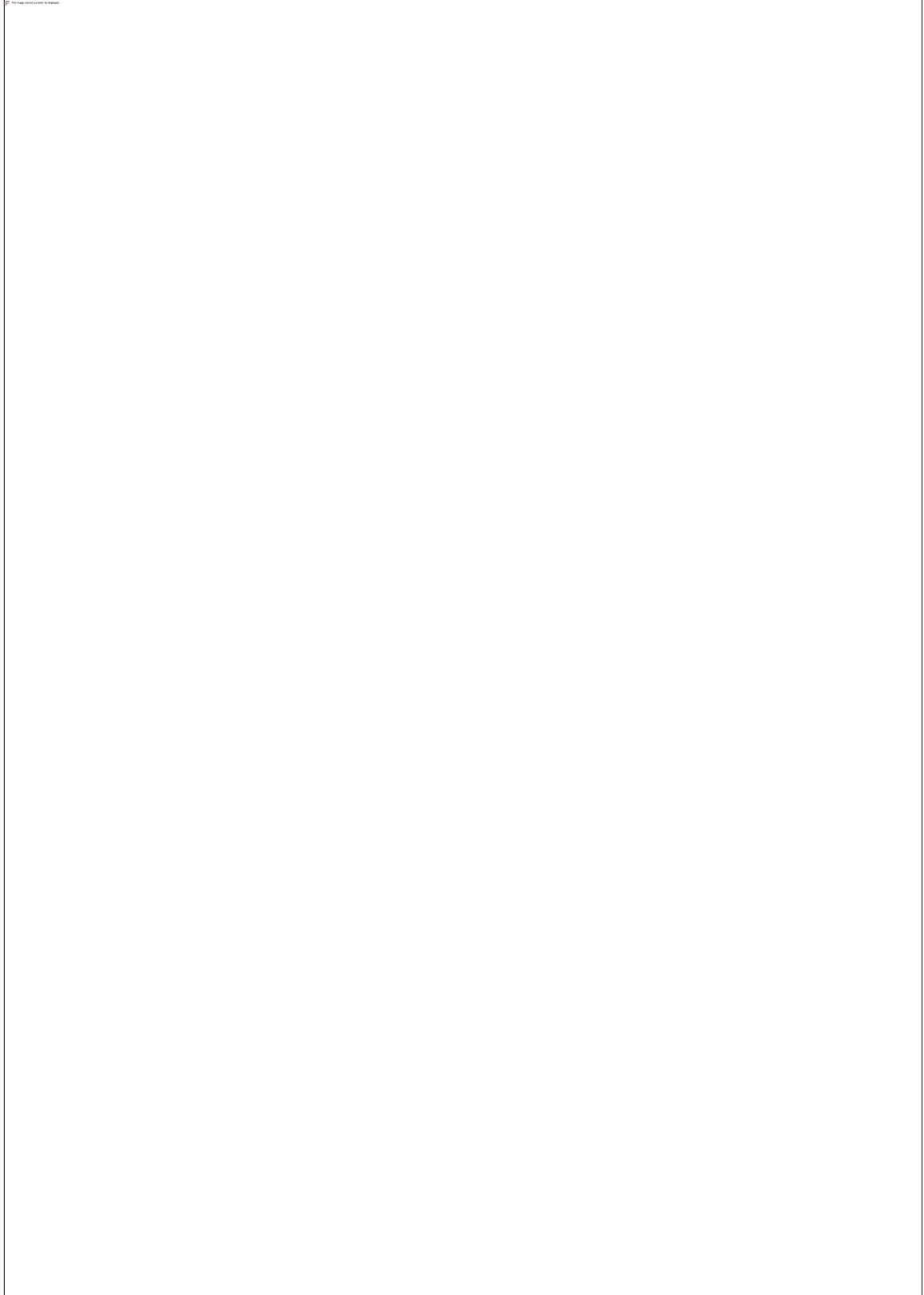
## Appendix 1.1 Summary Table of Welsh Policies

Policy	Targets and Objectives
Strategy for Older People (Welsh Assembly Government (WAG), 2003).	To (i) tackle age-related discrimination, whilst promoting a positive image; (ii) promote and develop opportunities for older adults to work and contribute to society; (iii) promote health through the development of integrated services; (iv) develop high quality services and support to facilitate independent living; and (v) provide appropriate funding for change, development and planning for older adult services.
National Framework for Older People in Wales (WAG, 2006).	(i) Rooting out age discrimination; (ii) person centred care; (iii) promotion of health and wellbeing in older age; (iv) challenging dependency; (v) intermediate care; (vi) hospital care; (vii) stroke; (viii) falls and fractures ;(ix) mental health in older people; and (x) medicines and older people.
National Dementia Action Plan for Wales (WAG, 2009).	Improve (i) service quality; (ii) information provision; (iii) rates of earlier diagnosis; (iv) and training.
1000s Lives Report: Improving Dementia Care (WAG, 2010).	Improve (i) memory assessment services; (ii) care on general hospital wards; (iii) community care (including in care homes); (iv) increase support for caregivers; and (v) quality of care in NHS dementia inpatient units.
Dementia Supportive Communities (WAG, 2011).	Improve (i) service provision, accompanied with improvements in joint working across NHS, social care and other organisations (including third sector); (ii) early diagnosis and timely interventions; (iii) access to information resources, specifically advocacy, and support for PWD and caregivers; and (iv) training for people providing and delivering care, including areas of research.
The Strategy for Older People in Wales 2013-2023 (WAG, 2013).	To ensure (i) people in Wales feel valued and supported, whatever their age; and (ii) all older people in Wales have the social, environmental and financial resources they need to deal with the opportunities and challenges they face.

## Appendix 1.2 Summary Table of English Policies

Policy	Targets and Objectives
<p>Living Well With Dementia: a national dementia strategy (Department of Health (DoH), 2009b).</p>	<p>(i) Improving public and professional awareness and understanding of dementia; (ii) good-quality early diagnosis and intervention for all; (iii) good-quality information for those with diagnosed dementia and their carers; (iv) enabling easy access to care, support and advice following diagnosis; (v) development of structured peer support and learning networks; (vi) improved community personal support services; (vii) implementing the Carers' Strategy; (viii) improved quality of care for people with dementia in general hospitals; (ix) improved intermediate care for people with dementia; (x) considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers; (xi) living well with dementia in care homes; (xii) improved end of life care for people with dementia; (xiii) an informed and effective workforce for people with dementia; (xiv) a joint commissioning strategy for dementia (xv) Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers; (xvi) a clear picture of research evidence and needs; and (xvii) effective national and regional support for implementation of the Strategy.</p>
<p>MHP Health Mandate (2011).</p>	<p>(i) Driving an integrated approach to dementia services; (ii) delivering the information revolution for dementia care; (iii) improving the funding arrangements for dementia services; and (iv) commissioning on the basis of quality and user involvement.</p>
<p>Prime Minister's Challenge on Dementia (DoH, 2012a).</p>	<p>The challenge set out three champion groups, designed to drive improvements in health and care, creating dementia friendly communities and improving dementia research.</p>
<p>Government's Challenge on Dementia 2020 (DoH, 2015).</p>	<p>There is a need to (i) improve health and care, including risk management and reduction; (ii) improve diagnosis; (iii) provide support following diagnosis; (iv) increase support for carers as outlined by the Care Act 2014 and NHS England's Commitment to Carers (2014); (v) have greater provision of innovative and high quality dementia care at home; (vi) prioritize care in hospitals and care homes, with 'all hospitals and care homes meeting [and] agree[ing to] criteria to becoming a dementia friendly health and care setting' (p.33); (vii) reduce inappropriate hospital admissions 'as an emergency through better provision of support in community settings, which enables people to live independently for longer' (p.33); (viii) reduce inappropriate prescribing of antipsychotic medication; (ix) review end of life care; (x) train the workforce, whilst 'promoting awareness and understanding and building social action by actions of individuals, communities and businesses' (p.39); (xi) invest and improve research in a variety of domains.</p>

## Appendix 1.3 Flow Chart of Systematic Review Process



**Appendix 1.4 Summary Table of Studies Included in the Systematic Review (information adapted from papers itemized in the 'author(s) column).**

Author(s), Date and Region.	Aim	Method (i) design, (ii) data collection/ measurements and (iii) analysis	Participants	Results	Discussion
<b>Qualitative</b>					
Bauer, Fitzgerald and Koch (2011). (Australia).	<p>To understand:</p> <p>(I) the family carers' experience of hospital discharge planning, preparation and support;</p> <p>(II) how well hospital discharge met their needs; and</p> <p>(III) what improvements they believed could assist them to help the older PWD make the transition home, or to residential or sub-acute care.</p>	<p>(I) Qualitative constructivist design.</p> <p>(II) Non-probability sampling techniques. Semi-structured interview.</p> <p>(III) Constant comparative method of thematic analysis.</p>	25 carers of PWD: 14 daughters, 5 wives, 4 husbands, 1 son, and 1 foster sister.	<p>Three main categories were identified to explain family carers' expectations and needs of hospital discharge:</p> <p><b>I) Co-ordination</b> - Family carers reported: lack of consistency with regards to care provision; lack of organized systems to support discharge; discharge ad hoc; arrangements often failed to meet their needs; and services that were promised and later not delivered, due to a lack of communication.</p> <p><b>II) Capability</b> - Staff capability in hospital was thought to have an impact on both in-patient care and</p>	<p>It was reported that the needs of family carers were consistent with other studies, with carers wanting more information re: patient's condition; education re: on going care; assistance with understanding and working with care providers; and improved psychosocial support. The researchers found that carers want to be: acknowledged and valued by staff; and involved with discharge process.</p> <p>The quality of care in hospital was found to impact on carers' perceived preparedness for discharge and it was reported that there were many references</p>

				<p>discharge. Quality of care in hospital was thought to impact on the family preparedness and ability to manage on discharge. Staff failure to maintain routines in hospital were reported to be a concern at discharge. Participants expressed a belief that if the staff utilized knowledge of the person whilst in hospital, discharge would have been better informed. Family expressed forgiveness towards nurse's incapability, based on a variety of reasons. Families left feeling distressed, frustrated and disappointed with care system.</p> <p><b>III) Consultation –</b> frequency and quality of contact with the family declined over the hospital stay. Families experienced this as disinterest, reinforced by staff reluctance to communicate with family carer re: discharge and</p>	<p>to poor clinical practice in basic provision of care for PWD. The researchers identified a need for greater education of staff for caring for PWD.</p> <p><b>Relevance to this study:</b> The carers described the journey of care from admission to discharge, identifying problems with the trajectory of care and also the quality of care. Carers reported that some staff failed to continue with routines that were in place at home and also, to utilize their intimate knowledge of the PWD, impacting on the quality of care; this was reported by the researchers to be below practice standards. These observations therefore, inform staff communication with family and, also, the quality of the provision of care impact on PWD in in-patient settings.</p>
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				<p>subsequent aftercare of PWD. Difficulties in finding who to ask re: wanting information and advice. Families wanted individualized care, so that discharge would be appropriate, where there were gaps in care, carers found themselves providing individualized care themselves, for which they felt unvalued. A timeline for discharge was important, but was rarely offered or obtained.</p>	
<p>Bloomer, Digby, Tan <i>et al.</i> (2014). (Australia).</p>	<p>Overall aim of study: To explore the experience of carers of PWD through hospitalization, rehabilitation and transition in to residential care.</p> <p>Aim of findings reported: To explore the carers' experience when the PWD they care for is an inpatient</p>	<p>(I) Descriptive qualitative design.</p> <p>(II) Purposive sampling techniques. In-depth semi-structured interview.</p> <p>(III) Thematic analysis.</p>	<p>20 carers of PWD: spouses, adult children and friends. Distribution not recorded.</p>	<p>Five core themes emerged:</p> <p><b>(I) Feeling helpless and lost:</b> hospital admission emotional, because of illness and injury of PWD and also due to loss of role, feeling helpless, lost and lonely. Carers also missed the PWD.</p> <p><b>(II) Losing control:</b> Carers described losing control of</p>	<p>The researchers found that admission to hospital is a highly emotive and challenging experience for carers. It was reported that there was a need for carers' emotional wellbeing along with other needs, to be prioritized, because there is a link between outcomes for both patient and carer. The researchers, therefore, highlighted the centrality of</p>

	in hospital.			<p>decision-making.</p> <p><b>(III) Family support and conflict:</b> Carers described family members as being supportive or unsupportive, with regards to post-hospital care and the PWD placement.</p> <p><b>(IV) Feeling undervalued:</b> Carers reported feeling undervalued by clinicians, despite having valuable knowledge of PWD.</p> <p><b>(V) Opportunities for improvement:</b> Carers reported wanting more information on what was happening re: care of PWD. Carers wanted staff to consider the dynamic between carer and PWD when planning care. It was also noted that staff would make incorrect assumptions about carers' relationship with the PWD and the carers' availability (i.e.</p>	<p>the dyad of carer and patient, to delivering effective care. It was also noted that carers expressed concern with regard to the PWD and their ability to communicate their needs, in the absence of their carers' support and how staff might misinterpret or neglect the PWD needs. The researchers also found that it was important for the carers to believe that the PWD was being cared for in an empathetic way.</p> <p><b>Relevance to this study:</b> The study highlights the importance of the patient-carer dyad, implicitly suggesting that carer and PWD needs cannot be separated and that the relationship needs to be valued and acknowledged in the delivery of care, thus suggesting it is important to understand the PWD experience in the context of</p>
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				emotional and physical) to continue care. It was also reported that one carer wanted staff to be more patient with the PWD.	the carers' lens.  The report also highlights how carers are concerned about how staff communicate with patients, especially in relation to empathy, patience and understanding the needs of the PWD.
Clissett, Porock, Harwood <i>et al.</i> (2013b). (United Kingdom).	To explore the experiences of family carers whilst their relative with cognitive impairment receives care in an acute hospital.	(I) Interpretive ethnographic and qualitative interview design.  (II) Non-participant observations (not reported) and semi-structured and naturalistic approach to interviews.  (III) Constant comparison.	32 carers: 9 wives, 8 daughters, 7 sons, 2 nieces, 2 female friends, 2 sisters, 1 son-in-law, 1 granddaughter, 2 relationships not recorded.	The findings distinguish between and elaborate upon a core problem: 'disruption from normal routine' and a core process: 'gaining or giving a sense of control to cope with disruption.'  <b>The core problem: Disruption from normal routine:</b> This occurred as a natural consequence of admission and because of the illness, which had caused admission. Admission also caused disruption, due to the need to visit, which was experienced by some as	Carers believed that the PWD was more distressed than others without dementia, as they were confused about where they were, what had happened and were worried about being abandoned. Carers needed to know that the PWD was being provided with reassurance.  The researchers concluded that family carers are not passive with regards to the disruption caused by hospital admission and develop ways to overcome some of the difficulties, through involving



				<p>pointless, as the PWD was often unable to interact. There was also anticipated disruption to provision of community care on discharge, which contributed to carer worry. Furthermore, the hospital environment was not considered conducive to the management of the PWDs' distressed behaviors. Also, emergency departments were considered disruptive, uncomfortable, slow and exhausting.</p> <p><b>The core process: gaining a sense of control to cope with disruption:</b> Carers used 3 strategies to promote their sense of agency, which included (I) attempts to protect the PWD (through counteracting perceived inadequacies of the system and maintenance of personhood of PWD) (II) evaluating quality of care, which led carers to either</p>	<p>themselves with the PWD's care.</p> <p>The researchers assert a need for hospitals to be aware of triadic communication, rather than dyadic when working with PWD and their families.</p> <p><b>Relevance to this study:</b> It was noted that it was difficult for families to determine, outside visiting hours, the quality of care a PWD receives, thus suggesting, that it is still unclear how PWD experience hospital. This was further supported by some participants believing that visiting was pointless, as the person was too ill to interact.</p> <p>Furthermore, the carers took the position of trying to make the staff aware of the PWD's personhood, rather than staff eliciting this information</p>
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				justify quality of care or hold a fixed opinion. Their stance had an impact on their trust of staff and whether or not they submitted a complaint (III) rationalizing the situation to cope with the disruption, which in some cases led carers to support staff in the provision of care for the PWD.	<p>themselves. This highlighted how the carer can be central to the PWDs care and subsequently their experience of care.</p> <p>In addition, PWDs were described as being more confused than other patients without dementia; it is not clear how patients were helped to settle, nor what is like for them to feel like it.</p>
Digby, Moss and Bloomer (2010). (Australia).	To understand how older patients with mild to moderate dementia experienced the transfer from acute to sub acute care and a settling-in period.	<p>(I) Descriptive qualitative design.</p> <p>(II) Purposive sampling techniques. In-depth semi-structured interview.</p> <p>(III) Content analysis.</p>	8 patients with various medical illnesses and co-morbid dementia. Only three of the patients were able to recall the transfer to the new hospital site.	<p>Four themes identified:</p> <p><b>(I) Settling into a new environment:</b> Patients reported feeling disorientated, feeling lonely and alienated. They also reported being disturbed by sounds and feeling anxious.</p> <p><b>(II) Staff attitudes towards people with dementia:</b> Patients reported being spoken to in a patronizing way and there was a use of care-speak. Some people felt unable to disclose their</p>	<p>The researchers concluded that PWD require more support than others to settle in to a new environment and that the family can be central in assisting with this transition.</p> <p>It was recognized that orientation materials could also help with the settling in period.</p> <p>The researchers also reported that person-centered care transcended</p>

				<p>confusion, because they were concerned that the staff would attribute it to their dementia.</p> <p><b>(III) Loss of control:</b> Patients reported they felt unsettled and experienced powerless against the system i.e. decision-making around their care. They also reported a loss of control over their environment and treatment.</p> <p><b>(IV) Family support:</b> Participants described how their carer's concern helped them to feel consoled and comforted.</p> <p>It was also noted that participants expressed concern about discharge, in relation to changing ability and the environment to which they would be discharged.</p>	<p>many of the issues, with staff needing to be mindful of their language, to avoid care-speak and not to rush the PWD. It was also recognized there was a need to better understand staff attitudes to PWD.</p> <p>Furthermore, it was recognized that it was difficult for PWD to articulate their experience of care.</p> <p><b>Relevance to this study:</b> The focus of the study is the transition to sub acute care, highlighting how the change of environment can have a significant impact on a PWD; however, anxiety concerning staff judgments prevents some from seeking help. This suggests that hospital environments and transitions can be confusing and unsettling for PWD; however, it is not clear as to how this is experienced in</p>
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					acute care.
Jurgens, Clisset, Gladman <i>et al.</i> (2012). (United Kingdom)	To understand why family carers of people with dementia are dissatisfied with general hospital care.	(I) Interpretive ethnographic and qualitative interview design.  (II) Observational and semi-structured interview (observations not reported).  (III) Grounded theory using constant comparison method.	32 carers for people with dementia, with or without super-imposed delirium: 9 wives, 8 daughters, 7 sons, 2 nieces, 2 female friends, 2 sisters, 1 son-in-law, 1 granddaughter. (2 of the people admitted had mental health problems and 1 had a learning disability, rather than cognitive dementia).	Through the analysis, it was identified that the carers often reported significant turning points, of which there were six foci: PWD, family carers; communication with professionals, organization of hospital; treatment; influence of family and friends. Three key themes were identified:  <b>(I) Expectations:</b> Carers described expecting personalized care which attends to physical needs and dignity. There was an expectation that hospitals would have a system in place to manage behavior that challenged and that it would be a safe place. Carers' expectations were also dependent on previous experience and also their knowledge of the PWD.  <b>(II) Events:</b> There was a	It was reported that the experience of hospital care was often negative: this was conceptualized through a cycle of discontent, which was used to illustrate a pattern of family carer responses in relation to concerns of the quality of care and loss of agency. The cycle outlines links between events and expectations; bewilderment and suspicion; hyper-vigilance and monitoring; evidence gathering; anger and conflict.  It was identified that carer and patient needs could be addressed through inclusion and proactive communication.  <b>Relevance to this study:</b> Carers can be dissatisfied with hospitals for a number of reasons, other than the

				<p>high frequency of crisis, which was often linked to change of health before, during and after admission.</p> <p><b>(III) Relationship breakdown:</b> There were breakdowns in relationships between staff, carers and patients. Carers reported feeling ignored and patronized and unable to contribute information, which would help the care process. Poor communication was interpreted as stress and inexperience. Lack of information also contributed to anger.</p>	<p>experience of the patient. For example, the way they are involved and included in the patients care; this may bias the way they interpret care.</p> <p>Furthermore, carers have tendencies to describe hospital admission in relation to other care experiences.</p>
Norman (2006). (United Kingdom)	To explore what happens to a PWD when they are admitted to a ward on a general hospital; specifically the processes and care provision that occur during the stay and consider the patient's responses.	<p>(I) Observational design.</p> <p>(II) Observational method- hybrid participant/ non-participant approach.</p> <p>(III) Grounded theory.</p>	8 participants in a large general hospital, considered to have dementia (no formal diagnosis).	<p>Five categories detailing the relationships between patients, nursing staff and care environment, were identified.</p> <p><b>(I) The person with dementia expressing 'self':</b> Participants expressed self through actions, words and</p>	PWD experiences depended largely on the relationship of the nurse and the PWD. The nurse largely negotiated the nature of the relationship; however, PWD did try to communicate their own identity and sense of agency through their actions or words. The way in which

				<p>attempts of autonomy e.g. through exerting control over care provision and treatment; and communicating their own identity in the ward environment.</p> <p><b>(II) The nurse identifying and acting towards the person with dementia:</b> Interpretations of patients were based on previous experience, categorized as either 'positive and acceptable' or 'negative and unacceptable' patients. These perspectives impacted on how PWD were treated and also differed between nurses and varied across time.</p> <p><b>(III) The dynamic interactive process:</b> Two types of interaction were identified as 'shared interactions' and 'staff-led interactions.'</p>	<p>the PWD was responded to i.e. a person as a whole or parts (objectified/ depersonalized) depended on nursing staff and also varied across time.</p> <p>The researchers identified a need for staff to engage in a two way relationship with PWD.</p> <p><b>Relevance to this study:</b> The study highlights the role of the relationship between the nursing staff and the PWD in relation to their experience of care and the care received.</p>
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				<p><b>(IV) Nurses' roles and work:</b> Their work was identified as either practical or emotional. The former was defined by minimal collaboration and the latter saw high levels of collaboration and consideration of patient needs.</p> <p><b>(V) The hospital environment:</b> The environment impacted on the way care was delivered and received. The staff experienced the ward as a place to stay, whilst PWD viewed it as a place to explore or leave, as if they perceived it as a place of residence. These constructs were viewed as inappropriate by staff.</p>	
<b>Quantitative</b>					
Whittamore, Goldberg, Bradshaw <i>et al.</i> (2014)	To identify patient and caregiver characteristics associated with	(I) Secondary analysis of data from RCT.  (II) Patient and	Caregivers (N=488) related to cognitively impaired	54% caregivers dissatisfied with some aspects of care.  Overall 87% satisfied with	The findings suggested that overall carers were happy with the provision of care, regardless of the setting;

<p>(United Kingdom)</p>	<p>caregiver dissatisfaction with hospital care of cognitively impaired elderly adults.</p>	<p>caregiver health status measured at baseline; caregiver satisfaction collected after patient discharge or death.</p> <p>(III) Univariate and multivariate analysis.</p>	<p>people (65 years+) randomly assigned to specialist unit or standard geriatric ward or internal medical ward.</p>	<p>care.</p> <p>Areas of dissatisfaction: communication (&gt; 33.3%); and discharge planning and medical management (25%).</p> <p>Dissatisfaction associated with: behavioral and psychological distress on admission, caregiver strain and poor psychological well-being at admission, presence of delirium and relationship between carer and PWD.</p> <p>Less dissatisfaction associated with patients on Medical and Mental Health Unit than standard ward.</p>	<p>however, areas of dissatisfaction were identified, as were areas which were likely to increase carer dissatisfaction.</p> <p><b>Relevance to this study:</b> Carers can only provide partial feedback on the quality of care, as they are only present for part of the day and PWD are not always able to feedback to them re the quality of care they have received. Therefore, it remains unclear as to how the PWD experiences the admission. However, it does show that wards where the culture is dementia aware and staff are well educated on dementia and thus more person-centered in nature, are more, likely to enhance the carers satisfaction with care provision. However, this does not mean that all carers are satisfied with the quality of care, suggesting that PWD needs may still not</p>
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					be met when admitted to hospital, regardless of staff training etc.
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## **Appendix 2**

2.1 Research Diary Extracts

2.2 Interview Schedule and Revised/Additional Questions

2.3 Risk Assessments

2.4 Cardiff School of Psychology Research Ethics Committee Approval

2.5 Cardiff School of Psychology Research Ethics Committee Revised

2.6 Information Form

2.7 Consent Form

2.8 Debrief Form

## **Appendix 2.1 Research Diary Extracts**

### **Extract from diary entry following interview with participant 5:**

Paramedics were good and aware of dementia- the structure of the local community meant that they knew the PWD. How common would this be in other settings geographical locations?

Experience at A&E was difficult, long wait and the hospital went in to crisis, meaning an additional transfer. What is it like for families and PWD when they transfer? Does the experience depend on stage on dementia? How does multiple experiences of hospitals impact on the story?- Carer appears to discuss all hospital admissions over last 18 months- is it possible to tell one experience without the other?

The theme of geography re-appeared, this time in the context of distance being greater as carer could not drive. Is geography and understanding of distance subjective? How does this link to participant 1? Is this a methodological problem e.g. recruiting a number of people from one area- do people, based on their geography and ability to commute, judge distance differently?

### **Extract from diary entry following interview with participant 6:**

Carer described a long deterioration (diagnosis in 1998)- how does dementia in the community link to hospital experience? I.e relationship to help? Familiarity with caring? Caregiver strain and emotional buffers?

The PWD changed ward during admission- transferred to a single room. The carer appeared to value the privacy, but how does this link to the PWD experience? As the transfer was done due to her distress- how does this link with participant 4's experience?

The carer was keen to share with me how good they thought the care was, despite the waiting times in A&E- he appeared to acknowledge deficits in care, which he justified through the problems in the system.

**Extract from diary entry following interview with participant 7:**

The carer described a number of admissions, this links with other participants i.e p1. It appears that people are admitted several times, before one big admission. For this person it appears decline happens quite quickly (within 6 months); therefore, it was noticeable that there was a rapid increase in care package. This relates to participant 3 and 1. A home care package was implemented, however, was not received well by PWD. They were confused about the change in routine and found it difficult to receive care. This links to p1 and also 4; people appear to be reluctant to receive care in the community. Therefore, several themes appear to be emerging in relation to the PWD and experience of care in the community and also deterioration. This links to hospital stay, as it seems to link to pre-admission and also discharge, as some homecare links to discharge care plans.

## **Appendix 2.2 Interview Schedule**

Subheadings have been used to organize the questions and to guide the interviewer's thinking. 'x' represents the name of the person who is cared for. Questions which were developed through the process of interviewing are in **BOLD CAPITAL** font.

### X and the Carer

Tell me about x.

How would you describe your relationship?

How do you think x would describe your relationship **IN THE PAST AND NOW?**

### Prior to the Hospital Admission

Could you describe the events that led up to x's stay in hospital? **HOW DID YOU SUPPORT THE PWD?**

How was x at this time?

Who was involved with the decision surrounding the admission? How do you think x would describe this time and the decisions made?

**TELL ME MORE ABOUT THE DECISION TO ADMIT-**

**WHAT WAS THE PROCESS LIKE? HOW DID THE PWD RESPOND TO THIS DECISION?**

**WHAT WAS THE PW LIKE AT THE TIME OF CRISIS?- CAN YOU DESCRIBE THEIR EMOTIONS? HOW AWARE WERE THEY THAT THEY WERE UNWELL?**

**HOW DID THE PWD EXPERIENCE THE JOURNEY TO HOSPITAL?**

### Hospital Stay

#### Admission:

How would you describe what it was like for x when they were admitted to hospital?

Did x go straight to a ward or did they have to wait? What was that like for x?

**CAN YOU DESCRIBE A AND E? HOW DID THE PWD EXPERIENCE THIS TIME?**

#### Environment:

How did x experience the environment?

Did x feel safe? Was it a quiet environment? How did x respond to this?

Did x know where they were? Was there anything on the ward that helped with orientation? Were staff available to help with orientation?

Was x allowed personal and/or comforting items on the ward? How did x respond to this?

Staff:

How did x experience the staff- **AT THE VARIOUS STAGES OF ADMISSION I.E. PRE-ADMISSION, DURING ADMISSION, DURING STAY AND AT DISCHARGE?**

How did the staff work with x? How did x respond?

Did the staff talk to you about x and their likes and dislikes, their life history or personality?

**HOW DID YOU EXPERIENCE SPEAKING WITH THE STAFF? WHAT WAS THE NATURE OF YOUR COMMUNICATION? WERE STAFF EASY TO TALK TO AND ACCESSIBLE?**

How was information explained to x? Do you feel x understood? Were you or x invited to take part in conversations with professionals and decisions about x's care? **HOW DID STAFF INTERACT WITH THE PWD? HOW DID THEY RESPOND TO THE PWD'S NEEDS/REQUESTS/PREFERENCES FOR CARE?**

Day-to-Day Experience:

Could you describe a typical day for x when they were staying in hospital?

Were there activities to do on the ward? Was x invited to take part? How did x experience this?

How did x experience physical aspects of care? **HOW DID STAFF RESPOND TO THEIR NEEDS AND PREFERENCES?**

Were you able to visit x? What are your memories of this time? How would x describe the visit? Was there a private place to talk? What was the ward like at visiting time? How did x respond? **HOW OFTEN WERE YOU ABLE TO VISIT? HOW DID YOU SPEND YOUR TIME TOGETHER? WHAT LED YOU TO PROVIDE CARE ON THE WARD?**

How did x experience their basic needs being met e.g. food and drink? **HOW DID YOU EXPERIENCE THEIR NEEDS BEING MET? WHAT WAS YOUR RESPONSE TO THIS?**

Did x want to talk with other people on the ward? Were there opportunities to do this? How did x experience this? **DID THE PWD HAVE COMPANY?**

Were there times during x's stay where x wandered or shouted? How was x supported by the staff at these times? How did x respond to the staff? **DID THEIR DISTRESS REDUCE OVER TIME?**

Did x have any challenging moments whilst on the ward? **HOW DID STAFF FEED THIS BACK TO YOU?**

### Leaving the Ward

At the time of discharge, was x ready to leave the ward? Did x understand what was happening next? **DID YOU UNDERSTAND WHAT WAS HAPPENING? HOW WAS THIS COMMUNICATED TO YOU BOTH?** Were you happy with this transition?

How did x experience leaving the ward? E.g. were they relieved? Anxious? Worried? Pleased? **WHAT WAS THERE AWARENESS LIKE?**

Did x keep want to keep in contact with people they met on the ward? Was this possible?

Where did x go when they left the ward? Did they return to where they were living? How did x feel about this? **HOW DID YOU FEEL ABOUT THIS? WHAT WAS IT LIKE FOR THE PWD GOING TO A NEW HOME?**

**HOW HAVE THINGS BEEN SINCE DISCHARGE, FOR BOTH YOU AND THE PWD?**

**HOW HAVE YOU AND THE PWD EXPERIENCED THE DISCHARGE CARE PLAN?**

### Looking Back

How, if at all, has x's view of hospitals changed? Is there anything that you or x would have liked done differently? Are you or x more worried or less anxious about future admissions?

Do you and x talk about the time they spent in hospital? What are both of your lasting memories of this time?

Should x require support with their physical health from hospital again, what would you and x hope for? Would you or x have any concerns, based on x's previous experiences?

### *Closing the Interview:*

Is there anything that you had thought about before the interview that you haven't had the opportunity to say?

Is there anything you would like to add?

Is there anything you would like to ask me?

## Appendix 2.3 Risk Assessment Approval



PSYCH Risk Assessment

Tue 12/08/2014 15:12

Mark as unread

To:  Elina Telford;

 You forwarded this message on 15/08/2014 20:19



RiskAssessmentForm Eli...

183 KB



1 attachment (183 KB)

Hi Elina

How lovely to receive a really good assessment, it quite made my day! I have re-attached it as I have just added on line stating that you will carry car breakdown cover so hope that is ok. If not then we need to add alternative measures.

Your ethics receipt number is below.

Thanks

Val

**From:** TelfordEH@cardiff.ac.uk [mailto:TelfordEH@cardiff.ac.uk]

**Sent:** 21 July 2014 16:43

**To:** Laura Morris; PSYCH Risk Assessment

**Subject:** Risk Assessment - Application Pending - Applicant Name: Elina Telford



## Appendix 2.4 Cardiff School of Psychology Research Ethics Committee Approval

Ethics Feedback - EC.14.09.09.3844R



← Reply

↶ Reply all

→ Forward



psychethics

Mon 22/09/2014 15:43

Mark as unread

To:  Elina Telford;

Cc:  neil.frude@ntlworld.com;  lin\_telf@hotmail.com;  alun.walters@wales.nhs.uk;

Dear Elina,

The Chair of the Ethics Committee has considered your revised postgraduate project proposal: Exploration of the Dementia Carers Perspective, When a Person with Dementia is Admitted to a General Hospital Ward (EC.14.09.09.3844R).

The project has been approved.

Please note that if any further changes are made to the above project then you must notify the Ethics Committee.

Best wishes,

Natalie

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## Appendix 2.5 Cardiff School of Psychology Research Ethics Committee Revised Approval

← Reply   ←← Reply all   → Forward   ...



psychethics

Wed 07/01/2015 11:25

Mark as unread

To:  Elina Telford;

Cc:  neil.frude@wales.nhs.uk;

● You forwarded this message on 07/01/2015 11:31

Dear Elina,

The Ethics Committee has considered the amendment to your postgraduate project: Exploration of the Dementia Carers Perspective, When a Person with Dementia is Admitted to a General Hospital Ward (EC.14.09.09.3844RA).

The amendment has been approved.

Please note that if any further changes are made to the above project then you must notify the Ethics Committee.

Best wishes,

Natalie

**School of Psychology Research Ethics Committee**

## Appendix 2.6 Information Form

School of Psychology, Cardiff University

### Information Sheet

We would like to invite carers of people with dementia to take part in a study to help us better understand the experience of a hospital admission from the perspective of the carer, when the person they care for is admitted to hospital for a physical health condition. We are specifically interested in talking to carers who have had the experience of the person that they care for being admitted to a general hospital ward for a minimum of 1 day. Carers are invited to take part in the study if the admission is current or in the past, however, it is important that the admission is no longer than 18 months ago.

Carers who would like to take part in the study will be invited to an interview, where you would explore with the interviewer, your perspective and understanding of what happened for the one for whom you care. The interview could last as long as sixty minutes or more, depending on how much of your experience you wanted to share with the researcher. The interview will be recorded and later transcribed. The researcher will then look for themes arising from all interviews, which will help inform our understandings of hospital admissions for people with dementia through the eyes of those who care for them.

It is important that you know that should you change your mind, you are free to withdraw from the study at anytime. Also, should you wish, the interview can be done over several meetings, if this is easier for you.

The information you provide will be held confidentially, so that only the researcher (Elina Telford) can trace this information back to you individually. The interviews will also be anonymised on completion of the transcription of the interview and that after this point no one will be able to trace my information back to you.

Participants should they consent, will also be invited to look at the findings that emerge from the analysis. However, this is not a requirement of the study.

The study will be written as a doctoral thesis and it is anticipated that findings may also be published in the public domain.

Should you have any questions or would like more information, please contact Elina (Linnie) Telford by telephone: 07968271890 or by email [TelfordEH@cardiff.ac.uk](mailto:TelfordEH@cardiff.ac.uk) Alternatively contact Professor Neil Frude (Project Supervisor) by email: [Neil.Frude@wales.nhs.uk](mailto:Neil.Frude@wales.nhs.uk)

Thank you.

## 2.7 Consent Form

School of Psychology, Cardiff University

### Consent Form - Confidential data

I understand that my participation in this project will involve undertaking an interview, which will include questions about my experience of being a carer of person with dementia, who has been admitted to a general hospital ward. I understand that the interview will be later transcribed and analysed.

I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason.

I understand that I am free to ask any questions at any time. I am free to withdraw or discuss my concerns with Professor Neil Frude, who is supervising the project.

I understand that the information provided by me will be held confidentially, such that only the researcher (Elina Telford) can trace this information back to me individually. I understand that my data will be anonymised on the completion of the transcription of the interview and that after this point no-one will be able to trace my information back to me.

The information will be retained until August 2015 when it will be deleted/destroyed. I understand that I can ask for the information I provide to be deleted/destroyed at any time up until the data has been anonymised and I can have access to the information up until the data has been anonymised.

I also understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study.

I, \_\_\_\_\_(NAME) consent to participate in the study conducted by Elina Telford School of Psychology, Cardiff University with the supervision of Professor Neil Frude.

I also understand that the researcher may contact me to ask me for my feedback on the themes that they identify from the interview.

I do consent for them to contact me after the study. (Please tick).

I do **not** consent for them to contact me after the study. (Please tick).

Signed:

Date:

## Appendix 2.8 Debrief Form

School of Psychology, Cardiff University

### Debriefing Form

Exploration of the Dementia Carer's Perspective, When a Person with Dementia is Admitted to a General Hospital Ward

**About the study:** Thank you for taking part in the study. As you may be aware the aim of the study was to explore the dementia carer's understanding of a time when a person for whom they care was admitted to a general hospital ward for a physical health condition. We hope that each of our interviewee's experiences will help aid our understanding of hospital admissions through the eyes of people who care for them in their home environment.

**Confidentiality and your right to withdraw:** We would like to take this opportunity to remind you that the recorded interviews and associated transcripts will be held confidentially and anonymously. Furthermore, you retain the right to withdraw your data without explanation and retrospectively, until the point that your interview is anonymised.

**Looking after you:** We recognise that the role of caring can be difficult. If you are concerned about someone who you think may have dementia or are concerned about yourself and your own wellbeing, contact your GP as a starting point.

If you would like support from other organisations, please see the names, numbers and internet addresses below. These organisations are able to provide you information on a range of topics and may also be able to offer support for you as a carer of someone with dementia.

#### **Alzheimer's Society:**

- **National Dementia Helpline: 0300 222 1122** can provide information, support, guidance and signposting to other appropriate organisations. The Helpline is usually open from **9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm**. The service may be closed occasionally during these times for operational reasons or because of staff shortage. Callers speak to trained Helpline Advisers.
- **Website:** [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

#### **Age UK:**

- **Age UK Helpline:** 0800 169 6565 Call this number for advice or information.
- **Website:** [www.ageuk.org.uk](http://www.ageuk.org.uk)

## **Dementia UK:**

- **Helpline:** 0845 257 9406
- **Website:** <http://www.dementiauk.org/>

## **Carers Trust**

- Head Office Telephone: 0844 800 4361 They can signpost you to services in your area and region.
- **Website:** <http://www.carers.org/>

**Contacting the research team:** Should you wish to contact the researcher (Elina Telford, Post Graduate Trainee Clinical Psychologist), you can do via email: [TelfordEH@cardiff.ac.uk](mailto:TelfordEH@cardiff.ac.uk) You can also contact the project supervisor, Professor Neil Frude, via email: [Neil.Frude@wales.nhs.uk](mailto:Neil.Frude@wales.nhs.uk)

Both Elina and Neil can be contacted via the admin team for the South Wales Doctoral Programme in Clinical Psychology on: 029 2087 0582 or via their postal address:

South Wales Doctoral Programme In Clinical Psychology  
School of Psychology  
Cardiff University  
Tower Building  
Park Place  
Cardiff  
CF10 3AT

**Making a complaint:** Should you have any concerns or complaints that you would like to make, please contact:

Secretary of the Ethics Committee  
School of Psychology  
Cardiff University  
Tower Building  
Park Place  
Cardiff  
CF10 3AT

Tel: 029 2087 0360

Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)