

**Caring for patients with dementia in acute  
physical health settings**

**Thesis submitted in part fulfilment of the degree of**

**Doctorate in Clinical Psychology**

**(DClinPsy)**

**By**

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## **Declaration**

I confirm that the research contained within this thesis is my own original work.

It was completed in part fulfilment of the degree of Doctorate in Clinical Psychology (DClinPsy) and has not been submitted for any other academic award.

# **Caring for patients with dementia in acute physical health settings**

**Frankie Bower**

## **Abstract**

There are approximately 800,000 people in the UK with a diagnosis of dementia (Alzheimer's Society, 2007). The ageing population is leading to increased pressures on dementia care facilities and acute hospital settings. As a result the care of patients with dementia is often suboptimal and staff tend to experience high levels of distress.

Review of the literature examined the quantitative evidence base regarding the predictors of distress in staff working in 24 hour dementia care facilities. A narrative synthesis of 12 articles was carried out and identified three areas of predictors, these reflected intrapersonal, interpersonal and environmental predictors of distress. It was found that little attention was paid to environmental predictors of distress, most studies explored individual and relational factors, environmental predictors were often found to be linked to distress when research questions were broad and often investigating predictors of distress generally. Distress as a concept is ill defined, leading to many theories being applied and many tools being used, making synthesis of the results difficult. The findings are discussed in line with the existing evidence base on distress research.

The research consisted of interviews with 21 acute care staff to explore how they experienced caring for those with dementia in acute medical units (AMU). Thematic analysis (TA) was used to develop four main themes and twelve subthemes, allowing for identification of the main concerns for staff caring for patients with dementia in their general practice. Findings inform changes that AMU could make to allow for staff to care for patients with dementia in a more effective way. The critical appraisal offers a reflective description of the experience of completing the research and its limitations.

## Acknowledgments

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\* Denotes mandatory Appendix



## **Addenda**

Transcripts of research interviews have been provided as an electronic addendum.

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## **Part 1 Literature review**

### **Psychosocial predictors of distress in staff who care for those with dementia in 24 hour care settings**

## **Abstract**

**Background context:** Dementia is an umbrella term for neurodegenerative diseases with cognitive and behavioural presentations. People with dementia are highly represented in 24 hour care facilities, where care staff engage residents in all aspects of care. Caring in such organisations are recognised to be highly stressful for staff and work in these environments is associated with burnout, high rates of turnover and absenteeism; with potential adverse effects on quality of care.

**Objectives:** This review seeks to systematically review the published literature investigating potential predictors of distress in staff who care for those with dementia in 24 hour care settings.

**Methods:** Three databases (Medline, Psycinfo and Scopus) were interrogated for studies which explicitly assessed predictors of distress for staff working in 24 hour dementia care.

**Findings:** From 640 papers initially identified, twelve articles were eligible for inclusion. The findings of the review were synthesized with regards to an already existing body of research encapsulating predictors of staff distress as individual, relational and environmental.

**Conclusion:** Methodological weaknesses and the quality of the studies were reported, with particular attention paid to the operationalization and measurement of distress. Clinical implications and recommendations for further research are suggested.

# 1. Introduction

## *What is dementia?*

Dementia is an overarching term for pathological, neurodegenerative changes that progressively impair cognitive function. Expressions of the disease process may include: memory loss; problems with retaining and encoding information; impairment of language; confusion and personality changes. Those with dementia usually require support with self-care, activities of daily living and interventions to manage behavioural changes, such as aggression (NICE, 2010).

## *Personal and societal costs*

Dementia is one of the most prevalent chronic diseases amongst older adults and is the leading cause of disability placing a huge demand on care services for older people (Wimo *et al.*, 2013). There are currently an estimated 800,000 people in the United Kingdom (UK) with a diagnosis of dementia, a number anticipated to increase to 1.7 million by 2050; the economic impact of dementia on the UK is £23 billion a year and is set to rise to £26 billion a year in 2015 (Alzheimer's Society, 2014).

## *How care is delivered*

Two thirds of people with dementia live in the community, where unpaid caregivers (often defined as informal caregivers) currently save the UK over £11 billion each year (Alzheimer's Society, 2014). Informal care givers have been found to experience anxiety, depression and coping difficulties (Hepburn *et al.*, 2001). Indeed when people with dementia exhibit behaviours such as wandering, aggression, physical dependency and incontinence, carers are more likely to consider 24 hour care (Armstrong, 2000) where those with dementia are cared for by formal paid caregivers in environments such as geriatric wards and residential homes.

Approximately one third of people with dementia in the UK live within 24 hour care facilities (Royal College of Psychiatrists, 2013). As many as 80 per cent of older adults are noted to have dementia or severe memory problems in residential homes (Alzheimer's Society, 2013) resulting in limited care resources and extreme pressure on those with dementia, staff and organisations (Sloane *et al.*, 2002).

### *Burden of care for staff*

Occupational stress has been identified as a substantial health problem within those working as health professionals (Shin *et al.*, 1984). In the UK, 39 per cent of work-related illnesses have been attributed to distress or other common mental health problems, contributing to approximately 11.3 million working days lost nationally (Health & Safety Executive, 2015). Caring staff are amongst the professions reporting highest levels of stress (Lambert & Lambert, 2001). Staff caring for people with dementia in 24-hour settings are subject to the effects of stress, burnout (Duffy *et al.*, 2009) and compassion fatigue as their resources may be limited, their exposure to difficult situations is increased and salaries are low (Beck *et al.*, 1993; Pincquart & Sörensen, 2006). Burnout and low job satisfaction have a strong relationship with absenteeism and job turnover (Applebaum *et al.* 2010; Cohen & Golan, 2007; Davey *et al.*, 2009), this is especially true of staff working in 24 hour dementia care which creates a high cost for organisations and is difficult to sustain (Kovane, 2015).

### *Issues in providing sustained care*

Optimal care is central to a resident's quality of life (Zimmerman *et al.*, 2005), therefore distress may have adverse effect on those receiving care, potentially resulting fewer positive care behaviours, reciprocated aggression (Duffy *et al.*, 2009; Schmidt *et al.*, 2012) and less willingness to help those with dementia (Todd & Watts, 2005). Yet, despite formal carers experiencing elevated levels of distress they also demonstrate high levels of resilience, reporting a high emotional investment in their patients (Edvardsson *et al.*, 2009). Empathic staff enjoy close contact with people with dementia and have a reduced risk of burnout (Åström, *et al.*, 1991). Albrech *et al.* (2013) found that the majority of staff found caring for people with dementia difficult, but were committed to further training and remaining in careers within dementia care. Yet, whilst there is pressure on staff, there is potential for an impact on caring standards. This was most recognisably presented in the Francis report, where the high complexity of dementia care, the organisational and staff related pressures collided and resulted in neglectful staff behaviour (George *et al.*, 2013). This emphasised the importance of dementia care in 24 hour facilities and has developed more focus in this area.

### *Previous reviews*

Whilst burden and distress of staff providing 24 hour care for those with dementia is well documented, there has been very limited systematic scrutiny of the literature in this area. Pitfield *et al.* (2011) investigated the prevalence of psychological stress-related symptoms in staff caring for people with dementia in residential settings using a narrative synthesis. Their evidence did not support high prevalence of distress in staff. This is in contradiction to the broader body of research suggesting that distress is common (e.g. Astrom *et al.*, 1991; Zimmerman *et al.*, 2005). The review has a number of limitations, since all studies appeared under powered or used measures with suboptimal psychometric properties, meaning that conclusions were limited due to inadequate quality. The review used a small sample (of five papers), with staff stress ambiguously and variously defined. However, it showed strengths in its use of multiple relevant search terms that will have captured informative articles. This review measures the prevalence of stress rather than looking at the predictors of distress and as such.

### *Rationale for this review*

There is sufficient evidence to suggest that staff caring for people with dementia are at risk of experiencing high levels of distress. Given few previous systematic reviews, it will be useful to examine the predictors of distress amongst care staff working with dementia in 24 hour care. Identifying predictors of job strain could help identify those at risk of experiencing burnout and may further inform services in ways to help them enhance their mechanisms of staff support to reduce distress in their teams. This in turn could increase the quality of care for those diagnosed with dementia.

## **1.1 Aims of the present review**

Thus the current paper aims to systematically review the published literature investigating potential predictors of distress in staff who care for those with dementia in 24 hour care settings.

## **2. Method**

Initially databases PsycInfo, Medline and CINAHL databases were interrogated to assess literature relevant published, as well as any previous reviews. These particular databases were selected to ensure that a range of medical, nursing and psychological resources were included. Searches were limited to articles which had been peer

reviewed and published in the English language, there was no limit placed on date of publication. Searches were completed in October 2015 and again in March 2016. Reference lists of elicited papers were examined to further identify relevant literature.

## **2.1 Search strategy**

In order to address the review question, a systematic search of the peer reviewed literature was completed. A quantitative focus was adopted due to the nature of the research question focusing on predictors of distress, therefore qualitative studies were excluded. Table 1 denotes the terms used in the scoping process, how they were combined and where truncation was used, so that all variants of the terminology were captured. The terms were grouped into four categories, reflecting the research question. “What are the psychosocial predictors of stress (group 1) in staff (group 2) who care for those with dementia (group 3) in 24 hour care settings (group 4)?” The search strategy process was developed and enhanced with the aid of library and research experts, recommending suitable terms and related literature.

The organisational distress literature was also searched to find the terms used to define staff distress since it can be manifest in various ways and can be captured by different psychological concepts. Within the current literature review the term ‘stress’ was generally used to encompass psychological upset and includes terms such as stress, distress, burden, depression, anxiety and frustration, overall implying a negative impact on psychosocial wellbeing. Search terms such as “wellbeing” were also looked at so as to search for relevant positive psychology studies.



**Table 1 Search Terms**

<b>Group terms combined by “AND”</b>			
Combined by “OR”	Combined by “OR”	Combined by “OR”	Combined by “OR”
Group term 1	Group term 2	Group term 3	Group term 4
Distress	Staff	Dementia	Ward
Stress	Nurse*	Alzheimer’s	Hospital
Burnout	Carer*	“cognitive impairment”	“care home”
“compassion satisfaction”	“formal carer”	Confusion	“residential care home”
Wellbeing	Workers		EMI
Resilience	“care workers”		“dementia ward”
“compassion fatigue”	employees		Gerontology
“secondary trauma”			Acute
			“twenty four hour care”
			“old pe* home”
			Residential
			“24 hour care”

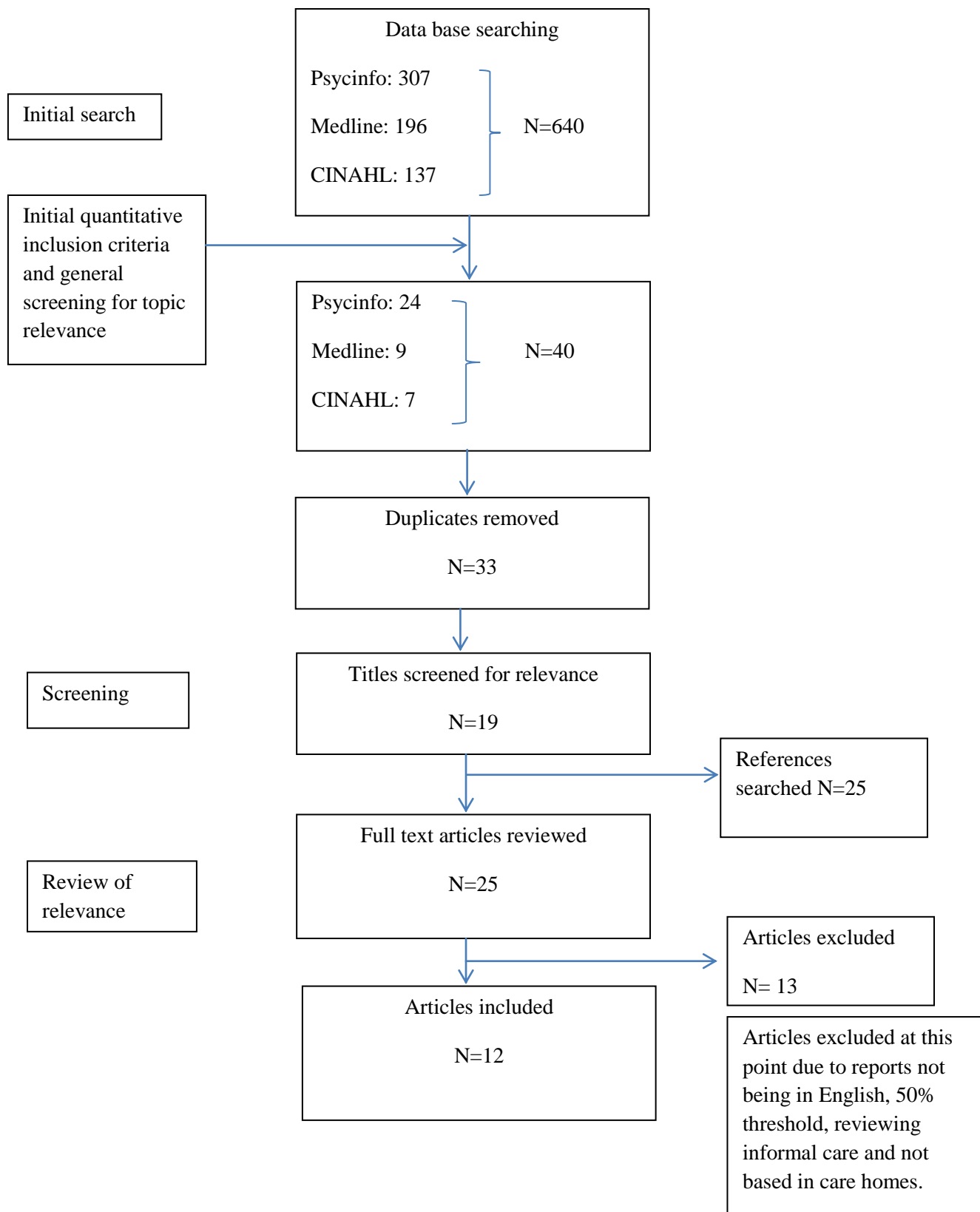
## 2.2 Initial inclusion and exclusion criteria

Before screening, initial exclusion criteria were identified to focus the systematic filtering process. Papers were deemed irrelevant and excluded if they were; qualitative, meta analyses, reviews or narrative accounts of information, case studies or abstracts for conferences, evaluating training or training programs, measuring stress in informal care givers, assessing stress in relation to older adults rather than dementia, assessing staff who look after people with dementia in non 24 hour care, measuring physical health problems, and less than 50% prevalence of dementia in care setting; it has been found that caregivers experience lower levels of distress when caring for older people without dementia, (Bertrand *et al.*, 2006); Aronson *et al.* (1992) reported that care of residents with dementia needs more effort, resulting in higher levels of distress than does care for residents without dementia. Therefore, to create a level of homogeneity between the studies, a cut off level of 50% prevalence of dementia in care facilities was adopted. The cut off of 50% was in part selected on pragmatic grounds, to limit the number of papers to a level that was reasonable to manage, but also to ensure that caring for people with dementia was a significant aspect of the work.

## 2.3 Screening

A total of 640 articles were identified from searching the three data bases; 307 from Psycinfo, 196 from Medline and 137 from CINAHL. A PRISMA diagram illustrates the process from identification to selection of appropriate papers (Figure 1). The 640 paper titles were screened for keywords and relevance to the research question. After duplicates were removed, 33 possibly relevant abstracts were identified to review. From these 33 abstracts reviewed, 14 papers were excluded as qualitative, reviews or papers that explored non-24 hour care. This resulted in 19 papers warranting a review against the inclusion and exclusion criteria and full texts were acquired. The reference lists of the 19 relevant papers were also searched for pertinent citations. Six studies from this additional search were also reviewed in full bringing the total number of eligible papers to 25. These papers were scrutinized and 13 papers were excluded as they did not meet full inclusion criteria, three papers could not be sourced in English, five papers were not evaluating care homes, four papers were under the 50% threshold of evaluating people without dementia and one paper was evaluating informal care rather than formal care. Twelve papers in total were included in the current review.

**Figure 1 Prisma diagram**



## 2.4 Data extraction

A data extraction form was developed to help gather relevant information for review (Appendix F). The data extracted included authors and location, purpose of study, sample, research design, outcome measures and significant predictors or factors which were noted to affect levels of distress. Abbreviations for the measures used can be found in Appendix E.

## 2.5 Quality appraisal

Strengths and weaknesses of the studies were also evaluated with use of a data extraction form and review of the studies' findings and limitations (Table 2). Articles were read in full and evaluation of quality was guided with regards to a modified version of the Downs and Black (1998) quality assessment tool. This tool was utilized due to its previous use in systematic reviews, appraisal of non-randomized studies and its scope for adapting to fit different methodologies. The tool was initially developed to extract information from intervention studies using a broad range of questions. It was amended by the author as a better fit for purpose for cross sectional methodology, as this was the main methodology used by papers in this review.

Each study was given a quality percentage score (Table 2), with regards to the quality threshold developed by Downs and Black (1998) based on five dimensions: reporting (Total/5), external validity (Total/1), internal validity (Total/ 3), power (Total/ 1) and study design (Total/2). Further outline of the questions asked can be found in Appendix D. Questions regarding interventions and control groups were removed from the original tool, due to a lack of relevance to the studies' methodologies. One of the twelve studies had a low score ( $\leq 50\%$ ), four had moderate scores ( $>50\%$ ) and seven had high scores ( $>70\%$ ). Results of the quality assessment are provided in Table 2. All of the studies were included in the review as they represent the current status of studies available. Therefore ratings were used in weighing up how reliable findings of particular papers were, and to inform critical evaluation of the research.

**Table 2 Quality Ratings**

<b>Label</b>	<b>Paper</b>	<b>Reporting</b>	<b>External validity</b>	<b>Internal validity</b>	<b>Power</b>	<b>Study design</b>	<b>Study quality score %</b>
1	Edvardsson <i>et al.</i> (2008)	5/5	0/1	2/3	0/1	0/2	58
2	Kokkonen <i>et al.</i> (2014)	5/5	1/1	3/3	1/1	1/2	92
3	Baillon <i>et al.</i> (1996)	5/5	1/1	3/3	0/1	1/2	83
4	Miyamoto <i>et al.</i> (2010)	5/5	1/1	3/3	0/1	1/2	83
5	Testad <i>et al.</i> (2010)	5/5	0/1	3/3	0/1	1/2	75
6	Willemse <i>et al.</i> (2015)	4/5	1/1	3/3	0/1	1/2	75
7	Rodney (2000)	4/5	0/1	2/3	0/1	1/2	58
8	Zwijssen, <i>et al.</i> (2014)	4/5	0/1	1/1	0/1	1/2	50
9	Brodaty, <i>et al.</i> (2003)	5/5	1/1	1/3	1/1	1/2	75
10	Edvardsson <i>et al.</i> (2009)	5/5	0/1	2/3	0/1	1/2	67
11	Saarnio, <i>et al.</i> (2012)	5/5	1/1	2/3	1/1	1/2	83
12	Barber <i>et al.</i> (1996)	2/5	0/1	1/1	0/1	1/2	33

## 2.6 Analysis

Due to the heterogeneous nature of the studies, it was not possible to conduct a meta-analysis. Studies varied in their definitions of distress, use of measures, statistical procedure, method of analysis. The findings of the systematic review were therefore narratively synthesized. Given that a body of research exists which can categorise predictors of staff distress as individual, relational and environmental; this framework was used to organize the findings of the review (Karasek 1979; Lazarus & Folkman, 1984; Maslach *et al.*, 2001). The main characteristics of the studies in this literature review are presented in Table 3. Discussion of the studies and their significant results are presented as narrative synthesis and summarised in Table 4.

### **3. Results**

The main characteristics of the twelve studies included in this review are outlined in Table 3 and 4.

**Table 3 Studies outline and key findings**

<b>Label</b>	<b>Author/year/Location</b>	<b>Aim</b>	<b>Design</b>	<b>Measures used/ psychometrically robust/ operationalization of distress</b>	<b>Sample  Staff type/ participants (n)/ residents with dementia (n)</b>	<b>Strengths</b>	<b>Weaknesses</b>
1	Edvardsson <i>et al.</i> (2008)/Sweden	To investigate associations between work characteristics of nursing staff and prevalence of behavioral symptoms among people with dementia in residential care settings	Cross sectional	Self-reported job strain assessment scale and MDAAS/ Reliability for MDAAS reported No reliability report for self-report job strain assessment scale/ Yes, Job Strain model (Karasek & Theorell, 1990)	Nursing staff in residential care units for people with dementia/ N=346/ /100%	Large sample size (no power reported). Assessed both residents and staff to gain better understanding of associations	Univariate analyses with no adjustments for multiple comparisons



2	Kokkonen <i>et al.</i> (2014) UK	To explore relationships between burnout, staff attachment styles, geriatric nursing self-efficacy and approaches to dementia	Cross sectional survey?	ECR-R; Inventory of Geriatric Nursing Self Efficacy; ADQ; MBI:  / All reported good psychometric properties/ Yes, based on Burnout: (Maslach, Jackson & Leiter 1996) Attachment theory: Bowlby (1969, 1973, 1980), Across the lifespan (Cassidy & Shaver, 2008).	Health care assistants, support workers or staff nurses inpatient wards/ N=77/ 60% dementia	Study powered to detect medium-to-large effect sizes.  Valid and reliable tools used.	Only 60% of residents had dementia.  Participants' interpretation of the questionnaire items may have influenced their responses. Response rate of 44.3% is relatively low.
3	Baillon <i>et al.</i> (1996) UK	The relationship between staff stress and attitudes towards the elderly, and job satisfaction	cross sectional survey	GHQ; MSQ; Kogan Attitude Towards Old People Scale; SEQ; SARAH/ validity and reliability not reported. SEQ new scale, no data on reliability and validity./ Staff stress attitudes and job satisfaction constructs not based on theory or operationalised besides utilisation of questionnaires.	Three Local Authority Social Services residential homes for the elderly/ N=38/ 82%	Representative sample of Leicester. All care staff were asked to take part	Not generalizable outside of Leicester. SEQ is a new scale, does not have data on reliability and validity. A significant number of non-responders in homes 1 and 2 in comparison with home 3. Not all workers responded therefore results are not representative of all staff.

4	Miyamoto <i>et al.</i> (2010) Japan	Burden of formal caregivers who care for people with dementia	Cross sectional	Zarit Caregiver burden interview, personal strain items, the personal self-maintenance scale, the troublesome behavior scale/ valid and reliable/ not operationalized but inferred from measures used measuring burden	Formal caregivers for residents with dementia. Nurses and direct care givers. Care units in psychiatric hospitals and geriatric care facilities/ 445/ 100%	Representative sample of Japan.  100% of dyads were with dementia patients	There may have been replication of completion of questionnaires by the same carer.
5	Testad <i>et al.</i> (2010) Norway	Investigate the association of psychosocial factors and patients factors with stress in care staff in nursing homes	Cross sectional	Perceived stress scale; Hopkins symptom checklist; subjective health complaints; Cohen Mansfield agitation inventory; general Nordic questionnaire for psychosocial and social factors at work / Hopkins checklist reported to be valid, none others reported/ not operationalized but inferred from measures used	13 dementia wards/ N= 197/ 100%	Large number of care staff and patients. High participation rate. Questionnaires distributed by researcher, not member of staff-increased validity.	The mean hours of work were less than full time. Shifts managed in an easier way. Low level of agitation reduced the power to detect a relationship between patient's agitation and staff's job stress. Agitation was measured based on subjective opinion of the care staff. Psychological distress may influence the rating and increase reported level of agitation

6	Willemse <i>et al.</i> (2015) Netherlands	To explore the role of nursing staffs person centeredness caring for people with dementia in relation to their work environment and job related wellbeing	Cross sectional	Subscale ADQ; Leiden quality of work questionnaire, Dutch version of MBI /all reported as valid and reliable/ yes, demand control support model and person centeredness.	135 Living arrangements for people with dementia, health care staff/N=1093/ 100%	Representative sample. Only long term staff reviewed. Large sample size	Willemese suggests staff know  they are supposed to in an individual ized , influencing answers or ADQ is outdated as staff are more person-centred. ADQ needs more sensitive items to measure  Differences in person-centredness.
7	Rodney (2000) Australia	Nurse stress associated with aggression in people with dementia: its relation to hardiness, cognitive appraisal and coping	Cross sectional	Rating scale for aggressive behavior in the elderly. Personal views survey. 58 coping methods (Dewe, 1987). Stress section of the mood adjective checklist (Mackay 1978)/ tools valid and reliable/ yes, based on hardiness theories	Nurses, Nursing homes/ N=102/ 100%	15 homes sampled, more generalizable.	Relating to two patients, not generalizable. Asking people who are higher up because it is assumed they know more.  Arbitrarily decided value of 30 or above, as cut off point for inclusion. Didn't say how the 15 homes were chosen or the people who participated. No demographic information reported.

8	Zwijssen, <i>et al.</i> (2014) Amsterdam	The relation between frequency and severity of individual neuropsychiatric symptoms and distress of care staff.	Explorative cross sectional	Nursing Home version of the Neuropsychiatric Inventory (NPI-NH) questionnaire  Global Deterioration Scale (GDS)/ All reported valid and reliable;  ./ not operationalized, but implied through measures used.	Care staff in 17 nursing homes for people with dementia/not reported / 62%	Large sample size.	No statistical analysis apart from mean scores. Zwijssen reports emotional distress not familiar concept, hard to discuss leading to underreporting of distress. Distress experienced increased assessment of severity and frequency of symptoms.
9	Brodaty, <i>et al.</i> (2003) Australia	Investigate nursing home staff strain related to dementia care and satisfaction with work, describe challenging resident characteristics and work most satisfying	Cross sectional	BEHAVE-AD; SNC; SNCW / The validity and reliability of the English versions of the SNC and SNCW have not been established yes valid and reliable/ not operationalised but inferred from measures used- stress and strain.	12 Nursing homes / N=253/ 100%	Nursing homes were selected to cover the range  of small (under 60 beds), medium (60–90 beds) and large  (over 90 beds) homes and to be geographically dispersed over the area.	Lack of data on the representativeness of the sample,  missing demographic data limited  analyses. No information on distribution  rate or response rate or non respondents. Instrument limitations.

10	Edvardsson <i>et al.</i> (2009)  Sweden	To identify predictors of job strain in residential nursing care staff working with people with dementia	Cross sectional	The self-report demand and control questionnaire (Karasek & Theorell 1990)  Self-devised perceived unit caring climate and own knowledge scales/ yes valid tools/ yes, the Job strain model (Karasek and Theorell, 1990)	Nursing staff residential care units for people with dementia/ N=35/ 100%	88% participation rate	The whole regression model explained 19% of the variability in job strain scores. There are a number of other factors not accounted for.
11	Saarnio, <i>et al.</i> (2012)  Finland	To explore Stress of Conscience in personnel caring for older people in Finland	Cross sectional	SCQ / testing validity of dutch version of the tool in the study/ yes, based on stress of conscience.	Healthcare centre wards, Municipal nursing home, Municipal dementia treatment unit, Private nursing home, / N=350/ 100%	High response rate	Testing the SCQ in Finland, reporting the reliability.
12	Barber <i>et al.</i> (1996)  USA	Examining caregiver characteristics, workload and caregiving involvement, work environment characteristics, social support as predictors of burnout	Cross sectional survey	MBI / valid and reliable/ supported by theory and operationalised.	Nurses, nurse aides, social workers, primary care staff in long term care facilities/ N=75/ 100%	Strongly supported by theory	No strengths or weaknesses reported. Results were limited in report; may have missed areas for potential predictors.

**Table 4 Predictors of distress**

Study label	Predictors of distress	Category
1	High job strain reported related to young ( $p=0.004$ ) women ( $p=0.046$ ), with less experience ( $p=0.007$ ), negative view of environment ( $p=0.000$ ), less time to talk about problems ( $p=0.019$ ). Residents with lower communication skills ( $p=0.005$ ) and motor abilities ( $p=0.001$ ). Verbally disruptive behaviour more prevalent ( $p=0.027$ ) where rated job strain as higher. The following behaviours more prevalent in least positive climate: escape behaviour ( $p=0.028$ ), restless behaviour ( $p=0.027$ ), and wandering behaviour ( $p=0.001$ )	Relational factors, interaction with individual factors.
2	Higher attachment anxiety associated with higher emotional exhaustion ( $r=0.26$ , $p<0.05$ , $N=75$ ) and lower personal accomplishment ( $r=-0.44$ , $p<0.000$ , $N=75$ ). Higher attachment avoidance associated with higher emotional exhaustion ( $r=0.27$ , $p=0.01$ , $N=75$ ). Higher levels of attachment anxiety associated with less person-centred attitudes in staff ( $r=0.32$ , $p<0.01$ , $N=77$ ). Emotional exhaustion ( $r=-0.20$ , $p<0.05$ , $N=75$ ) and depersonalisation ( $r=-0.28$ , $p<0.01$ , $N=75$ ) significantly negatively correlated with self-efficacy. Correlation between self-efficacy and personal accomplishment ( $r=0.37$ , $p<0.01$ , $N=75$ ). Optimistic attitudes associated with more exhaustion ( $r=0.36$ , $p<0.01$ , $N=75$ ).	Individual
3	Symptoms of stress exceeded community samples (64% of staff exceeded threshold). Higher symptoms record less job satisfaction (Spearman's $r$ , $p < 0.001$ ). Staff had a positive attitude towards the elderly. Resident related items most frequently experienced not most stressful. Increased behavioural symptoms reported less job satisfaction (Spearman's $r$ , $p < 0.001$ ). Frequency $p < 0.01$ and stressfulness $p < 0.03$ correlated with GHQ total score (Spearman's $r$ , $p < 0.001$ ). Organisation as stressful as resident characteristics and behaviour ( $p<0.01$ ).	Relational factors explored, environmental and individual factors found to be more strongly correlated.
4	Impaired function, female sex, and aggressive and inappropriate behaviors, associated with formal caregiver burden. Behaviors that might affect others, were the strongest predictors of formal caregiver burden ( $r=0.52$ , $P = .001$ )	Relational factors
5	Workload, work experience and education had an influence on stress. Age ( $p<0.029$ ), and shift work ( $p<0.041$ ) correlated with health and well-being. Leadership ( $p<0.002$ ), mastery of work ( $p<0.008$ ) and control at work ( $p<0.004$ ), significantly associated with high distress. Resident's agitation wasn't associated with health and wellbeing	Environmental

6	No P values reported. Person centeredness moderates relationship between coworker support and three outcomes of job related wellbeing and supervisor support. Highly person centered staff found coworker support had a weaker and supervisor support had a stronger impact on their job related wellbeing	Intrapersonal
7	Resident aggression related to increased stress. Perceiving the possibility of aggressive behavior as threatening was related to a high level of stress. Stress higher when caring for aggressive resident than low aggressive resident ( $p=0.000$ ) Primary appraisal of threat had a significant positive relationship with stress ( $r[99]=0.50$ , $P < 0.01$ ).	Relational
8	No p values reported. Patients Agitation/aggression had highest mean distress score and most prevalent symptom. Disinhibition and irritability had high mean distress scores. Euphoria/elation, hallucinations and apathy had the lowest mean distress score. Symptom severity of each symptom strongly predicted the distress score, whereas the frequency of the symptoms was less important.	Relational
9	Staff found residents were more negative than positive. Age not correlated with attitude scores, but significantly positively correlated with total strain and negatively correlated with satisfaction ( $r = -0.079$ , $P = 0.249$ ; $r = 0.165$ , $P = 0.022$ ; $r = -0.137$ , $P = 0.041$ , respectively). Experience in nursing homes correlated significantly with total strain scores ( $r = 0.213$ , $P = 0.003$ ), but not with attitude or satisfaction. Attitude was negatively correlated with strain and satisfaction ( $r = -0.440$ , $P < 0.001$ ; $r = -0.192$ , $P = 0.004$ , respectively).	Intrapersonal
10	Staff reported more frequent high work demands ( $P < 0.001$ ) and less low work control ( $P < 0.05$ ). Staff reporting higher job strain were less educated ( $P < 0.01$ ), younger ( $r = 0.13$ , $P < 0.05$ ) perceived the caring climate as less positive ( $P < 0.01$ ), Fewer possibilities to have discussions of difficulties and ethical conflicts at work ( $r = 0.12$ , $P < 0.05$ )	Environmental
11	Lack of time to provide the care was most stressful. Staff felt incompatible demands resulting in a troubled conscience. Length of experience in working with dementia ( $p = 0.004$ ) working with more than 30 beds ( $p = 0.01$ ), somewhat significant differences in groups of different types of employment ( $p = 0.05$ ) related to higher lack of inner strength. Registered nurses ( $p = 0.006$ ) and participants with two children living at home ( $p = 0.007$ ) higher external forces	Environmental
12	No p values reported; Work environment characteristics- particularly role characteristics are better predictors of burnout than are personal characteristics of staff. The amount of direct contact with dementia patients or the amount of social support from co-workers.	





The main characteristics of the twelve studies included in this review are outlined in Table 3 and 5. Four studies were conducted in Nordic countries (1, 5, 10, 11); two in the Netherlands (6, 8); two in Australia (7, 9); two in the UK (2, 3); one in the USA (12) and one in Japan (4). The majority of studies recruited from multi-centre nursing or dementia residential homes (1, 3, 6, 7, 8, 9, 10); two studies recruited from wards specifically caring for those with dementia (2, 5); two studies recruited from a variety of long-term care placements (11, 4) and one Study (12) did not specify the type of facility they recruited from. Studies' sample sizes ranged from N=35 (10) to N=1093 (6). The majority of the staff represented in the research were qualified nurses, females in their forties; there was little ethnic or cultural diversity of participants reported. The characteristics of the staff who did not take part were not reported by any of the studies. Two of the studies, (4 & 8) explicitly reported residents' diagnoses of dementia consonant with the Diagnostic statistics manual (DSM IV-Trim, 2000); all other studies implied residents' cognitive status rather than measuring it and reporting it. Study 5 and Study 8 reported symptom severity of dementia using the FAST, (Study5) and the Global Deterioration Scale, (Study8) which allowed for severity in dementia presentation to be considered as a predictor of distress. Five studies reported the demographic information of the residents (1, 4, 5, 8, 10). Studies 7, 4, 1 and 8 specifically reported resident dementia symptoms and the interaction with staff distress. The majority of studies recruited from dementia specific locations, some recruited from facilities where not all residents had dementia (2, 3 & 8); Study 2 reported that 40% of residents in their residential unit did not have dementia.

Staff distress was conceptualised differently across the twelve studies (Table 3). Seven of the studies operationalized distress with reference to validated theoretical frameworks: Karasek's demand and control model (1, 6, 10); Maslach's model of burnout (2, 12); Stress of Conscience theory (11) and Cognitive Relational Theory (7). A number of studies did not define the terms used (9, 8, 5). Given the diverse models used to define staff distress, measures used by studies were also diverse, with thirty two different self-report measures used across studies. The majority of studies reported validity and reliability of measures used with exception of 1, 3 and 5 (Table 2).

When assessing studies' analyses, only three studies reported power calculations (2, 9 and 11); Study 2 reported that the research was powered to detect medium-to-large effect sizes; studies 9 and 11 reported high participation rates, reflecting sufficient

power. Investigation into predictors of distress was done in a varied way across the studies; considering multiple comparisons may not have been feasible in some studies due to small sample sizes; however, there is an increased possibility of identifying predictors if more factors are considered. Most studies focussed on one area (e.g. attachment or person centred) and investigated the relationship between these factors and distress.

### **3.1 Individual factors**

Three studies specifically examined individual factors as potential predictors of staff distress: 2, 6 & 9. Study 6 explored staff person-centeredness and its association with wellbeing; Study 9 investigated staff strain, job satisfaction and how these variables related to behavioural disturbance in residents with dementia; and Study 2 considered the relationship between staff's attachment style, coping skills and burnout in dementia care settings. The individual factors explored can be categorised as; demographic information, attitudes, beliefs and appraisals, and attachment style.

#### *Demographic information*

All studies in the review, other than 7, reported demographic information for participants. Some demographic factors related more strongly to distress, including: gender, age, education and length of work. Two studies reported on gender; Study 1 reported that being female was associated with greater distress ( $p=0.046$ ), Study 9 reported that there was no gender influence; no other studies found that gender was a predictor of distress. Study 1 ( $p=0.004$ ) and 10 ( $r = 0.13, P < 0.05$ ), reported that being younger was a predictor of greater distress; Study 5 found that age correlated with distress, but which direction was not clear. Study 5, 10 and 12 explored the relationship between education level and distress. All studies found that education was not a predictor of distress. Study 11 was the only study which identified length of working as a predictor; increased time in dementia care work was associated with greater stress of conscience ( $p = 0.004$ ). Exploration as to why demographic information predicted distress was not explored further, leaving speculation around this area.

#### **Attitudes**

Studies 2, 6 & 9 investigated staff attitudes as a predictor of distress, focusing on attitudes towards residents (Studies 2 & 9) and person-centred attitudes of staff (Study 6). In Study 9, positive and negative attitude statements were given to participants who

then rated their level of agreement against each statement; 66% of participants agreed with negative attitude statements. Study 9 and 2 both found that negative attitudes towards those with dementia were a protective factor against distress. Study 9 reported that negative attitude was associated with lower satisfaction and strain ( $r=-0.192$ ,  $p=0.004$ ,  $r=-0.440$ ,  $p=0.001$ , respectively). Contrary to Study 9's findings, Study 2 found that overall, staff had a positive attitude towards those with dementia; yet higher levels of optimism were found to positively correlate with reported burnout ( $r=0.36$ ,  $p<0.01$ ,  $N=75$ ). Both studies found that positive attitudes were associated with burnout and strain.

Study 6 focused on person-centred attitudes and distress. Staff who reported person-centred attitudes, rated interactions with residents positively; job related wellbeing was positively correlated with person centred attitudes. This potentially offers conflicting findings to Studies 2 & 9 which suggest that positive attitudes towards residents relates to staff distress.

### *Attachment style*

Attachment style and its relationship with burnout was investigated in one Study 2 which found that burnout was associated with insecure attachment style of carers, specifically attachment-related anxiety ( $r=0.26$ ,  $p<0.05$ ,  $N=75$ ). Attachment explained 9.6% of the models variance, which was statistically significant when controlling for other predictors. The interaction between staff attachment styles and resident attachment styles were not explored, suggesting a solely individual cause for distress.

## **3.2 Relational; resident behavioural factors**

Five studies explored relational factors as predictors of distress; 1, 3, 4, 7 & 8. Study 1 investigated the prevalence of behavioural symptoms in residents with dementia and the relationship with staff distress. Study 3 explored staff stress, job satisfaction and attitudes towards the elderly. Study 4 generally examined burden in staff and results indicate that relational factors are a strong predictor of burnout. Study 7 explored staff experience of resident aggression and its association with hardiness, cognitive appraisal and coping. Study 8 investigated the relationship between frequency and severity of resident neuropsychiatric symptoms and staff distress. The relational factors associated with distress are categorised as; frequency and severity of dementia; specific behaviours and attitudes/ perceptions of residents.

### *Frequency and severity of dementia*

Two studies explored the severity of dementia and staff distress (Study 3 and 8). Study C found that a higher frequency of behavioural symptoms related to less job satisfaction (Spearman's  $r$ ,  $p < 0.001$ ); whereas Study 8 reported that the severity of behaviours predicted the overall distress score more strongly than frequency did.

### *Specific behaviours*

Studies 1, 8 and 4 discovered that specific dementia related behaviours were associated with staff distress. Two studies found that aggression and agitation were related to distress (8&4). Study H also found that staff who experienced resident disinhibition and irritability had high mean distress scores, whereas euphoria/ elation, hallucinations and apathy had the low mean distress scores. Study 4 further reported that disruptive behaviours such as screaming and reduced "activities in daily living" (ADL) related to burden. Study 1 reported that resident escape behaviour ( $p=0.028$ ), restless behaviour ( $p=0.027$ ), and wandering ( $p=0.001$ ) related to distress when staff rated the caring climate as less positive. In contrast; Study 9 found no association between staff strain and challenging behaviours.

### *Perceptions of residents*

Studies 1, 3 and 7 reported findings on how staff perceived residents, attitudes towards residents and staff distress. Study 3 reported that participants had positive attitudes towards residents, however the participants reported higher distress than community samples; 64% of participants scored above threshold, suggesting that positive attitudes potentially relate to distress. Study 7 found that when staff perceived residents negatively, specifically when they anticipated aggression, increased distress also occurred ( $\beta$  (94)=0.50,  $P < 0.05$ ). In contrast Study 1 found that when staff perceived the working environment as less positive, staff also reported increased challenging behaviour: escaping ( $p=0.028$ ), restlessness ( $p=0.027$ ), and wandering ( $p=0.001$ ) and greater distress.

### 3.3 Environmental/ organisational factors

Four studies explored the work place environment and organisational factors as predictors of distress (5, 10, 11 & 12). All studies explored general factors associated with distress, but reported organisational/ environmental factors had the strongest relationships. Study 5 investigated resident factors such as symptom severity and resident agitation; staff factors such as distress after these experiences and demographic information; and environmental factors, such as information about the environment and organisation and the association these factors had with staff health, wellbeing and distress. Organisational structure was found to strongly relate to staff distress. Study 10 administered the self-report demand and control questionnaire to nursing staff (Karasek & Theorell 1990) to assess overall predictors of job strain. Study 11 explored stress of conscience generally, in staff caring for older people in Finland. Study 12 examined 4 variables as predictors of distress: caregiver characteristics, workload, work environment characteristics and social support. This was assessed in long term care facilities, with a number of different professions; nurses, social workers and primary care staff. They found that the greatest predictors of burnout in staff were work environment characteristics. None of these studies initially focused on environmental factors, but looked at general predictors of distress from an individual, relational and environmental perspective. All of the reported studies in this section found that environmental influences had strongest associations with distress. The findings are separated into; external demands, support, perceptions of the environment and self and organisational factors.

#### *External demands*

Studies 5 and 11 found results indicating that distress correlates with external demands; Study 11 found that when staff had a lack of time to provide care needed and incompatible work demands, there was an increase of stressful situations and an increased troubled conscience. Study 5 found that participants who worked shifts also reported higher stress symptoms ( $p < 0.041$ ). Study 11 was the only Study to examine life outside of work and its relationship with staff distress; participants living with two children were found to experience higher external forces than others. These studies suggest that greater external demands on staff are associated with increased levels of distress.

### *Support*

Studies 10, 5 and 12 explored whether support from other members of staff had a relationship with distress. Study 10 reported that staff experienced strain when they were unable to have discussions about difficulties and ethical problems ( $r = 0.12$ ,  $P < 0.05$ ). Further to this point, studies 5 and 12 found that distress linked to a lack of support from supervisors, or limited chance to talk about problems. Study 12, however did not find a relationship between general social support and emotional exhaustion, therefore suggesting more value over supervisory support. However, this finding could have been skewed due it not being measured specifically as a predictor; support could have been identified as a buffer for staff burnout if it was specifically measured as a predictor (Barber *et al.*, 1996). Overall, lack of support is linked to distress.

### *Perceptions of environment and self*

Studies 10, 9, 5 & 12 explored staff perceptions of the working environment and how this related to distress. Study 10 found that job strain was significantly associated with staff perceiving the caring climate of the unit as negative ( $r = 0.39$ ,  $P < 0.01$ ), this was also found by Study 9 ( $r=0.213$ ,  $p=0.003$ ). Study 5 reported that staff distress is related to the perception of the environment through a combination of low control and high demands, in keeping with the demand control model (Karasek, 1979); leadership ( $p<0.002$ ), mastery ( $p<0.008$ ) and control of work ( $p<0.004$ ) explained variance in distress. Study 12 also supported this finding, reporting that the greatest predictor of burnout was work environment characteristics, accounting for 60% of the variance. The majority of the variance was explained by role conflict, which suggests that external demands relate highly to levels of distress.

### *Organisational demands*

Study 3 was the only study to specifically report information about organisational demands. Staff who reported more problems with organisation and management factors reported more significant symptoms of distress. Aspects of the organisation were perceived as being as stressful as resident characteristics and behaviour ( $p<0.01$ ).

### 3.4 Methodological issues

All studies apart from Study 7 reported demographic information of staff and its association with levels of distress. Studies findings varied, other than consensus that education did not seem to have an effect. The characteristics of the samples are generally representative of care professions, yet the diversity of samples is limited. It was interesting when synthesising the results that Studies 2 & 6 both identified positive attitudes towards patients with dementia as predictors of burnout; both studies used the Maslach burnout inventory (MBI Maslach & Jackson, 1986) and the approach to dementia questionnaire (ADQ Lintern *et al.* 2000). Therefore, both utilising the same measures and operationalisation of burnout. It is possible that reporting similar results and using the same measures adds to the strength of their findings. Study 6 offers conflicting findings to Studies 2 & 9, suggesting that person centred attitudes result in staff wellness. Willemese *et al.* (2015) critiques the use of the measures in Study 6 by suggesting that staff know they are supposed to think about residents as individuals, due to this becoming a focal concept in the caring industry, leading to a bias in the results. Study 9's methodological issues reside in their reporting bias. The main percentage of people agreeing with negative attitude statements was 66.6%; the mean percentage of staff agreeing with positive statements was 62.7%. This latter finding was not explored further in the report, leading to a focus on the negative attitude statements, resulting in a potential bias in the report.

All studies in the relational section, apart from 9 indicated that behavioural symptoms of dementia were associated with distress. There was not a consensus of which behaviours were related more strongly to distress but there seems to be a general trend that negative behaviours, such as wandering and aggression, relate more highly to staff distress. Study 7 added in staff individual factors into the exploration of challenging behaviour, ascertaining staff perception of behaviour rather than accepting behavioural ratings at face value. If staff were reporting higher levels of distress this could have had an impact on their experience of the frequency and severity of challenging behaviour leading to a skew in findings (Saarnio *et al.*, 2012).

All of the studies explored staff responses in nursing homes; this therefore allows comparison of the environments to some extent; however all of the studies were from geographically different locations, potentially offering different services and creating limitations for each study's representativeness.

The studies focussing on environmental demands report that limited support, increased external demands and problematic organisations were associated with increased distress. Study 10 found that external forces related strongly to job strain, in comparison to inner strength. However, none of the studies focussed specifically on environmental demands and a limited amount of the studies overall included this area as a potential predictor. This area was significantly underreported compared to the other categories outlined.

## **4. Discussion**

The current review aimed to explore factors associated with distress in staff caring for those with dementia in 24 hour care facilities. The findings were categorised in three domains comprising of individual, relational and environmental factors, consistent with domains previously documented as predictors of distress in other nursing groups. The strength of evidence throughout the literature was variable, meaning that there was little scope for evidencing predictors of distress in each area.

A common finding was marked variability in how the term “distress” was operationalised meaning that synthesis was made difficult. Indeed, some studies did not operationalise distress and therefore it was unclear what was being measured. Given that difficulty, this discussion will tentatively summarise the findings; highlight methodological issues; state improvement to research and present strengths and weaknesses of the review and clinical implications.

### **4.1 Findings**

Twelve articles met inclusion criteria; within each article, a number of variables were explored with relation to predictors of distress, therefore synthesis of the findings was challenging, however a template was developed to organise the analysis based on the findings. This included; three papers examined specific individual factors and their relationship with distress, focussing on demographic information; staff attitudes or perceptions; and attachment style. Five studies examined the relational predictors of distress, mostly resident behaviour. Four studies found environmental factors had a strong association with staff distress; particularly aspects such as problematic organisations; lack of time; increased workload and shift work. The large numbers of variables were therefore assimilated into these three areas to allow for exploration of the different predictors of distress.



The main finding of the review was that there are many predictors of distress, creating difficulties in assimilation. This is consistent with occupational and mental health research which reports that many factors have an effect on distress (Mark & Smith, 2008). The use of a template allowed the variables to be amalgamated.

### *Individual factors*

Demographic factors pertaining to staff were reported in a number of the studies; gender was explored as a factor related to distress throughout most of the reviewed research. The review provides inconclusive evidence as to whether gender has a relationship with distress. This relationship has been explored in detail in other literature. In many studies it has been reported that women have higher prevalence of anxiety, depression and burnout than men, (Etzion, 1984; Innstrand *et al.*, 2011; Kessler, 1994; Pinguart & Sörensen, 2006; Simonds & Whiffen, 2003). However, a more recent review using more nuanced exploration of gender impacts on burnout reports that specifically, women show more emotional exhaustion than men but that men experience higher levels of depersonalization (Purvanova & Muros, 2010). Van der Lippe and Van Dijk (2002) state that middle aged women are overrepresented in distress research and in the service sector; leading to limited representation of male staff and an emphasis on female mental health. This was also evidenced in the reviewed literature as the samples largely comprised females in their 40's. However this demographic is generally representative of care professions.

Through reviewing the literature, it was apparent that there were no studies which explored the relationship between ethnicity and distress. Caregiving staff in the UK are currently a very diverse workforce, particularly due to policy emphasis on recruiting staff internationally to “grow” the workforce in the NHS (Department of Health, 2004). Yet to date there has been limited investigation into the association between ethnicity and distress in health care. Potential cultural differences in how staff experience distress suggests further research is needed to explore this question. The utility of exploring solely demographic factors appears limited. Exclusive focus on demographics is likely to offer only descriptive value with little scope to alter behaviours that might render professionals vulnerable

It is common for distress to be conceptualised as an individual process, especially since individual cognitive behavioural therapy in the NHS has increased. Lazarus (1991) proposed a cognitive relational theory, which states that distress occurs due to a person's perception of situations and personal ability to cope; implying that cognitive alterations can make a difference to experience of distress. This review demonstrates that in relation to individual factors, elements outside of the individual may also be instrumental to staff experiences of distress.

### *Relational factors*

A number of the studies in the review explored the association between staff distress and resident behaviour. However consensus was lacking across the studies as to which relational variables related to distress, particularly with regards to the variable of staff attitude towards residents. There was disagreement in the reviewed literature between whether positive or negative attitudes towards residents related to distress. The majority of other research reports that person centred, positive and empathic attitudes leads to an increase in wellbeing, both for the resident with dementia and the staff (Åström *et al.*, 1991; Norbergh *et al.*, 2006; Zimmerman *et al.*, 2005). Positive attitudes and person centred care has been an area of focus over the recent years, particularly in dementia care (Kitwood, 1993). Two of the three reviewed studies reported that person centred values are linked to distress, the question of why was not reported in the reviewed literature, nor does it seem to have been explored in other literature, therefore it seems this is an area for further research. However, the concept of person centred care has been criticised by Nolan (2004), who stated that person centred care is often misrepresented in health care and can “perpetuate, rather than eliminate, poor standards of care for older people.” Therefore question over what does person centred care look like for individual staff is also possibly an area for exploration.

The reviewed literature generally agreed that staff distress is linked to behaviours that challenge, this association has also been evidenced in other areas such as intellectual disabilities (Rose *et al.*, 2004; Skirrow & Hatton, 2007), forensic services (Dickinson & Wright, 2008) and dementia care (Pulsford & Duxbury, 2006; Todd & Watts, 2005). In the reviewed literature, there were differing findings about whether symptom severity, frequency or type of behaviour had strongest associations with distress. However, Hastings (2002) suggested there are potentially a number of variables which mediate the

relationship between challenging behaviour and distress, such as negative staff emotion (Mills & Rose, 2011). Further investigation into the mediating factors of distress in dementia care is needed to discern which elements of challenging behaviour are associated with distress and facilitate, training in understanding and managing challenging behaviour which could be beneficial for both staff and residents.

### *Environmental factors*

Literature examining occupational distress is available in many different care settings and environments, including: intellectual disabilities (Skirrow & Hatton, 2007); hospice care (Vachon, 1995); schools (Wisniewski & Gargiulo, 1997) and general nursing (McVicar, 2003) to name a few.

Within the current review, environmental factors were not set as a main focus for the studies but were often a by-product of the research exploring a number of variables, yet environmental factors generally produced a stronger association with distress than other factors, specifically resident behaviour. Further research from Maslach (2003) supports the notion that organisational/ environmental factors produce more of an effect on burnout than individual factors.

Only one Study specifically explored the role of organisational factors and their relationship with distress; one could speculate that this is possibly reflective of individualised culture and care. Further research reports that organisational issues mediate levels of burnout, such as limited staffing (Laschinger & Leiter, 2006), value conflicts, limited rewards (Leiter & Maslach, 2009), working conditions and satisfaction with life (Demerouti *et al.*, 2000). Four of the reviewed studies reported a link between limited support and distress; this is also evidenced in further literature which found that limited social support (Ben-Zur & Michael, 2007) and supervisory support (Kalliath & Beck, 2001; Sargent & Terry, 2000) further mediate burnout. Due to the ever pressing demands on care organisations, it seems clear from the reviewed literature that more research needs to focus on the influence of organisational factors on staff distress, to evidence the need for organisational change and support in 24 hour care settings.

## **4.2 Quality of research**

The quality of the studies overall was moderate, which reflects the cross sectional nature of the research, this results in limitations of ascertaining causality and

generalisability. All of the studies used opportunistic samples and therefore may be unrepresentative of all staff. None of the studies attempted to recruit staff who were absent from work due to illness and no studies used physical illness or visits to the doctor as indicators of distress; this could have led to a healthy subjects bias; people experiencing high levels of distress may not be represented in the studies. This idea is also supported by further research, Morrison (2014) argued that nurses who are most resilient to distress are over represented in research findings; (Zeiss *et al.*, 1999) states that carers who have worked for longer are more likely to participate in research; this is consistent with the review findings as the majority of samples were older staff who had worked in services for a number of years, potentially highlighting a sample bias in staff distress literature.

### **4.3 Improvements to research**

Larger-scale, multi-centre, mixed-methods approaches using unified, validated measures would offer a more reliable contribution to the evidence base. Longitudinal research or research which utilises a control group would also give a better perspective of the predictors of distress.

Distress lacks a unitary theoretical framework, meaning that it is difficult to compare results, leading to inconsistent conclusions; the complex nature of defining distress also affects how it is measured. The majority of the measures used in the literature review were valid and reliable, however there were so many used that they could not be explored in detail. It would have been useful to compare and contrast the measures; this is a possibility for further review.

There was limited research presented in this review which focussed on all three areas of distress; an all-inclusive assessment of predictors and would facilitate understanding of which factors separately associate with distress and which factors relate to each other. There is evidence of links between positive attitudes and distress in a number of papers in this review; yet in other research it seems there has been a tendency to explore distress in dementia research with orientation to negative events. Folkman and Moskowitz (2000) report that negative and positive emotions co-exist when caring, suggesting that distress models should also include positive affect. This would also fit with the review findings. Diverse personal effect of staff is underexplored. Depaola *et al.*, (1992) suggested that those who work with older people may themselves experience

numerous emotions, including greater anxiety about ageing and their own mortality, and calls for further exploration of its impact.

#### **4.4 Strengths and limitations of review**

The strengths of the current review include a clearly described systematic search strategy and utilization of a range of different databases which reflect psychological, nursing and medical studies. Clear inclusion and exclusion criteria and quality appraisal of the chosen studies were also defined.

The review also had a number of limitations; due to the heterogeneity of the articles, a meta-analysis was not possible. The systematic search was also completed exclusively by the author, which could have increased bias in inclusion and evaluation of the literature. A quality assessment tool was used, whilst this adds value to the review: allowing for assimilation of the literature quality, the tool was modified by the author to gain more focus on the presenting studies which alters the tools validity and reliability. The review is limited in its generalisability to the UK, as multinational articles were included and models of care differ significantly between and within countries. In the UK alone, there is a difference in privatised, local authority and NHS care facilities along with number of staff, setting, training and remuneration (Iliffe & Manthorpe, 2014). Castle (2008) stated that it is difficult to compare dementia care facilities and providers as these vary. It is important to consider the current changes in the NHS, as it is developing into a business model of care provision and commercialised industry are competing for tender (Ham, 2012). Therefore, whilst the models of dementia care differ between private and local, this difference is potentially becoming less apparent. As the current review represented mainly non-UK based sites, its generalisability within the UK should be addressed with caution.

With so much current focus on staff and patients becoming vulnerable, resulting in abuse and neglect, it is important for staff and organisations to develop environments for optimal care. It makes sense to do this with reference to good psychological burnout models to reduce the pressures on staff and as a result to develop better care for patients. The research in this review lacked an organisational focus, which is problematic for the current care culture as it allows distress to be viewed as a purely individual process and places more expectation on staff to be well, without organisational support.

#### **4.5 Clinical implications**

The findings described in the current review may influence the way that staff and organisations view predictors of staff distress. As discussed, the reviewed literature indicated that distress is experienced from a number of different sources; individual, relational and environmental. There was limited focus on organisational factors but literature suggests that organisational factors are normally mediating factors of distress. The majority of the research focused on relational and individual factors; focus on staff change rather than organisational change potentially makes it easier for the organisation. It is important for dementia care facilities to understand that distress is a multifaceted experience and therefore employ protective factors at all levels; training and education of front line staff, management and staff who influence organisational structure will be important. There is scope for Psychology to work at all levels to facilitate reduction in distress; psychologists are currently under-utilised in 24 hour care facilities.

As there was inconsistency across studies, the implications of the findings are limited. This in itself is a finding worth contemplating, as resources are limited and policy makers need empirical evidence to allocate resources which are limited (Acton & Kang, 2001). Therefore, any action around staff distress needs to be established on an evidence base which is consistent and reliable which it currently is not.

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## **Part two Research Report**

### **Caring for patients with dementia in acute physical health settings**



## **Abstract**

The population is ageing, with projections in the UK reaching 15.5 million older people in 20 years and 19 million by 2050 (Cracknell, 2010). As the population ages, the prevalence of dementia is likely to increase, creating increased strain on acute care services and the health care professionals (HCPs). Acute medical units (AMU) are the first admission point for patients who have been referred by the emergency department. The prevalence of people with dementia on AMU is reportedly high and HCPs are typically not trained in dementia care proficiently. Patients with dementia often present to AMU with several co-morbid physical health problems, leading to suboptimal treatment of all physical health problems and management of dementia. Whilst the literature has examined staff experiences of caring for dementia in acute care, little has explored the context of the AMU specifically, therefore this research aimed to contribute to acute care evidence.

Twenty one HCPs working in AMU, across two different hospitals were interviewed about their experiences of caring for patients with dementia in AMU. These were analysed using Thematic Analysis (TA) and four main themes were identified; impact on staff, experience with patients; tension; ideal vs real world and ideas for change. Subthemes explored features contributing to these themes.

Participants described their deep desire to care for patients with dementia in a person centred way, they spoke about nursing being a way of life rather than a job title, presenting empathically and compassionately. However, the tensions that were evident in AMU and the limited resources due to organisational pressures ultimately left participants expressing frustration and exhaustion when caring for patients with dementia. The care was often impaired. Participants identified ideas for change and ultimately did not feel that the environment of AMU was suitable for patients with dementia.

## 1.1 Introduction

### *Incidence of dementia*

There are approximately 800,000 people in the UK with a diagnosis of dementia. With a 2% prevalence in age range 65-69, rising to 16% in those aged 79 or more (Alzheimer's Society, 2007). Dementia is the primary reason for mortality in women aged over 65 years and the fifth lead reason for mortality in men aged over 65 years (Office of National Statistics, 2012.) Dementia is an illness and not a normal part of aging; however as people age there is an increase in prevalence of dementia.

There are 10 million people in the UK alone who are over 65 ("older people"). The population is ageing, with projections in the UK reaching 15.5 million older people in 20 years and 19 million by 2050 (Cracknell, 2010). As the population ages, the incidence and prevalence of people with dementia is likely to increase; The incidence of dementia is estimated to increase to 1.7 million by 2050 (Alzheimer's Society, 2014).

### *What is Dementia?*

Dementia encompasses a range of diseases in the brain that produce a loss of brain function. These disorders are normally progressive and ultimately fatal. Symptoms can include confusion, behaviours that challenge, memory loss and problems in communication and understanding (Alzheimer's Society, 2014). There are various aspects of functional impairment e.g. reduction in activities of daily living and cognitive decline e.g. deficits in memory, attention and concentration, (Royal College of Psychiatrists, 2013). Ultimately an individual with dementia becomes increasingly dependent on others.

Challenging behaviour is a common symptom of dementia, such as aggression (Margallo-Lana *et al.*, 2001). Reasons for aggression are suggested to be due to a lack of privacy or activities, limited staff attention, overcrowding or poor communication and relationships between staff and patient (NICE, 2006); many of these conditions are likely to occur in acute health care settings.

### *Dementia in acute health care*

Dementia is under recognised in acute care (Laurila *et al.*, 2004), even though 25 percent of NHS hospital beds are occupied by people with dementia (Alzheimer's Society, 2014). It is unsurprising that there are a growing number of older people in

acute physical health care presenting with dementia and co-morbid physical health problems, as people with dementia have, on average, three co-morbid physical health problems and are often not admitted to hospital with dementia as their primary diagnosis (NHS England, 2014; Schubert *et al.*, 2006). Causes of admission mainly include falls, broken hips, urine infections, chest infections or strokes (NHS England, 2014). Dementia is often not clearly diagnosed or identified when entering hospital and current diagnosis is often missed; the converse can also occur as physical health problems can also be overlooked, (Schubert *et al.*, 2006).

The combination of physical health problems and dementia often culminates in longer admission time in acute care (Lyketsos *et al.*, 2000); this is problematic, as it creates conflict with organisational demands to shorten stays and create more acute bed space (Cunningham & Archibald, 2006; King *et al.*, 2006). Demands exceed the means in acute hospital settings as there is a higher prevalence of dementia and limited resources available, putting pressure on a system where the focus is on speed and throughput of patients (Department of Health, 2013). Acute care emphasises prompt diagnosis and treatment, with the implicit assumption that those admitted can express their own needs and wishes; there is therefore little time to meet the additional communication needs of patients with dementia in acute care settings (Department of Health, 2013).

The Francis Report discussed the difficulties of meeting the needs of dementia patients in acute settings (George *et al.*, 2013). The elderly face high levels of neglect in general hospital, alongside a lack of person centred care (Francis, 2007). The report has highlighted the challenges to provide good care for patients with dementia in acute care and has consequently led to more focus on this area; the current government has issued a challenge on dementia, which focuses on improving health care, improving research and creating dementia friendly communities (Department of Health, 2012). Initiatives have been developed and highlighted publicly, however the tension of caring for patients with dementia in a potentially unsuitable environment is demanding for staff and potentially increases challenging behaviour in people with dementia. This will be expanded on in the next section.

#### *Impact on staff*

The pressures of providing care for patients with dementia may result in significant effects on NHS staff, the organisation and the people with dementia leading to this area becoming a research priority (Moyle *et al.*, 2008). High levels of sickness and reduced

employment means that the resources of health care professionals (HCPs) are stretched (Murray, 2005) and as caring for people with dementia can be highly stressful, both physically and mentally (Schubert *et al.*, 2005). A significant amount of nursing care in acute settings is spent with patients with dementia (Abley, 2012); whilst this is the case, many staff have a limited knowledge of dementia, due to the medical model focus in healthcare (McPhail *et al.*, 2009); for example, Watkin *et al.* (2012) reported that HCPs do not understand the impact of cognitive impairment on behaviours. Knowledge of dementia can affect staff attitudes and staff attitudes can influence how staff care for patients with dementia (Matsumoto *et al.*, 2007; McCann *et al.* 2014). There has been limited research into HCPs attitudes towards patients with dementia in acute care (Schmidt *et al.*, 2012).

#### *Impact on the patient with dementia*

Hospital environments can be detrimental for those with dementia; not having appropriate access to toilets and differences in floor type and texture can result in higher risk of falls and disorientation (Day *et al.*, 2004). Suggestions on how to adapt the hospital environment to be more “dementia friendly” include plain flooring to help with disorientation, increased usage of signage for clarification and easy access to toilets (Borbassi *et al.*, 2006).

People with dementia are at high risk of being moved to a number of different wards, due to misunderstanding of co-morbid health problems and dementia, leading to increased levels of distress and suboptimal treatment (Griffiths *et al.*, 2013; Zieschang, 2010 ). Patients with dementia tend to have increased hospital stays; hospital admissions involve reduced practice of daily living skills and increased confusion, leading to increased admittances to residential care after hospital (Abley, 2012). Often patients with dementia find acute environments and hospital processes distressing, experiencing an increase in confusion and sensory alteration, a decrease of orientation to time and place and a reduction in tolerance to stress and environmental stimuli (Archibald, 2002). Increased distress can often increase physical and mental health symptoms (Piazza *et al.*, 2013); when these needs are not met, it has been found that distress can escalate into displays of aggressive behaviour (Cowdell, 2010). This in turn can affect the quality of care that staff are able to offer and at times result in restraining or sedation of patients; this can be problematic and highly distressing for those with dementia and their family

members (Cowdell, 2010; Jones et. al., 2006). This highly challenging situation in the NHS is under investigation by current government/ NHS funded research.

### *How acute care for patients with dementia is being currently addressed*

Due to the impact that caring for people with dementia in acute care has on services, staff and patients, further attention is required to understand these challenges. Research suggests that there are a number of things that could be done in acute settings to increase quality of care including provision of specialist dementia nurses, specialist dementia wards, person centred care and an increase in training and supervision of health care professionals (Griffiths *et al.*, 2013; Goldberg *et al.*, 2013; Hayward *et al.*, 2013; Moyle *et al.*, 2008). There are no standardised measures of training within acute care; leading to some HCP's being trained to a low and inconsistent standard (Griffiths *et al.*, 2013).

Research has primarily focused on the impact of dementia care for family care givers (e.g. Brodaty & Donkin, 2009; Connell *et al.*, 2001; Papastavrou *et al.*, 2007) and long term dementia facilities (e.g.; Kennedy, 2005; Miyamoto *et al.*, 2010; Zimmerman *et al.*, 2005). There is limited research on formal/paid caregivers in acute settings (Jurgens *et al.*, 2012) The research that has been completed has frequently concentrated on staff attitudes and knowledge of dementia and is mostly quantitative, which does not allow for new and deep understandings of staffs experience as qualitative research does. There is therefore a need for research which qualitatively explores staff experience of caring for those with dementia in acute care settings.

## **1.2 Aims and Objectives**

It is important to ascertain information on staff experiences of caring for patients with dementia in order to inform best practice for policy and future research for patients, staff and the organization.

The aim of the proposed study was to broadly explore the following research question:  
How do nurses and HCA's manage and experience caring for people with dementia in acute physical health settings?

The main objectives are to identify:

- How do nurses and HCA's recognise that a patient has dementia?
- How do nurses and HCAs perceive and make sense of dementia?
- How do HCA's and nurses care for those with dementia on AMU?
- What impact does caring for patients with dementia on AMU have on nurses and HCAs?
- What changes could be made to help care for those with dementia more effectively?

## **2. Method**

### **2.1 Research Design**

A qualitative approach was used to explore how staff experience caring for patients with dementia. Semi structured interviews were used to explore staffs experiences of dementia in acute medical units. The interviews aimed to facilitate discussion related to how staff perceive and make sense of dementia, how they recognize that a patient has dementia, how they care for people with dementia on AMU, what impact does it have on them and what needs to change to be able to care for those with dementia more effectively on AMU. Nurses and HCA's working on AMU at two different hospital sites were interviewed individually for approximately an hour.

### **2.2 Ethical Approval**

Ethical approval was gained from the University of Leicester research and ethics committee and the needed NHS Trust Research and Development Committees (Appendix B).

### **2.3 Epistemological position**

A full account of the researcher's epistemological position can be found in Appendix H.

### **2.4 Recruitment**

Two hospitals with acute medical units (AMU, or clinical decision unit's) were approached for participation in the study. Contact with the two NHS trusts was made via lead consultants on acute physical health wards, which led to contact with respective trust's research and development teams. Ethical approval was given and the researcher developed a plan of recruitment with the consultants at each hospital. Nurses or health

care assistants (HCAs) were deemed as the most appropriate participants, due to the high level of contact with patients on AMU. Participants were identified by lead matrons and consultants, or through advertisement of the study in ward round meetings. Participants either made contact with the researcher through the expression of interest form (Appendix I), or in person. Details of the study were provided to interested members of staff (Appendix I- participant information leaflet); a convenient time for interview was arranged with the participant and the matron.

## **2.5 Inclusion/ exclusion criteria**

Inclusion criteria: Staff working as a nurse (of all grades) or a HCA were recruited due to their close contact with patients with dementia.

Exclusion criteria: Staff were excluded if they were not a nurse or HCA due to too much difference in work related activities; if they could not be interviewed for longer than half an hour; if English was not their first language. The researcher recognized that cultural differences could have an association with staff experiences of caring for those with dementia on AMU, however the use of interpreters was a complex and challenging issue and was constrained by the scope of the current research.

## **2.6 Participant information**

Participants comprised 21 members of staff working on AMU settings; there were 2 male staff and 19 female staff interviewed. Participants were recruited from two hospitals; site 1 (HS1) (N=13) and site 2 (HS2) (N=8), 12 staff were nurses and 9 staff were HCAs. HCPs had been working at the sites for a mean of 3.5 years, ranging from 4 months to 8 years and working overall for a mean of 4.5 years, ranging from 1 year to 14 years. Due to the relatively small number of staff who took part in the research, it was considered inappropriate to collect further demographic information as it may have compromised anonymity.

## **2.7 Materials and resources**

Research materials are outlined in Appendix I-M, including participant information sheet and consent form.

A semi structured interview schedule (Appendix G) was developed in consultation with the research supervisors and field supervisors, to allow exploration of how HCPs

experience caring for people with dementia in acute care. The interview schedule explored themes including staff experiences of dementia, how they make sense of dementia and recognize that patients have dementia, how HCP's are impacted by caring for dementia, how they cope and whether they had any ideas for change. The schedule remained flexible, allowing for the questions to evolve and develop throughout the interview process to elicit both inductive and deductive themes emerging from the interviews.

## 2.8 Procedure

Participants met with the researcher, where the information sheet was read aloud; clarification was given if needed and written consent was obtained. The researcher facilitated interviews using a semi structured interview schedule and open questions to explore different areas of conversation. Each interview was audio recorded, the interviews were transcribed verbatim and anonymized during transcription. A reflective journal was kept by the researcher and was completed as soon as possible after the interview had taken place (Appendix K).

## 2.9 Analysis

Thematic analysis (TA) (Braun & Clarke, 2006); was selected as an appropriate method to qualitatively analyse the data. TA is a method which allows for identification, analysis and reporting patterns within the data (themes) it also allows for a broad research question to be addressed in an area where there is a paucity of research. Analysis aimed to ascertain a rich description of the entire set of data instead of specific individual responses. Analysis procedures complied with Braun and Clarke's model of thematic analysis (2006); this process is outlined in Table 5.

The process of identifying codes can be deductive (driven by theory from previous findings in a 'top down' approach) or inductive (a 'bottom up' manner, with themes more grounded in the data). Thematic Analysis (TA) offers flexibility in analysis; both inductive and deductive processes were employed. The process of outlining initial codes within broad thematic areas was deductive. High level themes were introduced logically in line with aims of the study and previous findings. Inductive analysis then allowed sub-themes to emerge from the data in a more grounded, inductive approach. The latter approach is particularly useful in relatively new areas of research where appropriate



theoretical frameworks are not yet established (Joffe & Yardley, 2004). Thematic Analysis was selected for use in the present study for its flexibility in exploring data. The aim was to recruit 20-30 participants across the two sites. This was considered to be large enough number of participants to gain a broad spread of experience across two different sites and from both HCA's and nurses. A larger sample would have been beyond the scope of this study to manage with a single researcher and limits on time to complete the study.

**Table 5 Analysis procedure**

<i>No.</i>	<i>Procedure</i>	<i>Explanation of procedure</i>
1	Familiarisation with the data	All interviews were conducted by the researcher which allowed engagement of the data at the first level. The researcher completed transcription of some of the interviews; others were transcribed by a professional transcriber. When reading through the transcripts, the researcher's first impressions of the data were written down (Appendix K). The transcripts were read several times to allow immersion in the data. Ongoing supervision was utilised to allow for further reflection.
2	Generating initial codes	Potential codes were listed by making research relevant notes on the transcripts. Coding was done in an inductive way. Similar notes were created to make initial "codes": labels which summarised the content of parts of the data, which allowed the researcher to organise the data. The transcripts were then revisited to search for the presence of codes and to review to see if any codes were missed. All potential codes were listed.
3	Searching for themes	Clusters of codes were grouped into themes. Groups were sought which allowed all codes within a theme to reveal similar but distinct ideas from other themes. The use of post it notes was used at this point, so that codes and themes could be moved visually, in order to organise the themes and codes (Appendix M). All of the codes were listed and grouped into thematic areas, some were discarded from analysis. The transcripts and codes were re- examined at all phases.
4	Reviewing themes	Relationships between the themes were considered. A thematic map was developed (Figure 1) to allow grouping of the coded quotations into themes and demonstrate how the themes relate to each other. Themes were named and described after allowing for iterations. The themes generated were considered in relation to the full data set. Transcripts were re-read to ensure that the data was fully encapsulated. To further the study's validity, sections of the transcripts were subjected to independent review, as were the themes generated. Different points of view were taken on board and integrated into the analysis.
5	Defining and naming themes	The themes identified were compared to collected extracts of coded data. This allowed review of the data, to make sure that themes followed a narrative consistent with the research question and individual accounts. Themes were checked for areas of overlap, or where information may have been missed. Conversations were held between the researcher and supervisor to define names of themes, to encapsulate each theme fully. Subthemes were then identified in detail to allow further refinement. Overall, the first phase of analysis was more 'top down' sorting findings into broad thematic areas that were useful in organizing the data into themes pertinent to the research aims. Subsequent refining of the data contributing to these high level themes was more 'bottom up', allowing subthemes to emerge from the data.

### **3. Results**

Three main themes and eleven subthemes emerged as HCPs reported their experiences (Table 6). The subthemes identified were related to each main theme and still maintained internal consistency as smaller themes within the main research question.

**Table 6 Main themes and subthemes**

<b>Theme</b>	<b>Subtheme</b>	<b>Quote</b>
<b>Experiences of dementia</b>	People that stay in your head	“The people that stay in your head...are always the aggressive ones” Gary, nurse, HS1
	Everybody with dementia is different	“Some of them can be really nice” or “some of them can be aggressive” Ellie, HCA, HS1
	They’re not doing it on purpose	“I think they look quite scared, they’re just scared I don’t think they know what they’re doing” Cally, HCA, HS1.
	It’s people not numbers	“It just depends whether they need the beds, it’s all about the beds down here” Cally, nurse, HS1.
<b>Caring</b>		
	Frustrated and helpless	“It affects you cos it makes you feel like a rubbish nurse cos you can’t do enough for them...it’s frustrating cos you know they’re not getting what they need” Sarah, nurse, HS2.
	Nursing is a way of life	“I truly believe it’s not just a job it’s a way of life” Amy, nurse, HS1.
	Coping with caring	“I try not to take things home... you just have to switch off don’t you?” Queenie, HCA, HS2.
	What we do vs what we want to do	“You want to have a chance to sit there and comfort them but you don’t get that opportunity.” Sarah, nurse, HS2.

Theme	Subtheme	Quote
<b>Ideas for change</b>		
	There are not enough of us	“More staffing, MORE staffing, it would make it easier because you can have more time and everything...we’re shutting that independence away because there’s not enough of us to do it” Cally, nurse, HS1.
	We need to learn how to deal with dementia	“I know that I need to learn more. Because like I keep saying, I don’t understand it”. Ria, HCA, HS2.
	Changing the environment	“It’s not the right environment, it’s too loud, it’s too busy, and it’s too noisy, it’s too confusing” Denise, HCA, HS1.

The three main thematic areas identified are; experiences of dementia; caring; and ideas for change. Participants spoke about their experiences of people with dementia; including their perceptions of patients and how they made sense of behavior in dementia. They also spoke about how they cared for people with dementia, including how it impacted on them and how they coped. Ideas for change were cultivated from an experience of tension of not being able to care for people with dementia as they wanted to. Main quotes are reported below to support the themes; additional quotes are stated in Appendix O.

### Experiences of dementia

Staff were initially asked to speak freely about a recent experience of caring for someone with dementia, people generally reported a difference in dementia presentations. Staff also spoke about how they understood behaviour in dementia, it was clear that most people perceived people with dementia as scared and frustrated, however staff generally seemed unsure about why people with dementia behave in certain ways.

Participants also spoke about the impact that AMU has on patients, how they are often treated as numbers, not patients.

### **People that stay in your head**

Participants were able to recall details of exchanges with patients clearly. As Gary noted below, they “stay in your head” suggesting that these experiences have a strong impact on staff.

“I’ve had some bad experiences... another guy and I was looking after, he got dementia and he was getting very nasty with it, very very nasty with it, called me a slut, he said that he was going to kill my mum and my dad, he was throwing things at me” *Briony, HCA, HS1*

“It really is hard and it is difficult but the people that stay in your head...are always the aggressive ones... like do you remember so and so who kicked me, punched me in the face or smacked me around the face a few times with a frame?” *Gary, nurse, HS1*

When asked whether negative experiences were the norm, participants would talk about the “variety” of dementia presentations and positive experiences they also had.

A term which was used by staff to frequently describe patients with regards to positive experiences was “pleasantly confused” this meant that patients were “confused like they don’t know what day it is, or they’ll repeat themselves which is fine” *Tina, nurse, HS2*.

“Pleasantly confused...they’re not aggressive, they’re quite able but even, even when they’re not they just, they’re not getting themselves too worked up, it’s just something that they’ve got that’s not too much of an issue” *Laura, HCA, HS1*

“So you could be sat with them and they’ll have a lovely conversation and we’ll be doing things together, but as soon as a loud, loud bang or anything like that, it just sets them off.” *Olivia, nurse, HS2*

## **Everyone with dementia is different**

Participants spoke about how patients with dementia presented in AMU. It was thought that dementia does not mean that people behave in a prescribed way, but that there is variance in their behaviour.

“Dementia is so different, it comes in different forms... you could be having someone with dementia that is confused and is really really aggressive with it and you have someone with dementia and they’re really polite and pleasant and, it’s all different” *Briony, HCA, (Hospital site; HS)1*

“I’ve had experiences where someone’s said that they’ve got dementia and you’ve thought, it’s going to be a tough one but they’ve been the most pleasant fun person ever to deal with and it’s been a joy” *Gary, nurse, HS1*

When patients were being compared to each other, it was often done with contrasting statements noticing that there was often a large difference between patients; “some of them can be really nice” or “some of them can be aggressive” *Ellie, HCA, HS1*

When participants spoke about how they recognise that a person has dementia, they often spoke about people with dementia being recognisable by physical signs, again these were varied.

“Obviously, they look a bit older” *Farah, nurse, HS1*

“Their hair isn’t brushed...they’re not looking after themselves, they’re skins quite dirty...they’re skinny, like malnourished or...they haven’t been taking care of themselves with food obviously, you do see that with a lot of older people” *Briony, HCA, HS1*

However, some participants didn’t think that there was a noticeable physical difference.

“Nobody would have challenged him because he looked absolutely fine and being a bit younger as well nobody was thinking, oh that’s an old man (with dementia) walking out the front door” *Joy, nurse, HS1.*

“It depends on their behaviour (more than looks), I think sometimes their behaviour we recognise, oh well maybe they’ve got dementia” *Ria, HCA, HS2.*

Participants were more definite in their responses that there were clear behavioural differences in patients with dementia.

“Generally they’re a bit confused...might be a bit shaky...they’re not very coherent...kind of a bit vague, maybe forgetful, maybe not know where they are, disorientated.” *Ken, HCA, HS1.*

“Pushing you away, lashing out, kicking, throwing the sheets off. They just don’t want to know, they’re just not interested in anything you’ve got to do or say” *Queenie, HCA, HS2.*

“Confusion obviously, they don’t where they are, they keep asking questions... dropping stuff...not eating...not communicating...their mood, yeah, sometimes as well...forgetting where they are, or asking where they are constantly, or constantly keep buzzing and when you get there, they’ve forgotten what they want or they don’t know where they are and they think they’re somewhere else” *Ria, HCA, HS2.*

It was not just the difference between patients that was noticed, but the difference within patients when they were with different members of staff.

“With another lady he was quite aggressive towards her, he hit her and what not, but with me he was just pleasant, really pleasant” *Briony, HCA, HS1*

### **They’re not doing it on purpose**

Through negative and positive experiences with patients with dementia, attributions about patients were made to understand their behaviour. . A common idea that participants shared were that patients behaved as they did due to fear.

“You can see they’re scared” *Ellie, HCA, HS1.*

“I think it must be really scary for them, being somewhere like this and wanting to get out and having a stranger walking around with you. I feel bad for them” *Amy, nurse, HS1.*

Staff often demonstrated a lot of empathy towards patients with dementia, often offering I statements when asked about how people with dementia may feel. The way that staff



often made sense of patient behaviour was by reflecting on if they were “in their shoes” *Briony, HCA, HS1*.

“I think I would just get like quite upset and scared, it’s scary isn’t it? I imagine” *Queenie, HCA, HS2*.

“I want someone to listen to me, but they can’t say what they want us to listen to, I think it comes out as anger sometimes” *Cally, nurse, HS1*.

When participants were asked about attributions made about patient behaviour, they often alluded to the concept that patients did not have any insight into how they were behaving, or understanding of the environment. This seemed to act as a protective view for participants as it allowed them to be more accepting of patient behaviour.

“I don’t think they understand fully what’s going on all the time, I would like to think not (laughs)...Because you would not want someone knowingly hitting you would you I guess (said laughing). I think they look quite scared, they’re just scared I don’t think they know what they’re doing” *Cally, HCA, HS1*.

“They don’t know what they’re doing...Somebody young who’s aggressive, we, we shouldn’t have to stand for that at all...but an elderly person with dementia who’s aggressive, it’s not their fault” *Joy, nurse, HS1*.

“In fact I got hit the other day.... you think back and they don’t realise that they’re doing it... Half the time they don’t realise what they’re doing, what they’re saying” *Olivia, nurse, HS2*.

Acceptance of patient behaviour extended to staff expecting and allowing aggression in dementia.

“Sometimes it can be unpleasant, especially if they hit you and stuff, you know. It’s not nice. But then again it’s the job isn’t it? You just get on with it.” *Queenie, HCA, HS2*.

Staff often made sense of the behaviour by relating it to that of a child.

“You think you live on this earth all this, all your life and then you just, you’re back to being a baby really... Because you have to have somebody look after you twenty four seven, constantly telling you what to do, and what you should be

doing and you're wearing nappies, and making sure that you're clean, being fed. Everything like a baby really." *Queenie, HCA, HS2.*

"It's like me taking my grandchild away from what he's doing, park him here. First thing he's going to think about, what have I done wrong?" *Ellie, HCA, HS1.*

Whilst acknowledging that they believe that patients are not behaving in an aggressive way on purpose, it was still reported by staff that it was difficult to handle.

"You know that they're not doing it on purpose but they're still being quite aggressive about it and it is, it is really difficult" *Joy, nurse, HS1.*

"A lot of people, especially when I've handed over and saying that they've got dementia and you can see them, they step back and think, oh please say they're nice, please say they're nice because it is a challenge" *Gary, nurse, HS1.*

However, some participants shared the view that they couldn't understand why patients with dementia presented in the way they did, almost sharing in the patients presented confusion.

"I was thinking, why are you so mean? But obviously having worked here a lot longer now, you do understand, well you don't understand. There's nothing to understand because they don't know themselves what's going on. They're confused themselves" *Briony, HCA, nurse, HS1.*

"I didn't understand it and sometimes I still don't understand, you know... I still don't completely understand why you get it, how you get it" *Ria, HCA, HS2.*

"It's hard because you don't know why they're becoming aggressive." *Tina, nurse, HS2.*

### **Its people you're dealing with, not numbers**

AMU's main focus is to diagnose illness and allocate patients quickly to more specific wards for further treatment. Staff focussed on the impact that this organisational process had on patients.

Participants spoke of the challenges of caring for patients with dementia or other mental health problems in an acute physical health setting. They reported tension between meeting targets, and being able to care for patients as human beings. As Helen says below “remember it’s people...not numbers”.

“It just depends whether they need the beds, it’s all about the beds down here”  
*Cally, nurse, HS1.*

“You’ve got to remember, it’s people you’re dealing with, it’s not numbers or bed numbers or bed changes and I ignore that, I get shouted at but I just ignore it because it’s irrelevant really” *Helen, nurse, HS1.*

A particularly strong view was held by one participant when speaking about patients with dementia being treated in AMU:

“I would be mortified and I would be frightened to death to think that my (family member) could come into an environment like this and he isn’t safe, he isn’t understood and he isn’t safe... I think it’s because of lack of experience, lack of knowledge and lack of training. People in the NHS unless that’s their field that they work in, they don’t know how to deal, cope or look after mental health patients” *Denise, HCA, HS1.*

Other participants spoke about organisational processes which are considered to be the norm in a hospital, such as ward rounds, and how this could affect patients with dementia.

“Ultimately having strange people coming up to you... I think sometimes that can increase their anxieties. So if there’s four or five of you, it’s a ward round and that could be enough to trigger (behaviour)” *Nina, nurse, HS2.*

Ultimately, these tensions seemed to have an impact on the way that patients were treated, participants reported that patients get treated as “a body” and sometimes get “neglected”.

“It’s so busy on here, there are patients who will get neglected, not looked after properly because we’re so busy...If somebody’s sitting there quietly in a corner then we probably would not spend that much time with...It’s when they then do

something to make you jump up and think, ah, I've got to sort you out that they probably get more attention" *Joy, nurse, HS1*.

"I think sometimes it's too much emphasis on bed numbers, on targets and aiming, I hate it. It shouldn't, just because someone's been in A&E for four hours they shouldn't be moved to here and someone else moved" *Helen, nurse, HS1*.

"You do forget and then one person wants one thing and then another wants another and then you got three people all at once and it just skips your mind" *Briony, HCA, HS1*.

## Caring

This thematic area labelled caring, speaks about the way that staff experienced caring for those with dementia. This includes how staff care, how they feel about the care they provide, the impact that caring has on them and how they cope.

### What we do vs what we want to do

Participants discussed how they cared for patients with dementia on AMU. There were some activities that they had been told to complete to facilitate care, however there were some ways of caring that were more intuitive. Participants also spoke about the tension between how they wanted to care and how they were able to care on AMU, due to the organisational pressures, linking to the subtheme "it's people not numbers" above.

Staff spoke about activities that they were told to complete with patients with dementia, for example, using the "all about me" document, which "tells what they like, what they dislike, what will settle them" (*Cally, nurse, HS1*). This is a document that is provided by the care home or carers of the patient with helpful information to inform how to care for them. This was described to be "useful" by a number of participants, as it allowed them to understand the patient more and cope when they were becoming aggressive.

Participants also spoke about a machine in HS1 which was used to aid reminiscence, how the use of magazines, newspapers and radios are inexpensive and helpful.

“We have radios but then not every patient wants to listen to the radio which is a shame.” *Ellie, HS1, Nurse.*

“Different video clips and music which will, you can go on there and you can choose music from the 1930s, jazz.” *Gary, HS1, Nurse.*

“We don’t have a paper trolley come here...a lot of patients ask to be able to buy a paper and I know from sort of grandparents and my husband’s grandparents they love to, they love to just to read the paper...people would really like down here” *Laura, HCA, HS1*

Some participants alluded to the use of security staff on the AMU to help manage patients: “I’m aware of, security in, but if someone’s you know out of control then that would have to happen” (*Amy, nurse, HS1*) others spoke of needing to highlight that a person has dementia to keep them safe:

“If they are wanderers we will try and put a night dress on them so that at least if they do slip past us past reception at least they don’t have their own clothes on” *Cally, nurse, HS1.*

Overall participants spoke about acting in ‘natural or intuitive ways to work with patients with dementia, including using reassurance. The repeated use of the word obviously suggests that this approach is self evident.

“And obviously you’ve got to reassure her and keep telling her why, there’s no reason to say I’ve told you once, because obviously she’s not going to remember, so you have to keep on explaining and telling her” *Briony, HCA, HS1.*

They also spoke about their understanding of behaviour and how they managed it in practice.

“Every time you push him back down or tell him to sit back down he’s going to get agitated” *Dani, HCA, HS1.*

“If they want to wander, they’re going to wander no matter what you say or how you persuade them” *Sarah, nurse, HS2.*

“You do have things to keep them occupied so they don’t have to get to that stage where they’re angry” (*Briony, HCA, HS1*).

Participants also spoke about the value of communicating well with patients.

“I think I will always try to, to listen, to just try and spend as much time as possible, as much time as the patient needs and just be kind as possible; hold their hand, sit with them a while, that sort of thing, that’s what I try and do anyway” *Joy, nurse, HS1*.

Participants also spoke about how to intervene when patients with dementia regress. There seemed to be a tension between lying and telling the truth.

“Rather than saying, look sorry, your mum’s died, I would say, oh yes she’s just catching the bus , she’ll be here in a moment , which seems cruel, I don’t like doing it , but at the same time if I say to her, your mum’s died years ago, it’s the lesser of two evils really. So sometimes you have to distract patients. So I find if do that, I don’t like doing that but I do do it because you feel like lying to them , well really you are, so. But like I say, you feel then and they think onto another train of thought so cruel to be kind really” *Helen, nurse, HS1*.

Participants indicated that they often knew how to react to patients with dementia due to personal, family experiences.

“I think like my grandparents have suffered with dementia and I have quite a lot of patience and tolerance when it comes to them” *Sarah, nurse, HS2*.

“I had a granddad, a great granddad that had dementia so I’ve experienced dementia before so I think that helped” *Gary, nurse, HS1*.

However, other participants also spoke about not knowing what to do and how to care for patients with dementia.

“You’re in a stage where you think what can you actually do...trying to troubleshoot, well why are they being like that, there’s a reason” *Gary, nurse, HS1*.

Participants indicated that they could not care in the way that they wanted due to the tensions provided by the hospital. The tensions that were expressed by the participants were often done so with a huge sense of discomfort

“You want to have a chance to sit there and comfort them but you don’t get that opportunity. You don’t get the opportunity to sit there with them and have a discussion and talk and calm them down...dementia interests me cos obviously I’m passionate about the fact that what’s best for the patients, and being here isn’t” *Sarah, nurse, HS2.*

“I get frustrated but for the fact that I can’t give them the care sometimes that I know they need...it is upsetting to know that I physically cannot look after my patients properly...I hate going home knowing I could have done that better, but I physically couldn’t have, but they should of received better care” *Tina, nurse, HS2.*

“It frustrates you because it’s like, you’re putting me into a situation where’s there’s twelve patients who you know I’ve got to watch the patients with dementia, you know what dementia patients are like, don’t put me in that situation because then you’re going to frustrate me and then I’m going to think, well do I want, do I want to stay here, work in this Trust knowing that this is what you’re doing, you’re going to make me end up with a breakdown or I’m going to leave” *Ellie, HCA, HS1.*

### **Frustrated and helpless**

The impact of caring for patients with dementia was something which was spoken about in detail by a lot of participants. Generally staff reported negative affect around caring for patients with dementia, feeling “mentally drained” and “frustrated”.

“Frustrated, it makes me anxious cos I’m always worried about them falling or worried about them, cos you can’t see them cos then you’ve still got another five patients in your bay to look after” *Sarah, nurse, HS2.*

“It probably slows you down a bit, you need that extra cup of tea to keep you going..., it kind of makes you a bit snappy (laughs) sometimes you find yourself snapping and you think oh god no, I need to go and deep breathe, have a cup of tea and I’ll be fine... Mental exhaustion again, it’s just so mentally draining you just feel exhausted” *Cally, nurse, HS1.*

One participant noticed that staff may be feeling the same way as the patients.

“It’s like frustration. So I mean I’m going through what they must have been because they’re getting frustrated as well” *Ellie, HCA, HS1.*

One participant also spoke about the huge amount of fear felt when patients become aggressive.

“This man’s coming for me and it’s like, you’re going to run because he’s strong enough to kill you some of them . That’s their, what’s in their mind , and it’s like, you’re going to run, you want security there, you want someone that’s as big as that man to grab hold of. It is really scary” *Ellie, HCA, HS1.*

Participants also spoke about feeling “helpless” and “inadequate” when they weren’t able to help patients with dementia as they would want to.

“It affects you cos it makes you feel like a rubbish nurse cos you can’t do enough for them, if you know what I mean, cos you’ve got other jobs and stuff to do...it’s frustrating in the same sense cos you know they’re not getting what they need” *Sarah, nurse, HS2.*

“I think it can be very stressing sometimes. If you feel as though you’re not getting through, I think that stresses you then because then you feel inadequate” *Ellie, HCA, HS1.*

“A bit helpless really, you just feel like you want to be with them to do stuff and reassure them but then you’ve got to be like looking after your other patients as well” *Cally, nurse, HS1.*

Participants also expressed the impact that not being able to care effectively had on them.



“It makes me feel kind of I’ve achieved something...I’m happy if their happy”

*Denise, HCA, HS1.*

Whilst participants spoke about being compassionate and enjoying time spent with the patient; participants also alluded to becoming hardened to working in a nursing environment.

“It’s because we only meet them briefly it’s difficult to think of them as anyone else does, that’s just who they are, they’ve got dementia so it is hard. I don’t, I don’t get that emotionally attached” *Joy, nurse, HS1.*

“I cry a lot...a lot of people do do this job and I don’t know why they do it cos they, they don’t, they don’t care...you need to have a good heart, you need to care for people... I think when you’ve worked here a long time...you get hardened to it. And you do find that a lot” *Queenie, HCA, HS2.*

“It’s so easy as a nurse to become robotic in what you’re doing because you see it every day” *Amy, nurse, HS1.*

Empathy seemed to have negative effects on staff, as they often expressed the fear of their own mortality/ getting dementia.

“You know, get a lot of confused patients on the ward. I think that’s when I think of my own mortality” *Ursula, HCA, HS2.*

“Just think oh I hope this isn’t me one day.... it’s quite scary really, it’s like it can make you quite anxious with being around what you see and stuff, cos like I say it’s a massive reality check and we’re all going to get old. It could happen to anybody... when you’re here, and you see and how people are and what it actually does to you, it can be quite upsetting to think, you know, that you could end up like that” *Queenie, HCA, HS2.*

“That’s what we think, when they, you know, that could be me, as well. Cos it can happen to anyone can’t it?...Horrible! Yeah, it’s quite scary...try not to think about it, do you know what I mean, cos it is quite sad. I think it’s a horrible illness” *Ria, HCA, HS2.*

## **Nursing is a way of life**

Participants spoke about the difficulty of being a nurse in AMU.

“You’re thrown in the deep end but sink or swim” *Helen, nurse, HS1.*

Staff generally were hugely empathic and compassionate about patients with dementia, this was often attributed to nursing being more than a job and instead an inherent way of being, which helped them cope with caring.

“It’s common sense really. It’s how you speak to people...don’t lose the compassion. I think it’s everything” *Helen, nurse, HS1.*

“I think it’s... automatic...I don’t think you don’t need training to do it; it’s just what, what you would do” *Joy, nurse, HS1.*

“It’s part of what I do, it is a job but I truly believe it’s not just a job it’s a way of life, you can’t come into nursing if you come in for the money, or, you have to really love what you do. You care for people. It’s just natural, compassion is a natural thing that we have” *Amy, nurse, HS1.*

Participants spoke about the value of treating others as you would want to be treated, this ideology was shared by many of the participants across the two hospitals.

“It’s just kindness...I think I would not do nursing if I didn’t (see people as people). I think that’s the danger if you become a nurse who doesn’t then you’re not nursing, are you really? So I just think you treat people as you would like to be treated” *Helen, nurse, HS1.*

“No, I always treat people the same. I try to treat everybody the same and I always think, you know, that could be me one day, or it could be my mum or, no I always have that attitude towards patients” *Queenie, HCA, HS2.*

One participant questioned other staffs understanding of mental illness and alluded that this conflicted with staff roles.

“I get frustrated because um, staff don’t take mental health serious, it’s a joke, but it’s not a joke...Whether it’s fear or its lack of knowledge they tend to make light of everything and get quite sharp and frustrated with patients... they’re attention seeking, ignore her ...I’ve seen staff go up to a patient with mental

health dementia and they'll go in their face and it's like, I ain't going to tolerate you today" *Dani, HCA, HS1*.

Participants spoke about how the conflict of having good and bad days affected the perception of their jobs.

"Sometimes I can go home and think, I hate my job and then question, do I want to work in this environment, do I want that pressure?...No because I can walk away, I've got that right to walk away. But no, I come back in the next day and I start all over again. It's like, ok you've had a sleep, you've had a rest, we'll start again, we'll try another day, see what happens today. And then you come and then it's a circle, you come back and do it all again. ...Because I love doing it because I love my job. That or I'm mad. I've got dementia" *Ellie, HCA, HS1*.

"When people are happy and joking and laughing then it's a joy, it's a joy to nurse them, it is a real joy and they can make you laugh" *Gary, nurse, HS1*.

"When you're here you have to make sure that everybody's safe and well and even if, you know, you're not going to come into work every day and have a good day are you?" *Queenie, HCA, HS2*.

"I really enjoy when I can sit down and talk to somebody" *Ursula, HCA, HS2*.

### **Coping with caring**

It was evident that there were tensions in how to care for patients with dementia on AMU, participants often spoke about how they coped with having to care in such a way.

The way that participants coped with caring for patients with dementia was broad; with participants often speaking about their attitudes towards patients altering, their use of support and different interventions and skills that they had learnt to cope with the pressures of care.

One participant spoke about the importance of remaining upbeat to be able to cope with the pressures of caring.

“It doesn’t matter how hard the shift is...it doesn’t take any extra effort to smile” *Dani, HCA, HS1*.

Other participants spoke about space; having “a little breather and then come back” (*Ellie, HCA, HS1*), or giving the patient some “space, sometimes it makes them worse if you try and talk them down” (*Cally, nurse, HS1*),

A number of participants spoke about “not taking things home” as a way of coping with dementia care.

“I think once you leave here you kind of just, well you try to leave it at the door, don’t you? But, yeah, I tend not to, I try not to take things home... you just have to switch off don’t you?” *Queenie, HCA, HS2*.

“Have like gone home and told my partner a few like cute stories of like little ladies or little men with dementia but nothing, nothing lasting that bothers me” *Ivy, nurse, HS1*.

“No, it doesn’t take its toll on me... if I went home and took my work home with me, I don’t think I would ever get a life from it” *Briony, HCA, HS1*.

One participant spoke about how it felt to get attached to a patient; this seemed to be met with an element of embarrassment afterwards.

“We all got attached to them and we all got upset... we sort of just laughed it off afterwards” *Ria, HCA, HS2*.

Alternatively, some participants said that they did carry on thinking about patients when they were at home.

“I mean sometimes you go home thinking, could I have done this, could I have done that, I wonder how they’re doing, have they settled down?” *Gary, nurse, HS1*.

“I go home and cry sometimes, I go home to my husband and say it’s so wrong...I can’t understand how someone can stand in a room with a patient and not communicate with them” *Dani, HCA, HS1*.

Participants spoke about coping emotionally by using support from other members of staff. The majority of highly valued support was the allowance of time, space and helping to care.

“(They say get) a cup of tea, go and have five minutes peace and then we come back” *Cally, nurse, HS1.*

“Yeah the support’s been really, it’s just, just somebody coming into your bay and saying are you okay? Do you want me to do anything? Just helps...So even if it’s like, people making you a cup of a tea that you literally as you’re swigging as you’re walking past or just things like that” *Tina, nurse, HS2.*

Other participants spoke about not feeling supported and not feeling able to speak about emotional based problems.

“I don’t feel like I could really talk to anybody on here about it... I don’t suppose they’d be bothered to be honest...Especially nobody from management...I’m quite a private person anyway and I just don’t talk about things like that really.” *Ursula, HCA, HS2.*

“We had to get security and I was there for 12 hours and no one relieved me whatsoever... it is hard when you have a situation like that, because you are like oh my god, what do I do, what shall I do. There’s nobody there” *Briony, HCA, HS1.*

“We need a resident counsellor that we could talk to...I haven’t got time to listen” *Joy, nurse, HS1.*

A few participants reported that they did not think that they needed support from others

“I don’t think that I need the support, much more support because clinically if you’re unsure of something there’s always staff around. The emotional side it’s part and parcel of the job...you just have to learn to switch off” *Helen, nurse, HS1.*

“They have like a, um, a sessions here, stress...I don’t see how that would help...Cos they did them ages ago and now they’ve set them up with new

members of staff and it's not someone that you could talk to, without that sounding quite nasty" *Briony, HCA, HS1*.

### **Ideas for change**

Staff expressed wishes for something to be changed for patients with dementia and the way that staff are able to care for them. The question "what can be done?" was met with a sense of helplessness by some.

"I think something needs to be done, but I don't know what" *Ria, HCA, HS2*.

"I think it would be difficult (to be make changes), because of the stress and strain that the NHS is under" *Dani, HCA, HS1*.

Participants did however identify some ideas for change, which are reflected in this thematic area. These ideas include, increased support, training and environmental changes.

### **There are not enough of us**

The majority of staff spoke about the need for more staff. This was more highly evident in site 2, where the majority of the staff on shift were agency staff.

"More nurses, more health cares, more wards, more beds. That's what you need to solve the problem.... the thing is obviously we're an aging nation, and this is just only going to get worse" *Sarah, nurse, HS2*.

"More staffing, MORE staffing, it would make it easier because you can have more time and everything...we're shutting that independence away because there's not enough of us to do it" *Cally, nurse, HS1*.

Participants spoke about the limited resources available to care for patients with dementia effectively and how this effects how patients are treated in hospital: involving the pressure of having too many patients, lack of time and lack of staff.

Participants indicated that there are a high number of patients who present in acute care and that the pace is difficult to manage.

"There's nothing to stimulate them and, as I say, we don't always have the chance to go back and sit with them either" (*Ria, HCA, HS2*)

“You just try and balance everything and you want to give them as much attention as you can but you have other patients to look after as well. It’s really hard to balance everything and make sure everyone’s getting properly looked after, because as much as you want to give the dementia patient all of your attention you’ve got others who might be poorly and need attention too, so sometimes it’s hard” *Cally, nurse, HS1*.

“When you’ve got other admissions and poorly patients and every, everybody else to care for it’s so hard. And it’s really frustrating because you find yourself running to one patient, and then quickly running back” *Tina, nurse, HS2*.

“It’s just not feasible sometimes on here, there’s just too much going on, poorly patients, admissions, transfers, and if we’re short staffed, or even if we’re not even if we’re fully staffed sometimes you still need an extra five people. It’s just too busy to be able to sit there with one person” *Pheobe, HCA, HS2*.

Some participants stressed the difficulties also associated with the reduction of staff.

“You’ve got staff shortages, there’s funding, there really isn’t much more you can do really. But you just make sure people are safe, they’re ok and that’s what you can do” *Helen, nurse, HS1*.

### **We need to learn how to deal with dementia**

The importance for further training was articulated throughout the participant’s experiences of working with dementia; a lack of knowledge, skill and confidence was highly evident.

“I know that I need to learn more. Because like I keep saying, I don’t understand it... we do keep getting a lot of patients come in with it and we need to understand it, and we need to know how to look after them” *Ria, HCA, HS2*.

“Regular training on how to like deescalate situations when they do” *Gary, nurse, HS1*.

“I think you need a lot of training on it (why patients have challenging behaviour) just to help with that frustration is, is there something? I mean I can’t, I can’t say why, I don’t know” *Ellie, HCA, HS1*.

Participants developed ideas for training throughout the interview, including more “practical training” (*Dani, HCA, HS1*), or “role play” (*Gary, nurse, HS1*) about “how to deal with it” (*Sarah, nurse, HS2*) or “manage it” (*Gary, nurse, HS1*), rather than factual knowledge about the disease. However, ideas about problems of getting the training and implementing the training were also highlighted.

“It’s the fact that you don’t ever get put on the courses to do it, cos obviously funding is an issue... would we have time to put the training into action” (*Sarah, nurse, HS2*).

### **Changing the environment**

Some people described environmental alterations; including, ideas for colour coding, signposting or having a specific “dementia ward” (*Gary, nurse, HS1*).

“In certain hospitals they have special colours on the floor from the toilet back to their bed... like we were talking about better signposting and things so they don’t really get disorientated” (*Sarah, nurse, HS2*).

“If they could section off, and know it sounds awful because you’re segregating, but sort of have one particular part of the unit, just for dementia, Alzheimer’s, the mental health. And I know it sounds like well that’s not very nice because you’re keeping them away, it’s not about that it’s about controlling their environment. So they feel safe” (*Dani, HCA, HS1*).

Participants spoke about the tension between patients needing to be on AMU but also feeling like it was not the right setting for patients with dementia, due to the negative impact it had on them.

“AMU is not the right place for a patient that has dementia to have a long stay” *Sarah, nurse, HS2*.

“They end up staying here in AMU, cos it’s so busy they don’t get rest at night so the lights are on, there’s no, they’re so disorientated and that obviously must exacerbate their condition because if they’re not getting any sleep, there’s no set routine” (*Sarah, nurse, HS2*).



“I don’t know, this is not the, this unit is not the right environment for anybody with dementia. It’s not the right environment, it’s too loud, it’s too busy, and it’s too noisy, it’s too confusing” *Denise, HCA, HSI.*

It was clear that being in the AMU was viewed as a problematic environment for patients with dementia and was often seen as a direct link for problematic behavioural presentations.

“I mean if you’re listening to buzzers going off left, right and centre all day long it drives me mad never mind anybody else.” *Ellie, HCA, HSI.*

“When they hear certain sounds... they could link that to something due to war and then get quite aggressive or quite scared...there is just so many people, so many uniforms, so many loud noises and the unfamiliarity of the place I think...You try and relay that information and sometimes people don’t understand what you’re saying. And I think we would, we would get aggressive, we would get agitated” *Farah, nurse, HSI.*

One participant spoke about the tension between other patients and patients with dementia.

“It’s really hard (laughs) because obviously it’s really noisy any way, and you can’t calm them down when you want to relax, but sometimes it’s just the way their dementia is and they shout all day long any way, and then obviously we get patients who come in with migraines and things and then they have to listen to shouting all day” *Cally, nurse, HSI.*

Participants also alluded to the idea that more support and changes were needed from management level.

“I think to myself if those that are higher up the ladder, if they had a reality check. If when they come and pay us a royal visit, so to speak, actually see, the true picture, but because we’re told when someone is coming, everyone’s on their best behaviour, the units immaculate, so they get a false impression of what a day to day shift is like...And then maybe, maybe they’ll value the staff a bit more. So I think a bit more honesty would help and genuine understanding.” *Dani, HCA, HSI.*

One participant spoke about policy change to increase medication for patients with dementia:

“The only thing I can think of is like I’ve mentioned, giving them some sedation at night so their mind can rest” (*Ursula, HCA, HS2.*)

Ideas for changing the “pathway” for patients for dementia were also articulated, so that patients “go straight to a ward” (*Tina, nurse, HS2.*)

## 4. Discussion

### 4.1 Overview

The increasing prevalence of those with dementia in acute care has an impact both on the health care service and the staff who work within it. This research aimed to qualitatively explore the experiences of staff caring for patients with dementia in AMU settings, using TA to analyse semi-structured interviews. Analysis outlined three thematic areas; caring, experiences with dementia and ideas for change, along with eleven subthemes. The results indicated that the way that patients with dementia present is highly variable and the way that staff make sense of these behaviours also differs; a lack of knowledge about challenging behaviour was evident. The results indicated that staff had different coping styles and caring had different levels of impact on participants; a consistent view was of the role of staff and the integrity of nursing. The present study suggests that there is a tension which exists between how HCPs want to care for patients with dementia and how they are able to care due to limited resources and environmental/ organisational strains in the NHS. However, whilst some ideas for change seemed hopeless, there were ideas for improvement; these are discussed in clinical implications. The majority of staff agreed that the way the acute physical health service is currently delivered is not suitable for patients with dementia.

#### *How staff make sense of dementia*

The current research reported that staff understood that patients with dementia often presented with “challenging behaviour” as the patients did not know what they were doing. Staff felt that patients were not in control of their behaviour and therefore accepted difficult behaviour, including aggression. Todd and Watts (2005) supported this notion, they reported that when staff were sympathetic towards patients with

dementia, that they were more willing to help, however if staff had negative emotional responses to patients, they were less willing to help. It seems that the participants in this study were empathic and willing to help, therefore seeing patients as not in control of their behaviour seemed to allow for them to continue to care, even when behaviour was challenging.

The findings also suggest that patient behaviour was often attributed to a fear response, demonstrating the empathising abilities of staff; another explanation for this attribution has been outlined in further literature. Menzies (1970) reported that transference exists in ward settings, between staff and patients, resulting in both experiencing similar feelings. Participants in Menzies research reported similar feelings to those reported in this study including frustration, fear and helplessness. This suggests that staff could have been highly empathic towards patients feelings, and/or there were subconscious dynamics at play.

Many participants stated that they did not understand why patients with dementia behaved in the way that they did, this links to research which reports that hospital staff have little knowledge of dementia (Fessey, 2007). Participants reported feeling confused and helpless about what to do to help those with dementia; helplessness has been linked to a decreased ability to problem solve (Morgan *et al.*, 2002). The majority of participants also reported that they did not feel that they personally had an effect on the patient's behaviour. Challenging behaviour in dementia can be influenced by other people, the situation in which the behaviour happens, working practices and the environment, understanding this process can potentially help to create a sense of agency when working with those with dementia (Farrell *et al.*, 2010). Nakahira *et al.* (2009) report that staff fear being judged as incompetent if they cannot manage challenging behaviour; therefore if HCPs could be given the knowledge and skills to help effectively, it is likely that they would have increased satisfaction and wellbeing at work. It therefore seems as if further training is needed to help staff understand challenging behaviour and how it is influenced to enable change in practice.

#### *How staff care for patients with dementia*

Participants reported innate skills when caring and developing a rapport with patients with dementia; Smith and Godfrey (2002) report that nurses feel that having intuitive personal attributes, make a good nurse. Participants in this study valued spending time

with patients, the therapeutic relationship has been found to be an important aspect in nursing care for both nurse and patient in other research (McCabe, 2004). The notion of nursing being a way of life was a theme that arose on numerous occasions in this research. This is often how participants stated they knew how to care for patients with dementia. Rew and Barrow (2007) completed a systematic review looking at the role of intuition in nursing care, it was found that intuition was salient in expertise in clinical practice and was highly valued and taught in nurse practice. Intuition has also been recognised as a valuable source of knowledge (Smith, 2009), however in the current study it was evident that there were limited procedures outlined for how to respond to patients with dementia when they presented with challenging behaviour. Participants reported being unsure about what to do when patients were aggressive, wandered or when they regressed; they often spoke about relying on their intuition. It may be that when nurses respond in an intuitive way others view them as competent, meaning that training needs are not readily identified.

The NHS has championed person centred care in dementia to combat unwanted clinical outcomes; however it is clear that due to organisational tensions person centred care is often not achieved (Borbasi *et al.*, 2006). Person centred care needs to be valued at a staff and organisational level in acute care to be effective (Clissett *et al.*, 2013). Staff in this research study wanted to care and often did care in a person centred way, but this was difficult to achieve due to organisational and environmental restraints. Participants reported having limited resources, lack of time and ability to be able to care for patients with dementia as staff wished. Ramanujam *et al.* (2008), report that nurses perceive they are unable to care safely when there are organisational demands. With the current economic pressure, those with dementia and their carers end up being in problematic positions; leading to incidents described in the Francis report, such as neglect and abuse (Francis, 2007). The way that staff are able to care for those with dementia in AMU was reported uncomfortably by participants, expressing the desire to give more time, patience, attention and help to those with dementia.

The findings of the current research support previous research which suggests that more needs to be done to care for those with dementia in acute care settings, that hospital settings as they currently exist, are not the right environment to care for patients with dementia, and that whilst nursing staff may have sufficient experience of caring for the elderly, they may not have the expertise to manage challenging behaviour (Borbassi *et*

*al.*, 2006; Eriksson & Saveman, 2002; McCloskey, 2004; Moyle *et al.*, 2011). The research also mirrors the findings that nursing staff strive to give optimal care, but the conditions they care in often do not allow for this (Cowdell, 2010).

### *Impact on staff*

Participants reported often feeling frustrated and exhausted when caring for patients with dementia. This feeling has also been reported in nurses working in emergency care where Beck (2011) found the presence of secondary traumatic stress in emergency department nurses. Secondary trauma is a concept suggesting that staff become negatively affected when working with patients who are distressed or traumatised. There is limited research regarding this concept when caring for patients with dementia who are either distressed or traumatised; the concept of trauma in dementia is also relatively under researched. It is unclear whether participants in the current study experienced burnout or secondary trauma; however this seems to be a useful concept to further explore in AMU staff. Tehrani (2007) reports that all staff working with distressed or traumatised patients need to be supported. Participants in the current research reported feeling supported by other staff, however emotional support seemed limited. Some participants stated they would like more support and some reported that they would not use it if it was available. It would be useful to explore experiences of staff support when working on the AMU and the reasoning behind help seeking behaviour to ascertain whether it would be helpful to offer more emotional support to staff, to help avoid secondary trauma and burnout.

In the study, participants often commented on the negative impact of caring, such as feeling frustrated or upset, however they also reported feeling positive emotions when they could see that they were making a difference or had more time. Participants repeatedly communicated a deep compassionate desire to help others; however, it seemed that this aspiration to help was often met with resistance due to the tensions with targets or resources in the NHS. McNeese-Smith and Crook (2003) state that a reduced congruency between personal values and organisational values lead to lower levels of satisfaction, burnout and turnover, a process currently evident in AMU. HCPs in AMU could also be experiencing “compassion fatigue” a concept whereby nurses are exposed to trauma on a regular basis (Boyle, 2011). Hooper *et al.* (2010) reported that

86% of emergency nurses have moderate to high levels of compassion fatigue, and 82% have the similar levels of burnout, this needs further exploration in AMU.

Participants in the current research commonly expressed that caring for patients with dementia left them with a fear of getting dementia themselves. Hodgson and Cutler (1997) found that people develop a fear of having dementia due to having family members with the disease. There is limited research on how caring for patients with dementia affects staffs fears of diagnosis or mortality. Overall, participants seemed to perceive dementia as an “awful” illness; there seemed to be limited expression that some patients live well with the disease.

#### *Ideas for change*

Ideas for change are mostly outlined in the clinical implications section as they directly link with feasible changes that could occur in AMU to enable better care of patients with dementia. Overall, participants discussed the need for more staff, more training and environmental changes. The NHS is currently in a period of debt, meaning that cuts to expenditures are currently influencing how staff are able to care. There is a focus on staff meeting targets, set by people who do not work clinically. It was evident that in the current research there was a frustration in the pressures that HCP’s were under to care for patients in a pressured environment. There was also a high element of helplessness that there would be any way of changing how patients with dementia were cared for. It has been found in other research that nurses and patients who rate the work environment positively report better care (Aiken *et al.*, 2012). It seems that making changes to the hospital environment may increase more positive views of care.

## **4.2 Strengths and limitations**

This study has sought to explore the experiences of a more varied range of clinical staff, by including health care assistants; this allows for different points of view. A semi structured interview was used, allowing for an open dialogue exploring ideas in the current evidence base whilst allowing for a degree of freedom in conversation. However, this may have influenced staff to reflect upon areas which may not have arisen naturally.

This study is a new area of research which has not been explored before, as research has been limited in the AMU; it adds to the evidence base on caring for patients with

dementia. There is a paucity of research which explores staffs experiences of caring for those with dementia on AMU, research has focused on wards (Nolan, 2006) and emergency departments (Clevenger *et al.*, 2012). AMU is the first entry point into acute care after patients have been referred from emergency services and often offers inherent difficulties in its chaotic setting; this setting combined with dementia could result in unwanted clinical outcomes, such as neglect and abuse. The AMU plays an integral role in how patients with dementia are treated when they are first admitted to hospital, when people are potentially at their most physically ill and cognitively confused. Patients with dementia often report a decline in quality of life, cognitive and physical state after hospital admission (Borbasi *et al.*, 2006; Kovach & Wells, 2002; Morrison & Siu, 2000).

The study also investigated staffs experiences at two different hospitals, allowing for comparison across two trusts. The findings were generally similar across the two hospitals, both sites represented compassionate staff that were under organisational pressures. The major difference was that site two had limited staff and resources. Whilst 21 interviews across two sites were completed, further interviews would have increased the studies generalisability; this was not possible within the time constraints of this study. Time was a general limitation; staffing issues meant that participants had limited time for interviews; this reduced the amount of information ascertained. Another limitation is that demographic information was not collected; this was due to a need to protect participant's anonymity in a small system.

#### **4.3 Clinical Implications and Recommendations for Future Research**

Some areas for development have been revealed through applications of the research findings. The main finding of the research was that staff have an intuitive way of caring for others, and deep desire to care well which is only sometimes able to be expressed; participants did not seem to convey negative attitudes towards patients with dementia, but as a result of caring in an under resourced and pressured environment staff felt exhausted, frustrated and unable to care as they wanted to. This research suggests that currently HCPs seem to be operating through an act of good will and a desire to care. Person centred care and values based decision making were aspired to by participants, even though participants in the current research reported that organisational pressures invite staff to become distanced and robotic. It seems that increased time and attention for patients with dementia need to be implemented to encourage person centred working

and rapport, as outlined in NICE guidelines (2006). Areas for change resulting from the research include designated dementia trained staff; dementia pathways; increased staffing or specific bays for patients with dementia.

In this research, staff reported managing difficult emotions such as frustration, exhaustion, distancing from patients and emotions, sadness, anger and underlying guilt; Yoon and Kim, (2010) report that these feelings could result in many distressed members of staff, leading to increased turnover and burnout. The current research found that staff varied in their desire for emotional support, some reporting they needed support and others stating they would not use it. Further research into help seeking behaviour and emotional needs in staff could help ascertain whether emotional support is needed for staff working on AMU. Intuitively, it is plausible that reflective practice models could give health care professionals a clear and containing space to reflect on their reactions to clinical work and this merits further research. Need for support and development has been identified within numerous areas of AMU; with the organisation, staff distress, patient distress and managing challenging behaviour. It is possible that Clinical Psychology could offer support in all of these areas.

Environmental and organisational change were raised as a need in this research; however this idea was often met with a sense of helplessness due to the financial pressures on the NHS. Other trusts have tried to combat the issue of dementia in acute care by having dementia specific departments at admission; these include different environmental designs such as having a table to eat at, bold colouring and signage to allow patients to navigate the department better, changes to lighting and noise levels and upholstered furniture (Karlin, & Zeiss, 2006). Further research suggests altering the existing environment and training all staff to adjust to the increasing number of patients with dementia; such as attention to hydration, nutrition, communication and clear signage on the toilets (Leung & Todd 2010; Waller, 2012). Most of these ideas were also raised by participants in the current research, including relatively low cost ideas such as having more radios, TV's and newspapers.

As the population ages and there is an increased prevalence of dementia, it has been found that annual spending on dementia will reach £35 billion by 2026 (The Kings Fund, 2012). The amount of funding needed to care for those with dementia in physical health settings has not kept pace with growing demands. This has led to increased



pressure on services, distress in staff and reduced care for patients with dementia, which is evident in this research. Patients with dementia often present with several co-morbidities, leading to undiagnosed and untreated problems (Lopponen *et al.*, 2004). The NHS devotes most resources to physical health care, and largely the care for physical and mental health is provided separately. Patients with dementia spend longer in hospital and ultimately become more unwell than before they entered hospital (Lyketsos *et al.*, 2000), demonstrating that care of patients with dementia is not done so in an efficient and optimum way. It is evident that more needs to be done to care for those with dementia in acute care. An area identified in this research is that dementia care training, including management of challenging behaviour and communication skills is a need for all staff, either implemented during training or on the job. The most effective training method needs to be researched; however participants stated that it would be more useful to have hands on, experiential training, rather than didactic education. Visser *et al.* (2008) found that peer support and training helped alter the perceptions of staff with regards to dementia and challenging behaviour.. It also seems that AMU could also employ dementia specialists on AMU to help staff with issues of dementia and challenging behaviour.

There has been limited research into the experiences that staff have of working with dementia from different minority ethnic backgrounds, one participant highlighted the idea that families of western culture do not show as much support for their family members in hospital. This would be an interesting area to research to ascertain different values and attitudes.

The current research focussed on the experiences of health care assistants and nurses. Nurses are often over represented in health care literature (Van der Lippe & Van Dijk, 2002) meaning that views of other members of staff are often missed. Future research could ascertain the experiences of dementia in other health care professionals, such as physiotherapists, radiographers and doctors, this could give insight into how multi-disciplinary teams manage dementia care and how patients with dementia experience the multi-disciplinary team. AMU is also a relatively under researched area, yet it is a place where the majority of patients are admitted after A&E (Scott *et al.*, 2009). Therefore, dementia care in AMU environments has not been raised as an issue and as a result needs further exploration into best practice, dementia care pathways and staff training.

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## **Part three Critical Appraisal**

### **3. Critical appraisal**

#### **3.1 Introduction**

The following critical appraisal offers reflection on the research process based on a reflective journal and field notes which were kept throughout the development of the research. The trajectory of the research process will be outlined, including; the decision to explore the experiences of acute physical healthcare staff experiences of dementia; the choice of research methodology; recruitment and data collection; analysis and the lessons learned whilst participating in the research process.

#### **3.2 The decision to explore acute staffs experiences of dementia**

The choice of topic was influenced by personal experience of a member of my family. My grandmother had a diagnosis of Alzheimer's disease, and also had a number of hospital admissions with physical health problems. The quality of care for her as a patient with dementia seemed to vary greatly in different admissions. Sometimes the care experience was very positive, with staff taking time to talk and listen to both of my grandparents. This would result in what seemed to be a mutually positive experience with staff referring to my grandmother as a 'lovely lady'. However there were other times where she was labelled as a person with 'challenging behaviour', a description that did not seem to fit the person we knew.

It could be difficult enough for the family to fully understand my grandmother's physical health problems, let alone for health professionals to interpret this, for example she would refer to 'funny turns'. Visiting her in the hospital, I had some first-hand exposure to how difficult it was having dementia and being in acute physical health settings. For example my Grandma would indicate she was thirsty by sucking on her lips, she was not able to initiate the movement to give herself water, staff were often busy and would not have the time to notice or sit and wait for her to take water properly, I wondered how much they understood about how the dementia affected her. I often deliberated what it was about the hospital environment that could result in such a variation in the quality of experiences for her, my grandfather and the rest of us in the family as her loved ones. I wondered about how staff influenced or experienced this.

I noticed that after every hospital admission my grandmother's dementia seemed to get worse, and ultimately she was placed in a residential home as it became too difficult for my grandfather to care for her at home. My grandfather did not have dementia and was often described as wise and highly intelligent by doctors, staff and everyone who met him; this led him to question why the quality of care for my grandmother seemed so variable, it was difficult not to be very critical of some of the care received. Overall, he felt that those with dementia and their carers were stigmatised and uncared for. I have ever since been interested in patients, family and staff and their experiences of dementia in acute care.

Due to the close relationship I had with my grandparents and the amount of time I spent with older people growing up, it seemed very natural to me to want to work with older people clinically. I have worked in a number of different care settings for older people: including residential homes, community care, social services and during the doctorate, both in the community and in inpatient facilities. Throughout all of these experiences I have seen how difficult it is for staff (having been a member of staff myself) and also for the people with dementia and their family members. One area that I have not worked in is acute medical units. I was therefore interested in researching this area from a qualitative perspective as I knew little about how staff would experience it.

I was interested in producing findings which would add to the evidence base of dementia research. When searching the literature, it was evident that there was research which addressed informal and formal carers' experiences of caring for those with dementia in dementia specific environments, such as residential homes or geriatric units. However, what seemed to be missing were experiences of staff working with dementia in areas where dementia was highly prevalent but not exclusively designed for. I spoke to a number of different consultants in a few of the hospitals near where I lived and they reported that their staff had a lot of experience of caring for people with dementia, but there had never been a focus on dementia training for these staff.

Originally, the idea was to focus on physical health wards. It was decided that the research would take place in the hospitals acute medical units (AMU). The AMU had large numbers of staff and the amount of people with dementia seen on a daily basis was high. There was also a paucity of research in the area and it seemed to be an important environment to explore, as it is the first place of admission after A&E. In addition, dealing with an acute physical health concerns with someone with the

debilitating mental health problems of dementia was likely to be particularly challenging.

### **3.3 Selection of Research Methodology**

After recognising that I was interested in exploring the experiences of staff working with those with dementia in acute physical health settings, the choice to use qualitative methods appeared to be most suitable as it allowed an in-depth and flexible approach to explore an under-researched area. Thematic analysis (TA) was a methodology that I knew about, but I had never used in previous research. The idea of using interpretative phenomenological analysis (IPA) seemed more attractive due to the fewer number of participants needed, however due to the research question being asked, I was less focused on the phenomenon of dementia care and more on the associations staff made; TA seemed like a method that allowed me to capture hidden meaning, but remain methodical. I was also interested in how my staff sample represented mental health professionals in AMU (Joffe, 2012). TA therefore seemed like the right methodology to use. Braun and Clarkes (2006) paper was integral in assisting me to understand the method in detail and in allowing me to choose this form of analysis to address the research question at hand. It also allowed me to be flexible in choosing my epistemological position; as this was a new concept for me, it allowed me to develop my thinking in this area. Joffe's (2012) paper was integral in me understanding the how both inductive and deductive processes could work together in TA. They state that whilst themes driven from theory allow the researcher to extend and refute the evidence base, qualitative work is about drawing on naturally occurring themes in the data too. Both inductive and deductive methods can therefore be used together in TA; view the data with preconceived theory and remain open for new concepts to emerge from the data.

### **3.4 Recruitment and data collection**

Initially the idea was to recruit from three different sites, whilst two of the sites were enthusiastic about taking part in research, problems ensued with contact; as a result two sites contributed to the number of participants recruited. Consultants were very helpful in initially being able to ascertain who was best to speak to on the ward, making rooms available and permitting time to staff to interview. Matrons and staff nurses then carried forward this enthusiasm and encouraged participation from staff.

I often had large amounts of time where I was sat on AMU without seeing participants, waiting for them to be available after participating in their everyday caring activities. I did not realise that this would also be part of the process for me. I was subjected to how it must feel as a patient in a side room on the ward. I could hear the buzzers, the busy movement of the staff and all of the noises, sights and smells that patients could. I spent time reflecting on how I felt and experienced this setting, I thought that this was an important process as it allowed me to explore my own thoughts and biases when interviewing staff. It has made me think that I would enjoy completing a further research project with an ethnographic focus; this is something that I feel would be a valuable addition to the evidence base; researchers using ethnography aim to construct and represent information based on experiences that are personal and through observing (Pink, 2007). I reflected on the fact that I had had mostly negative experiences with hospitals; I had mostly experienced medical professionals as people who try to help, but can't; I was therefore slightly apprehensive about interviewing health care professionals. The process of completing the interviews changed my views, biases and allowed me to explore the reasons behind staff not being able to care efficiently at times; keeping a reflective journal and speaking to my research supervisors also helped challenge these views.

Aspects such as, time and staff available to participate in research interviews was particularly problematic in one hospital. When comparing the two sites, it was evident that at one had more staffing pressures and this resulted in more problems in recruiting participants. Staff appeared happy to take part in the research, but the idea of completing an hour's interview was not seen as feasible. Most HCPs were made aware of the research at staff meetings, however the only way to feasibility recruit due to time and staffing pressures were for matrons and staff nurses to identify HCPs free from caring duties or with limited work. When participants met with the researcher they were told that it was non mandatory and had the right to withdraw. Whilst all staff seemed keen to participate, they may have not naturally volunteered themselves; there may have also been HCPs who did not get given the option of participating due to their work load. Participants were also interviewed during their shift; therefore responses may have been influenced by the kind of shift they were experiencing.

It was evident, across both sites that the majority of the nurses held a great amount of compassion and empathy for patients with dementia. I found that I connected to the

accounts given and found myself empathising with them regarding pressures and experiences. There was much conversation about problems with the organisation, people being seen as numbers, Participants were frustrated by the NHS organisation and lack of government funding, as was I. This allowed me to be empathic and patient when staff were not be to give me time for interviews, I believe this helped me develop better rapport with staff.

When I was completing the interviews, initially I noticed how difficult it was to develop my interview style, as my skills in clinical interactions had been established. I found that in my first few interviews, I was asking leading questions and finding it difficult to develop a rapport without empathic and reflective statements; I found it hard not to slip into the role of a psychologist. I knew that people had possibly not had these conversations before and they were potentially difficult, especially for those with personal experience of dementia. Later transcripts showed my ability to develop a rapport through the use of questions in participant's words and using broad open questions to begin the interview, rather than empathic statements (Bloom & Crabtree, 2006). I used supervision to share transcripts and my supervisor helped me to develop my interview style, including demonstrating where I was being leading, or perhaps not allowing for full expression by not asking further questions.

I reflected on my role as an "expert" in psychology; when asking participants questions about why they thought that patients with dementia behaved in challenging ways, I wondered whether they did not give me as much feedback on their thoughts due to the fear of being wrong and me being right, or misrepresenting the service (Mayo & Duncan, 2004). Often when the tape finished recording, participants would ask me if I knew the reason behind challenging behaviour and a discussion would be had where I demonstrated that I had knowledge in the area but that they were the experts of the AMU and of their own experiences and thoughts. I also had this conversation before interviews but I do not think that participants let go of the feeling of "being right" and therefore these questions would be met with an "I don't know" in comparison to guesses behind why patients with dementia present with challenging behaviour.

When I felt as though I was being seen as an "expert" I also began to reflect on participants reports for staff at a higher level to experience what it is like to care for someone with dementia whilst experiencing organisational pressures. The implications



of having the health care service run by people who do not work in the area is that the focus becomes on running a business and focusing on cutting funding rather than focusing on how to best care for patients. I thought it could be useful for managers and leaders to spend time in acute settings to understand the true environmental pressures, to reduce the “expert” or “us vs them” mentality.

### **3.5 Analysis**

I decided early in the process that I would not transcribe all of the data myself. I had 21 interviews and whilst transcription would have helped to further immerse myself in the data, I did not feel like I had time to manage all of the demands being placed on me in a short amount of time. I transcribed five interviews myself and found that I did not feel my understanding was any deeper than the ones I did not transcribe. I read and re-read the data a number of times, listened to the audio repeatedly and paid close attention to what participants were saying. I kept notes regarding my initial impressions of the interviews and the transcriptions. My underlying sense of what was being communicated was what was most prominent in the analysis: the concept of tension. This was the sense I had when attempting to recruit staff and the overall feeling I experienced when sitting in the AMU. This was something which was spoken about by all staff members and therefore seemed like an important area to reflect on.

When I was initially coding the data, I was overwhelmed with the amount of information I had. I didn't want to miss anything. I noticed I felt protective over my research and wanted to encapsulate everything I had discovered. I feel I was able to do my research proud as I am happy with the outcome, however there were many accounts I could have included but the report would have been extremely long. I used supervision to narrow my initially vast concepts and to name the themes appropriately to represent my deductive and inductive methods of analysis; this was a useful process which allowed me to focus on my research question.

### **3.6 Lessons learned**

When reflecting on the process overall, I have considered how the experiences I have had throughout training and the research process have shaped and developed me personally and as a clinician. First and foremost, I think it is important that I have had this research experience to challenge my perspective of staff in acute care; it has allowed me to critically appraise the thoughts that I had previously and has allowed me

to develop a more empathic view of staff. I enjoyed contributing to the evidence base; one of the reasons I want to be a Psychologist is to aid in the development of dementia care. I would like to continue to strike a balance between clinical work and research. However, my ability to be “academic” has always been a concern of mine. I noticed that as I was completing the research, the parts that I enjoyed were the interviews and analysis; working in a quantitative way or writing in an academic style did not come as naturally. I feel I have developed my own writing style to some degree, maintaining a sense of identity in the way I express things is something I have struggled with, but feel I have gained that balance which will hopefully help me in the future when further completing research without the huge amounts of supervisory support.

Managing the competing demands of the clinical, academic and research work has been difficult. Something which became evident for me throughout the course is my family script of “get on with it”. Dealing with a chronic health problem for the past few years, I thought that this was a good mentality to take. What I noticed is that I needed time to rest and heal in order to be a “good enough” clinician. I am not a perfectionist and I know the value of being “good enough”, but there were times throughout the course when I was dealing with chronic pain, juggling coursework, clinical work and managing issues in my personal life where I didn’t feel that I was “good enough”. Failing the course has not felt like an option for me as I am driven and passionate about caring for those with dementia. However, I’ve noticed when I need to “get on with it” and when I need to take a step back and become more self-compassionate. Through doing this I have found that my ability to manage competing demands has been better. Over all, whilst the research process has been strenuous, I have enjoyed the process of my research project. It has helped me move in the direction I’ve wanted to go in for a long time. I’ve really appreciated being given the opportunity to show what I can add to dementia care research.

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## **Appendices**

## **\* Appendix A: guidelines for authors for targeted journal for literature review**

Guidelines retrieved on the 25/4/16 from

<http://journalauthors.tandf.co.uk/preparation/index.asp>

Please find complete guidelines in the link above.

*Aging & Mental Health* is an international peer-reviewed journal publishing high-quality, original research. All submitted manuscripts are subject to initial appraisal by the Editor and if found suitable for further consideration, to peer-review by independent anonymous expert referees. All peer review is double blind and submission is online via ScholarOne Manuscripts. We encourage the submission of timely review articles that summarize emerging trends in an area of mental health or aging, or which address issues which have been overlooked in the field. Reviews should be conceptual and address theory and methodology as appropriate.

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the manuscript is your own original work, and does not duplicate any other previously published work, including your own previously published work.

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### **Manuscript preparation**

#### **1. General guidelines**

Manuscripts are accepted only in English. Any consistent spelling and punctuation styles may be used. Please use single quotation marks, except where 'a quotation is "within" a quotation'. Long quotations of 40 words or more should be indented without quotation marks.

Manuscripts may be in the form of (i) regular articles not usually exceeding **5,000 words** (under special circumstances, the Editors will consider articles up to 10,000 words), or (ii) short reports not exceeding **2,000 words**. These word limits **exclude** references and tables. Manuscripts that

greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.

Manuscripts should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate Funding paragraph, as follows:

*For single agency grants:*

This work was supported by the <Funding Agency> under Grant <number xxxx>.

*For multiple agency grants:*

This work was supported by the <Funding Agency #1> under Grant <number xxxx>; <Funding Agency #2> under Grant <number xxxx>; and <Funding Agency #3> under Grant <number xxxx>.

Structured Abstracts of not more than 250 words are required for all manuscripts submitted. The abstract should be arranged as follows: Title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion.

Each manuscript should have 3 to 5 keywords.

Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance [here](#).

Section headings should be concise. The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content.

All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.

All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.

Biographical notes on contributors are not required for this journal.

Authors must also incorporate a Disclosure Statement which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.

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(outlined by link on the website)

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All figures must be numbered in the order in which they appear in the manuscript (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).

Figure captions must be saved separately, as part of the file containing the complete text of the manuscript, and numbered correspondingly. The captions should include keys to symbols, and should make interpretation possible without reference to the text.

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Authors should prepare and upload two versions of their manuscript. One should be a complete text, while in the second all document information identifying the author should be removed to allow the files to be sent anonymously to referees.



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## **\*Appendix B: Ethical approval and letters of access/ NHS to NHS proforma**

Received electronically on 7/2/15

To: **Frankie Bower**

Subject: Ethical Application Ref: **fb129-edd9**

*(Please quote this ref on all correspondence)*

---

**07/02/2015 16:03:07**

### **Psychology**

Project Title: **How do Health Care Professionals care for patients with dementia in an acute hospital setting?**

Thank you for submitting your application which has been considered.

This study has been given ethical approval, subject to any conditions quoted in the attached notes.

Any significant departure from the programme of research as outlined in the application for research ethics approval (such as changes in methodological approach, large delays in commencement of research, additional forms of data collection or major expansions in sample size) must be reported to your Departmental Research Ethics Officer.

Approval is given on the understanding that the University Research Ethics Code of Practice and other research ethics guidelines and protocols will be compiled with

- <http://www2.le.ac.uk/institution/committees/research-ethics/code-of-practice>
- <http://www.le.ac.uk/safety/>

The following is a record of correspondence notes from your application **fb129-edd9**. Please ensure that any proviso notes have been adhered to:-

Feb 7 2015 4:03PM Dear Applicant,<BR><BR>I approve this application.<BR><BR>Best wishes,<BR>Giorgio<BR>

--- END OF NOTES ---

**NHS to NHS letter of access: proforma confirmation of pre-engagement checks  
Version 1**

**For NHS researchers who have a substantive NHS contract of employment or clinical academics with an honorary clinical contract with an NHS organisation, and who need an NHS to NHS letter of access from an NHS organisation hosting their research**

**CONFIRMATION OF PRE-ENGAGEMENT CHECKS**

*To: R&D Office*

**Re: Researcher's name:** Frankie Bower

**Job title:** Trainee Clinical Psychologist

**Contract end-date:** 30 September 2016

**Workplace and postal address:** University of Leicester, Clinical Psychology,  
104 Regent Road, Leicester, LE1 7LT

(employed by Leicestershire Partnership NHS Trust while on the University of Leicester DClinPsy course)

**Electronic Staff Record number:** 24148699

As the representative of the NHS employer<sup>1</sup> of the above-named person, I can confirm that s/he is employed by this organisation. I understand that the responsibility for ensuring that the appropriate pre-engagement checks have been undertaken rests with us as the individual's substantive employer. I can confirm that the appropriate pre-engagement checks have been completed, commensurate with her/his job description and proposed research role in your NHS organisation, and in line with NHS employment checks standards



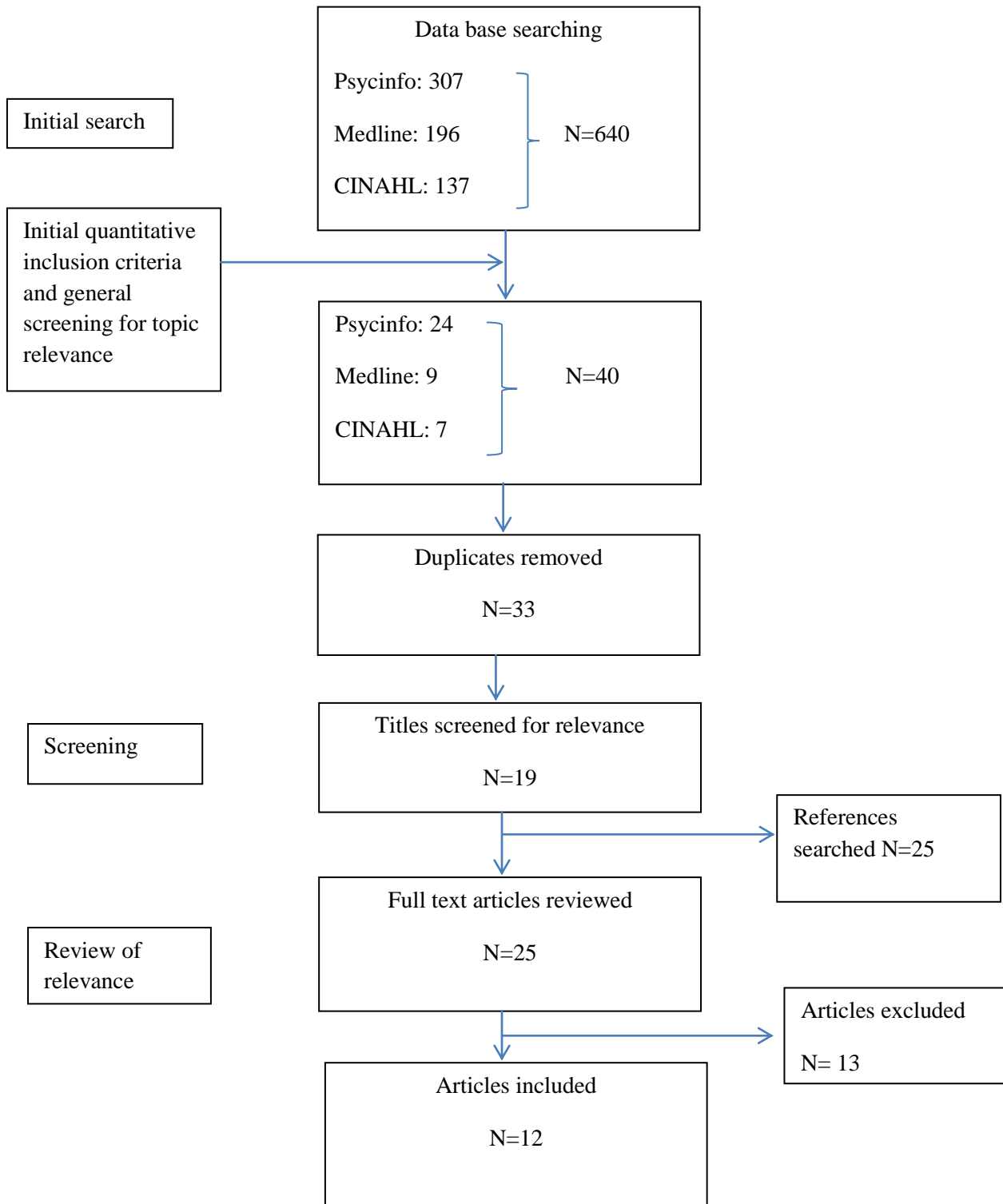
**Name of employer's representative:** Mary O'Reilly

**Job Title:** Senior Clinical Tutor and Frankie's line manager

**Workplace address:** University of Leicester, Clinical Psychology, 104 Regent Road, Leicester, LE1 7LT

<sup>1</sup> For clinical academics, this would be a representative from their HEI employer

## Appendix C: Prisma Diagram



## Appendix D: Quality assessment

1) Reporting: Do studies provide a clear description of aims, outcomes, characteristics of patients, findings and actual probability values? (Total/5).

2) External validity: Are those patients asked to participate in the study representative of the entire population from which they were recruited? Patients would be representative if they consisted of the entire source population, an unselected sample of consecutive patients, or a random sample (Total/1).

3) Internal validity: Are the statistical tests used to measure the outcomes appropriate? Are both adherence and alliance/communication measures validated and reliable? Was there adequate adjustment for confounding in the analyses from which the findings were drawn? (Total/3).

4) Study design: To what extent can the study identify causality? Scores differentiate between cross sectional, prospective/longitudinal and experimental designs (Total/2).

<b>Paper</b>	<b>Reporting</b>	<b>External validity</b>	<b>Internal validity</b>	<b>Power</b>	<b>Study design</b>	<b>Based on psychological models</b>	<b>Study quality score %</b>
<b>1</b>	5/5	0/1	2/3	0/1	0/2	Challenging behaviour and job strain	58.3
<b>2</b>	5/5	1/1	3/3	1/1	1/2	Yes, attachment and burnout	91.67
<b>3</b>	5/5	1/1	3/3	0/1	1/2	No	83.33
<b>4</b>	5/5	1/1	3/3	0/1	1/2	No	83.33
<b>5</b>	5/5	0/1	3/3	0/1	1/2	No	75
<b>6</b>	4/5	1/1	3/3	0/1	1/2	Yes	75
<b>7</b>	4/5	0/1	2/3	0/1	1/2	Yes, clearly	58.3
<b>8</b>	4/5	0/1	1/1	0/1	1/2	yes	50
<b>9</b>	5/5	1/1	1/3	1/1	1/2	No	75
<b>10</b>	5/5	0/1	2/3	0/1	1/2	No	66.67
<b>11</b>	5/5	1/1	2/3	1/1	1/2	Yes, stress of conscience	83.33
<b>12</b>	2/5	0/1	1/1	0/1	1/2	Yes. Burnout	33.33

## Appendix E: Abbreviations of measures used

Abbreviation	Long form
MDDAS	Multi Dimensional Dementia Assessment Scale
EC-R	Experiences in Close Relationships – Revised
ADQ	Approaches to Dementia Questionnaire
MBI	Maslach Burnout Inventory
GHQ	The General Health Questionnaire
SEQ	Stressful Events Questionnaire
ZBI	Zarit caregiver burden interview
MMSE	Mini mental state examination
TBS	Troublesome behaviour scale
CMAI	Cohen Mansfield agitation inventory
FAST	Functional assessment staging
QPS	Nordic General Nordic questionnaire for psychosocial and social factors at work
PSS	Perceived stress scale
HSCL	Hopkins symptoms checklist
BEHAVE-AD	Behavioural Pathology in Alzheimer’s Disease Rating Scale
MSQ	Job satisfaction-the Minnesota Satisfaction scale
SEQ	Stressful events questionnaire
SARAH	Items comprising the staff attitudes towards residents and home
SNC W	Swedish satisfaction with nursing care and work assessment scale
SNC	Swedish strain in housing care assessment
SQC	Stress of consciousness questionnaire

## Appendix F: Data extraction form

Authors and year	
Study Title	
Journal	
Study design	
Participants	<i>N: Age: Sex: Ethnicity: Medical condition(s):</i>
Setting	
Method of recruitment of participants	
Aim of study	
Constructs measured e.g. burnout	
Person measuring/reporting	
Measures used	
Are outcome tools validated	
Participation rate	
Missing data reported?	
Statistical Analysis e.g correlational/ regression	
Significant burnout findings	
Non-significant burnout findings	
Limitations/ strengths of study	
Other comments	



## Appendix G: Semi-structured interview schedule

### DEMOGRAPHIC INFORMATION

- **How long have you worked here?**
- **How long have you been a HCA/ Nurse?**
- **How much experience have you got of working with patients with dementia?**
- **Have you ever had any training on how to care for patients with dementia?**

Formal or informal training? When? How do you think it was helpful (or not)?

### EXPERIENCES OF MAKING SENSE OF DEMENTIA

- **Can you tell me about a recent experience where you cared for someone with dementia?**
  - What was that like?
  - Can you tell me about a good experience?
  - Can you tell me about a bad experience?
  - What did you do in that situation that was helpful/ unhelpful?
  - Was there anything that you could have done on reflection that you would have liked to have done differently?
  - What stopped you from acting in that way the first time?
  - What kind of things were going through your **mind** at that point?
  - Did you feel like you had influence over what was happening?
  - Do you think that the person with dementia could have **behaved differently**?

- What stopped them from behaving differently?

## **RECOGNITION OF DEMENTIA AND THE DIFFERENCES TO THOSE WITHOUT DEMENTIA**

- **What is different about caring for people with dementia?**

- What would you notice about them?
- Would you notice anything about their appearance?
- Would you notice anything about their behaviour?
- Would you notice anything about the way you felt when you were caring for them?
- Would anything different be going through your mind?
- How do you feel when you find you have a patient with dementia?
- What do you notice you care for someone with dementia compared to caring for patients who don't have dementia?
- **How do you KNOW they have dementia?**

## **IMPACT ON STAFF**

- **What proportion of patients that you care for have dementia?**

- How do you feel about this level or number of people with dementia presenting in a physical health ward?

- Does it have any impact on your stress levels?
- Does it have any impact on your levels of tiredness?
- Does it have any impact on your work load?
- Does it have an impact on how you feel about yourself afterwards?

### **SUPPORT**

- **Do you feel supported to manage this?**
- What helps you to feel supported?
- What makes you not feel supported?
- Can you give any examples?

### **IDEAS FOR CHANGE/ WHAT IS WORKING WELL**

- **Is there anything you do that makes it easier/ harder?**
- **Is there anything anyone else can do to make it feel easier/ harder**
- Patients, staff, management, family?
- What could be done to make you feel like you could manage this differently?

**What do you think you do well when dealing with difficult situations?**

## **Appendix H: Trainee's statement of epistemological position**

Braun and Clarke (2006) state the importance of identifying the epistemological stance of the researcher underpinning the thematic analysis process. The researcher identified with the critical realist position, which allows for reflection on the fact that reality is constructed both through individual perspective and existing mechanisms.

In the present research, this relates to both acknowledgment of external forces on HCPs (for example the cultural influence of person centred care and the clinical guideline in place to meet targets) and also identifying that HCPs accounts of their reality are constructed through their beliefs, language and attitudes.

# **\*Appendix I: Participant information sheet**

## **INFORMATION SHEET FOR PARTICIPANTS**



Dept. Clinical Psychology  
104 Regent Road  
Leicester  
LE1 7LT  
T: 0116 223 1639  
F: 0116 2231650

Reference Number:

**PLEASE KEEP THIS COPY OF THE INFORMATION SHEET**

### **Physical health staff experience of working with dementia on acute wards**

We would like to ask you to participate in this research project. We are asking you to take part on a purely voluntary basis, if you choose not to take part, this will not disadvantage you in any way. We have created this sheet, which provides you with information about the study, explains why the research is taking place and what becoming a participant will involve. Please take your time reading the information below, feel free to ask us if anything is unclear or if you would like more information.

#### Aims of the research

We are interested in how staff experience working with people with dementia on physical health wards. We are specifically interested in the views and attitudes that people have towards those with dementia on physical health wards and whether this leads to a change in the way that people with dementia are cared for. We hope that by completing the study that we can gain information on how staff members experience working with this patient group, whether there are any training needs identified and if there is any further support that staff need when working with people with dementia. We hope that the study can help inform improvements to the care that people with dementia receive. When the study is completed we will provide you with a summary of the main findings.

### Who Have We Asked to Participate?

We have asked non-registered and registered nurses in non-dementia specific physical health wards to take part in the study. Members of staff from two hospitals in Birmingham have been approached to take part. We have asked for all health care professionals to be involved to gain a broad perspective of different views across the spectrum of professions.

### What Will you be asked to do?

- You will be asked to take part in an interview with the researcher, Frankie Bower
- The interview will take about 60 minutes
- At the beginning of the interview, you will be asked for information on any training you have previously received on working with patients with dementia, and other relevant professional experience.
- You will be asked about your work with patients with dementia – how you recognise symptoms and what it is like caring for these patients.
- All of the interviews will be recorded using a Dictaphone.
- At the end of the interview you will be given the chance to ask any further questions and will be given contact information if you have any queries after the interview period is finished.

### When and Where Will the interview Take Place?

The interview will take place in your place of work, at a time that is convenient to you. The time and place will be arranged for each participant separately, with a member of the research team. Agreement has been given for you to take part during your shift.

### Are There Any Risks Involved in Participating?

There are no perceived risks in taking part in the study. If there are any questions that you find distressing or intrusive, you are free to not answer those questions or to withdraw from participating. You are given the right to withdraw at any point up until the data has been anonymised. Withdrawing will not cause any penalties.

### Are There Any Benefits Involved in Participating?

We hope that you will gain satisfaction from contributing to the research that aims to inform improvement to health care services. At the end of the research, we will send you a summary of the findings.

### How Will We Maintain Your Privacy and Confidentiality?

Everything that you say within the interview, including the demographic information given to us will remain confidential.

Your data will be given an individual identification number, and your name will be replaced with a pseudonym. This will be used to replace any personal information we have for you. All information that you give to us during the interview will be completely anonymised. Quotes may be used for the report from the interview data, however there will be no way of linking that information to any individual participant. The information you give us during the interview will be completely anonymised and the only thing to identify your responses to the questions will be your identification number or pseudonym.

All of the information given to us will be stored on secure computers, or kept in locked filing cabinets and in locked offices. Your name, or any personal identifiable information will not be attached to the recording of the interview.

All responses given in the interview will remain completely confidential. Confidentiality will only be broken if you state anything which indicated serious risk to yourself or others.

### Who is Organising and Funding the Research?

The main researcher, Frankie Bower is conducting this research as part of her Doctoral Thesis in Clinical Psychology at the University of Leicester.

### How do I agree to take part?

**Please fill out the slip at the end of this form which indicates your interest. There will be a box for you to place this interest form in, Frankie will then get in contact with you directly. Or, email Frankie Bower on [fb129@le.ac.uk](mailto:fb129@le.ac.uk) to express interest in taking part.**

**Frankie will reply to arrange the interview. She will ask for your written consent before going ahead with the interview. Please email Frankie**

Further information and contact details

You may contact Frankie Bower by email on Leicester University email address fb129@le.ac.uk (Other supervisor, Dr Sheila Bonas on [sb162@le.ac.uk](mailto:sb162@le.ac.uk))

Chief investigator, Dr Catherine Snelson is available to contact on [Catherine.Snelson@uhb.nhs.uk](mailto:Catherine.Snelson@uhb.nhs.uk).

Thank you for your time reading this information sheet and for considering taking part in this study.

.....  
.....

**Expression of interest form**

I am interested in learning more about the study and potentially participating.

Yes

No

I would like to be contacted (please tick)

☐☐

Phone number:

.....

OR

Email:.....  
.....

My name

is:.....



## Appendix J: Consent form



Dept. Clinical Psychology  
104 Regent Road  
Leicester  
LE1 7LT  
T: 0116 223 1639  
F: 0116 2231650

### CONSENT FORM FOR PARTICIPANTS

#### Physical health staff experience of working with dementia on acute wards

Reference number:

I confirm that, (please sign your initials in the box as appropriate):

Please  
initial

1.	I have read and understood the information provided in the information sheet.	
2.	I have had the chance to ask questions that I feel I need answering before completing the study.	
3.	I agree to take part in the study on a voluntary basis.	
4.	I understand that I have the right to withdraw at any time up to the point that my interview data has been anonymised. I understand that if I withdraw, I will not be penalised for doing so.	
5.	All procedures used to ensure confidentiality have been explained to me (e.g. how data is anonymised, and that any published research using quotes from interviews will not reveal the identity of those taking part)	
6.	I give consent for the interview to be recorded.	
7.	I understand that other researchers involved in the research project will have access to the anonymised data, following all of the restrictions placed on the project in terms of confidentiality	
8.	I, along with the Researcher, agree to sign and date this informed consent form.	

#### Participant:

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

#### Researcher:

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## Appendix K: Reflective diary; process notes example

Interview 27.7.15

Gary nurse newly qualified. male.

- Time
- Good support.
- Bad thoughts when have someone with dem
- Personal experience
- How to deescalate aggression. Role play.
- Separate ward / segregation
- As a w/dem need to be not integrated or is it society that needs to change to accommodate those people?
- Dementia friendly / disabled / MH friendly hospitals
- People who are happy & using are a joy to work with. BPD is harder to work with.
- It makes you feel helpless. Don't like not being able to help. It's within nurses blood to want to be able to help & make an impact.
- A little bit rose tinted? Unsure as newbie whether has experienced it yet. Seemed friendly. Are some people more inclined to help some staff over others?

Sitting in the ward. I have no idea whether it's day / night, rainy / cold / sunny. There is a constant <sup>long</sup> ~~beeping~~ beeping that is every few seconds going on. I can hear nurses laughing & talking to each other. Lots of people walking past my room without looking in. I can hear trolleys. Nurses walking quickly. Places to be. with bedpans, plastic aprons & gloves. things was somewhere to be & something bad. When nurses walk somewhere, they don't walk together

interrupt

Boasting attitude

No-one does it like me / thinks like me

Don't access support

Not right person to talk to

Personal experience

In their shoes

Lack of staffing / training

"Bless em"

Nothing about repentance / the fact that they can remember or hold it in their minds

All about talking to them & relating - no other tactics - ask questions. How else? Any corner of empathy.

Quite often it seems like HCAs & nurses aren't taught how to deal with situations that need de-escalation so they rely on "gut instinct" or their compassion. How they would want to be treated to de-escalate a situation.

Aware of our prejudices about level of intelligence. HCAs more honest, but nurses are more intelligent.



## Appendix L: Coded transcripts examples

... yesterday about dementia actually and it was the first part of Barbara's story, which I had seen it before, it's interesting because you look at it through her eyes. She has to come into hospital for an appointment and it does make you think, (well we all do that, we all rush round, we don't give eye contact, we all stick our heads down, you know, and it was quite, yeah, an eye opener to see how they look at it.

**Interviewer** - So, what did it make you think?

**Dani**- It made all of us really, it made me think we should all be aware of what we're doing or not doing and that we should do less of this, rush, rush, rush, I know were thinking of different things but maybe we should all pay more attention and think you know I'll look up a bit more and be a bit more observant and you know, so...

**Interviewer** - If you were more observant, what do you think would the ward be like?

**Dani**- I don't think it would make a difference to be fair, um, I think, I don't know, um. I suppose it would be difficult really, I think if we was all a little bit more aware and didn't let our job role consume us as much as we do, um maybe we could make it a lighter atmosphere, we could interact more with patients, they could feel more comfortable, um, maybe we could reassure them more and take away their fear factor, I don't know how much it would work, but it would work because I don't know how much affect it would have on a place like this. On a ward, which is more controlled it would be brilliant it would have a better response, but something like on here, maybe not, but if it did it might for like 10-15 minutes that you had spare to do that, but I don't know, but I think we should all be a little bit more aware. You know, it's a frightening thing to think that you

**Comment [rH44]:** How dem pat perceive the staff from the staffs point of view

**Comment [rH45]:** Training video, made an impact because it puts you in their shoes

**Comment [rH46]:** Time constraints, lack of personal contact. Everyone acts in the same way

**Comment [rH47]:** Need to be more aware of what you are doing. Time pressures

**Comment [rH48]:** Making more of an effort to be present with patients

**Comment [rH49]:** Contradiction that this wouldn't make a difference

**Comment [rH50]:** The role of the job is different to the job values


**Comment [rH51]:** How to help people with dementia in hospital

**Comment [rH52]:** Unsure, going back and forth as to whether being more aware would make a difference

**Comment [rH53]:** The comparisons between wards and AMU

**Comment [rH54]:** Time constraints

4





Interviewer- How does it mentally affect you

Briony- Mentally draining I think. I think sometimes are worse than others, it depends on the patient you have. Obviously when I was first looking after that guy that I talked about. That was mentally horrific, but other days, I looked after a man the other day, I was on night shift and he was just lovely. Absolutely lovely, and he had a catheter and he pulled it out the previous night, so they put him another one in and he liked to wander around, so obviously I was wandering around with him, and he was just like so sweet, he was quite good on his feet obviously, but they just didn't want him to pull out his catheter because that would do some damage. So I was trying to link his arm and he was like, no no no, because he just liked to hold my arm and then walk around till about 12:00 when he felt exhausted. And it was lovely you know it was so pleasant. But then he could switch too, to be quite aggressive. But with me, but with another lady he was quite aggressive towards her, he hit her and what not, but with me he was just pleasant, really pleasant. I forgot what we were talking about. So, yeah, with him it was like a rewarding factor, how he was with you and how you made a difference with walking around, because he was obviously enjoying it. If he was just sat down in his room and I was telling him you can't get out, you can't get out, he would just be getting more frustrated and it would be me that he hit.

Interviewer- So why do you think you had a good experience with him and someone else didn't

Briony- I can be quite soft toned; I can like talk an ear off anybody I can. So, me, and not saying no one else is, but I'm quite calm and I'm quite talk to them calmly, um. Talk them down; talk them down into calmness, or just yeah. I think everybody's different how they react to things. But I'm quite loving, as my nana calls me, the loving one of the family. So, uh.

Interviewer- So does that come across at work then? I

Comment [rH105]: Effect on your mental state

Comment [rH106]: Positive experience of working with dementia, this isn't as mentally draining on you

Comment [rH107]: Speaking and being kind to her, so enjoyed being with him

Comment [rH108]: But with me, different with her than others

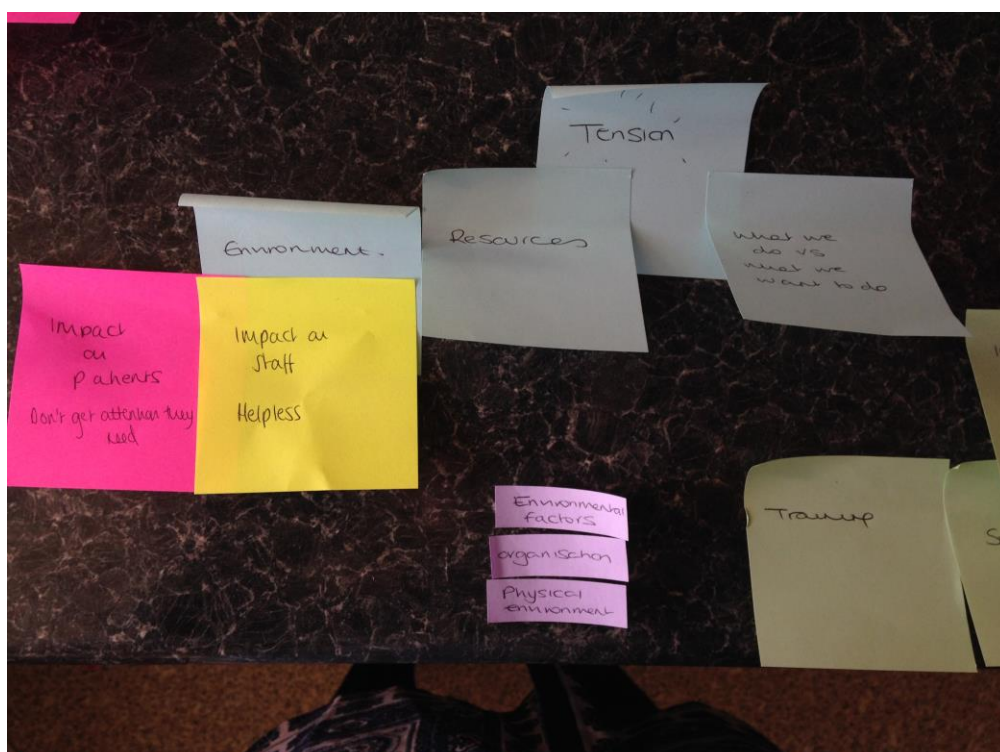
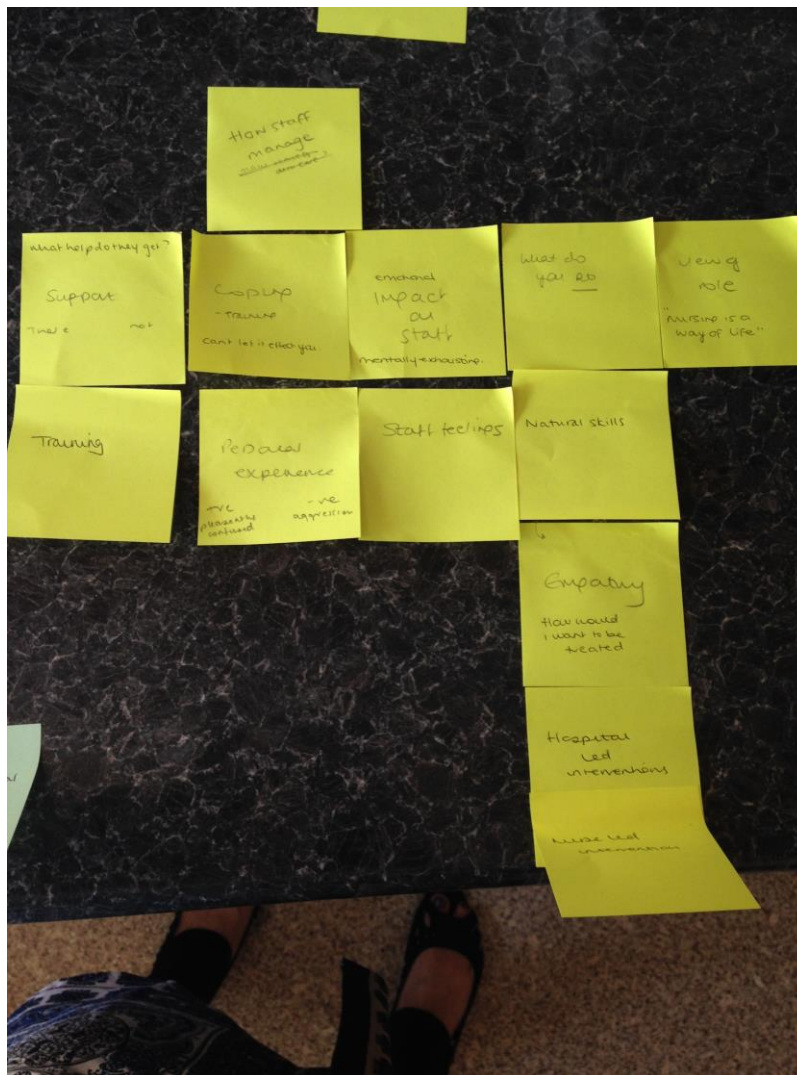
Comment [rH109]: Because he could be aggressive, when he wasn't with her it was rewarding

Comment [rH110]: Reasons for aggression in dementia, not being able to do what they want to

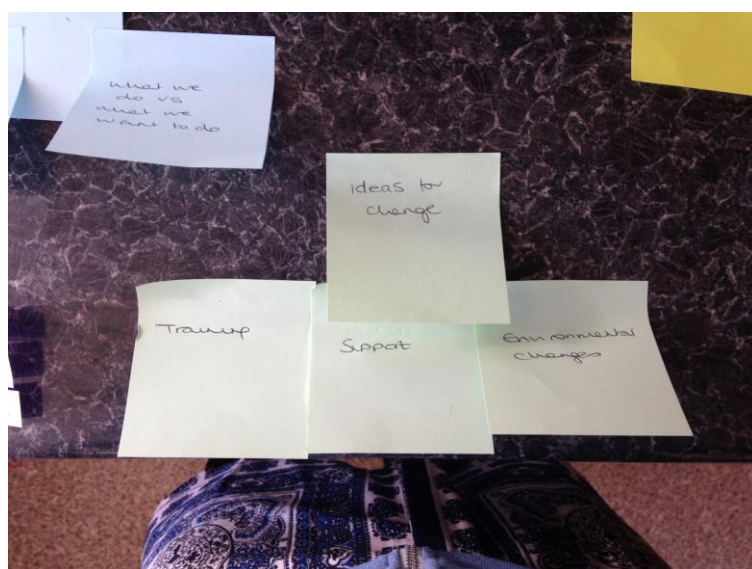
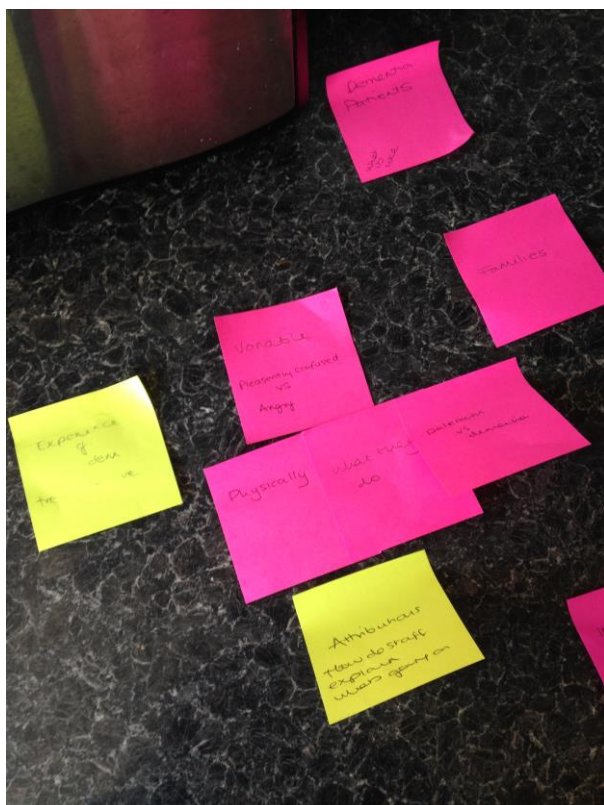
Comment [rH111]: Good ways to be with people with dementia, calm, talk them down

Comment [rH112]: Loving as a personality trait makes it better to work with people with dementia

## Appendix M : example of theme mapping







## Appendix N: Example of categorising quotes to themes

W26		e pg 4: it's a staffing issue . Most of the time there's not enough of us to be able to walk with		Alignment	Number
L	M	N	O	P	
Training- had/would like	Experience- family/other ho	Negative experience	positive experience	Interventions	
A pg 11: I think from the trus	A pg 5: I think oh, from my pe	B pg 4: Ive had some bad	A pg 3: If a patient wants to	A pg 14: Um, very ve	
A pg 11-12: Yes, it's called so	A pg 19: I again, going back to	B pg 5: when I had starte	A pg 3: people bring in thir	B pg 1: obviously you	
A pg 12: it's actually quite in	B pg 1: my grandma had dem	B pg 11-12: when I first st	A pg 6: I don't think our pa	B pg 2: she keeps calli	
A pg 12: probably in about 2	B pg 3: Say if my nan was all s	c pg 4: sometimes with d	B pg 8: I find it interesting ,	B pg 4: obviously if you	
A pg 12: OK, so everyone he	B pg 14: my nan was her care	c pg 6: Yeah its mainly ag	B pg 13: Mentally draining	B pg 4-5: But it's all cha	
A pg 13: its exactly the same	d pg 1: I suppose the entire t	d pg 3: it's not just here i	B pg 14: ( when you have g	B pg 6: you will get son	
A pg 14: , the Barbara story	d pg 2: have a mentally disab	d pg 3: We have a patien	C pg 3: - A good one, where	B pg 7: Obviously you h	
B pg 1: We have um, we havi	d pg 4-5: You know, it's a frig	d pg 6: don't know mayb	c pg 10: -You want to be ab	B pg 8: you just got to k	
B pg 1-2: sometimes if your	e pg 1: Until my dad was diag	d pg 12: if I was to be hor	d pg 6: it's like today beca	B pg 10: - You just got t	
B pg 17: do think a lot of peo	e pg 1: Well it would be abou	e pg 3-4: A little old man	e pg 16: at first when I first	B pg 13: - I can be quite c	
C pg 1: really they've just bo	e pg 10: Probably the later st	g pg 3-4: One that stands	g pg 14: It's hard, it really i	B pg 14: You cant sit the c	
d pg 1: No. (we dont have are	e pg 12: I know, perhaps it's l	g pg 14: It's hard, it really h	g pg 5: a gentleman and an	C pg 3: we just try and l	
d pg 1: , not as in training tra	g pg 1: It was good, it was go	h pg 9: h pg 9: So this is a	h pg 7: (do you look back a	c pg 3: our A grades wh	
d pg 1-2: , I think a lot of the	g pg 12: I can ring, we can, there's loads of staff that w	h pg 8: : I think it's the hist	c pg 4: We just have to	d pg	
d pg 4: I went on a study day	j pg 12: . I think because whe	l pg 9: Yeah quite, quite often. A few weeks ago I ha	c pg 4: Sometimes they d	pg	
e pg 1: I don't think a lot of t	j pg 12-13: I'm lucky no one i	d pg 3: A lot of the time, I know it's going to sound r	c pg 6: if they come in f	d pg	
e pg 2: : I probably have don	j pg 13: Yeah, definitely. I think they do, I'm sure they do because, if just somebo	c pg 7: I try to like, kee	e pg 5:		



## **Appendix O: Alternative quotes for themes**

### **Theme: Experience with Patients**

#### **Subtheme: Dementia comes in different forms**

##### **Micro theme: Pleasant or aggressive**

“I would think that there’s potential, like quite a lot potential for things to go wrong because they’re unpredictable, patients with dementia, you never know what sort of dementia they’ve got, how they’re going to be with it, whether they’re going to be trying to get up, some came be aggressive, so it’s just, I’d know straight away that I’d have to keep more of an eye on them because they’ll be a bit, there’ll be falls risk so I would not want them to be falling out of bed or getting up on their own and falling and hitting their head or some of them may then be assisted feeds with that, might take extra time to take their tablets or might not want to take their tablets. Quite often if you have, if you get handed over a patient with dementia you know automatically that some part of the care that you need to give them will take extra time than others may.” Ivy, nurse, HS1

#### **Subtheme: People that stay in your head**

##### **Micro theme: Pleasantly confused**

“I met a man who was on D-Day landings. He was lovely, pleasant, that was a couple of years ago, I was a student and he was such a proud man but it’s lovely” Helen, nurse, HS1.

#### **Subtheme: Making sense of patients behaviour**

##### **Micro theme: They don’t know what’s going on**

“They don’t know what they’re doing...Somebody young who’s aggressive, we, we shouldn’t have to stand for that at all. It’s our job, there’s notices around saying aggression is not to be tolerated. I probably, if they were, if they became aggressive and were shouting I’d refuse to speak to them till they calmed down, make them go outside, make them go away and we just would not care for them

in that situation if there was no reason for it and they're just being horrible. But an elderly person with dementia who's aggressive, it's not their fault, we still have a duty to care for them, we can't tell them just to shut up and go away so we will, we have to, we have to treat them differently and try and make sure that they're safe and do everything we can for them while they're here" Joy, nurse, HS1.

**Theme: Impact on Staff**

**Subtheme: Nursing is a way of life**

**Micro theme: Treat others how you want to be treated**

"It's not just a job, it's a caring job basically and, the way I view nursing, if my mum and dad, if my mum was in hospital then I'd want her to be looked after and I think that's how you view to do it and you do your upmost aaand sometimes you just can't do enough really" Farah, nurse, HS1.

**Theme: Impact of caring**

**Subtheme: Mentally drained and frustrated**

"That can be quite stressful, yeah. Cos if you're here for the long day- the twelve hour shift and you've got to sit with them for the twelve hours, then yeah. By the end of the day you'll be like (laughs) you'll be like oh god I wanna go home (laughs). So yeah, it can be quite hard, mmm... It's quite mentally draining I think" Ria, HCA, HS2.

"I think your attitude and your voice might change... For the worse, not as in like a nasty way, but you know when you keep repeating yourself and repeating repeating yourself to the point where you're just like, I told you five minutes ago... bit worn out, a bit worn out of having to say the same thing" Briony, HCA, HS1.

**Theme: Tension**

**Subtheme: What AMU is like for patients with dementia?**

**Micro theme: It's not the right environment**

“I hope someone thinks the way I do because I don’t want to be shoved in a room and left saying, ah she’s got dementia, just keep her in there because you don’t know what she’s going to be like” Ellie, HCA, HS1.

**Micro theme: Too many patients too little time**

“So it’s hard to keep up with the pace of the turnover which is what’s expected from AMU and have the same, obviously acuity of the patients with dementia...So you still have a quick turn over of patients for say, like you have three people in your bay but you’ve got two people who have dementia who could need, you know, feeding. Who need prompting to drink. So even really simple things like that is hard work when you’ve still got the turnover of patients and there’s just you kind of thing... I don’t think they have the care they need and they deserve... I think that’s what they suffer with more, probably” Sarah, nurse, HS2.

“You can only give so much of your time until you’ve got to go somewhere else, or you know, you’ve, you’ve got emergencies” Queenie, HCA, HS2.

## **\*Appendix P: Chronology of research process**

<b>Date</b>	<b>Research activity</b>
December 2013-May 2014	Development of research ideas
May 2014	Submission of research proposal for internal review
June 2014- January 2015	Internal peer review obtained (month)  Further refinement of research protocol and development of methodology  Ethic paperwork for university and R&D completed
February 2015	Approval obtained from R&D  Site access approval obtained and letters of access granted
June 2015- February 2015	Interviews carried out and transcription of interviews completed
December 2015-March 2016	Analysis
January 2016- April 2016	Write up period
May 2016	Thesis submitted
May 2016- July 2016	Preparation for viva
July 2016- September 2016	Preparation of manuscript for publication  Dissemination of research  Trainee research conference