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HOW DO INPATIENT PSYCHIATRIC NURSES MAKE SENSE OF AND RESPOND TO BEHAVIOURS IN DEMENTIA?

Vidya Fatania

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THESIS ABSTRACT

Introduction: Existing literature suggests that the perceived understanding nurses have of behaviours in dementia can influence how they respond to persons with dementia (PsWD) (Todd & Watts, 2005; Eriksson & Saveman, 2002; Dupuis, 2012). Their responses can be influenced by a range of factors, such as organisational pressures (Stacey et al., 2010) and staff burnout (Edvardsson et al., 2008). However, this is likely to have an impact on PsWD's quality of life and sense of self (Kitwood, 1997). Absent from literature is the psychological process nurses go through to make sense of and respond to behaviours that could help to provide comprehensive knowledge of the complexities involved. Furthermore, there are very few research studies looking at nurses' experiences in inpatient dementia care, where the environment is very different to a long-term care setting.

Aim: To explore how inpatient psychiatric nurses make sense of and respond to behaviours in dementia.

Design: A qualitative methodological design was used.

Method: Eight inpatient psychiatric nurses were recruited from two National Health Service (NHS) sites across one Trust. Semi structured interviews were conducted, transcribed and then analysed using Interpretative Phenomenological Analysis (Smith et al., 2009). Quality was assessed using criteria specifically developed for IPA (Smith, 2011). A reflective diary was kept throughout the research process, which included examples of reflexivity.

Results: Four interrelated superordinate themes were identified, with no one theme taking primacy over another. These four themes were: 'Effort to sense make', (which consisted of three subthemes: Trial and error, Drawing on existing knowledge and "Putting myself in his shoes"), 'Pressures of the organisation', 'Balancing personal and professional selves: The underlying emotional connection' and '"Looking back on it…"'.

Discussion: This study adds to the current research base by identifying that sense making is a dynamic process, which occurs through a range of psychological processes. It can change moment-by-moment, dependent on the influences on the nurse, such as environmental pressures and the personal and professional negotiations that occur. When sense making was psychologically and socially informed, the corresponding response resulted in less overall distress for PsWD. The study further adds to existing research through identifying an emotional connection with the patient, which can either be conscious or unconscious. Those that demonstrated a conscious empathic emotional connection appeared to be the ones that were more likely to want to reconnect with patients, following a need to disconnect in-line with professional duties. The study findings are

important from a research and clinical point of view, as nurses need to be supported to move flexibly through a range of emotional connections. Furthermore, a managerial approach that promotes reflective space and supervision is likely to increase psychologically informed sense making, which is specifically important given the positive impact this has on both staff and PsWD's wellbeing.

STATEMENT OF CONTRIBUTION

I, Vidya Fatania, declare that this thesis is the product of my own original work, which I have carried out whilst enrolled on the Trent Doctorate in Clinical Psychology since 2013. I was responsible for obtaining ethical approval, the recruitment of participants, data collection and analysis for the study. I have received regular input and supervision from my research supervisors, Dr. Anna Tickle and Dr. Danielle De Boos. As well as guidance and supervision from my field supervisor Dr. David Connelly and supervision from Dr. Rachel Sabin Farrell during a period of time my research supervisors were absent.

SYSTEMATIC LITERATURE REVIEW

Dementia: The international journal of social research and practice

Staff experiences of caring for persons with dementia: A systematic literature review

Vidya Fatania
School of Medicine, University of Nottingham, United Kingdom

Anna Tickle
School of Medicine, University of Nottingham, United Kingdom

Danielle de Boos
School of Medicine, University of Nottingham, United Kingdom

Corresponding author
Vidya Fatania, University of Nottingham, Jubilee Campus, Wollaton Road, Nottingham, NG8 1BB
Email: lwxvf@nottingham.ac.uk
Telephone number: 0115 846 6646

Abstract
This paper reviews literature on the experiences of staff caring for persons with dementia. 13 articles were included from various countries, looking at staff experiences of caring for persons with dementia. All 13 studies used a qualitative design. The review identified five themes across the 13 studies. These included Impact of organisational culture on nursing care; Emotional experience, staff struggles and management strategies; Relationship building; Understanding and approach to symptoms of dementia; Importance of staff support. Methodological limitations of the research literature studies are highlighted as well as limitations of the review. Implications for clinical practice and future research are also discussed.

Keywords
Caring, dementia, experience, qualitative, staff

Introduction

Dementia is defined by The National Institute for Health and Clinical Excellence ([NICE], 2012, page 4) as "a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function". As the condition progresses, persons with dementia (PwD) can experience progressive decline in some or all of the following: memory, communication (Department of Health [DoH], 2009; NICE, 2012), loss of self and identity and out-of-character behaviour (for example, aggression, wandering or disinhibited sexual behaviour) (DoH, 2009; NICE, 2012). These symptoms can result in increased levels of confusion causing PwD to become less familiar with their surroundings, which can leave them feeling frightened and scared (Hinton & Levkoff, 1999; Hammer, Emami, Engstrom & Gotell, 2010) further reiterating the vulnerability of this population (NICE/Social Care Institute of Excellence [NICE/SCIE], 2007). Given the nature of dementia and the increasing elderly population, dementia is a global "public health priority," with a projected 85% proportionate increase in prevalence worldwide, from 2010 to 2030, among people aged 60 years and older (Alzheimer Disease International & World Health Organization [ADI & WHO], 2012, p. 18; Prince et al, 2013). The demands that caring for PwD have on health care systems are increasing significantly and as a knock on effect this impacts hugely on health care professionals who provide care for PwD.

The role of staff

Staff caring for PwD need the capacity to adapt rapidly, assess and meet complex needs, handle ethical dilemmas, co-ordinate care and communicate sensitively and effectively with not only PwD but also their families, the broader team and other agencies (Teel & Carson, 2003; Toot et al, 2013; Wackerbarth, 1999). Staff also have a role in promoting and maintaining the independence, including mobility of PwD (NICE, 2012), and encouraging care which enable PwD to go at their own pace and increase participation in activities they enjoy.

Kitwood (1997) proposed the notion of personhood or person-centeredness as an approach to care when working with PwD. This approach reinforces person-centred care as moving away from a medical, task orientated approach to

holistic, personalised care which focusses on the individual (Edvardsson, Winblad & Sandman, 2008; McCormack, Karlsson, Dewing & Lerdal, 2010). This would involve staff promoting shared decision making, prioritisation of the relationship with PwD, and valuing and respecting their rights, dignity, and self-worth as part of their everyday role (Edvardsson et al, 2008; Kitwood, 1997; McCormack et al, 2010). With the development of this approach there was also a shift towards a broader relationship-centred focus in recognising the importance of relationships with the family of PwD (Nolan, Davies, Brown, Keady & Nolan, 2004) as they best know the PwD.

Although staff working with PwD clearly have a great amount of responsibility and globally are prepared to a high standard to provide effective and safe, person centred care; international research suggests that staff are insufficiently prepared and that they face many challenges in providing the high standards of care outlined (Hsu, Moyle, Creedy & Venturato, 2005; Robinson & Cubit, 2007; Chang et al, 2009; Baillie, Cox & Merritt, 2012a; Ryan, Gardiner, Bellamy, Gott, & Ingleton, 2012). These challenges are related to the presentation of PwD and the organisational culture of the 'system'.

Challenges in care – PwD presentation

Research highlights the difficulties staff experience in caring for PwD in relation to the management of the behaviours and symptoms associated with dementia. Due to difficulty in communication with PwD, staff experience difficulty in understanding the individuals core needs (Holst, Edberg, & Hallberg, 1999), which can result in staff distress and the needs of PwD not being effectively met (Rodney 2000; Skovdahl, Kihlgren & Kihlgren, 2003). This can lead to ethical dilemmas for staff whereby they have to face situations they feel uncomfortable with i.e. forcing themselves on PwD if it compromises their safety. As a result staff feel as though they are violating the individual's integrity (Eriksson & Saveman, 2002).

These challenges that nurses face in relation to PwD behaviour are likely to impact on their approach within their role as a carer i.e. rushing jobs and not giving verbal prompts whilst carrying out a personal activity, which are important to acknowledge as they impact on the PwD. This impact has been found to be through triggering out of character behaviour i.e. aggression and further confusion (Hellzen, Kristiansen, & Norbergh, 2004; Duxbury, 2002; Somboontanont et al., 2004; Skovdahl et al, 2003) which further impacts on PwD quality of life and their sense of self and identity (Hellzen, Asplund, Sandman & Norberg, 1999).

Referring back to Kitwood's concept of 'personhood', Kitwood (1997) reinforces that in dementia, aspects of self are not only preserved through memory but also can be sustained through relationships with others. Supporting this, Harris and Sterin (1999) (proposal) identified three core values that comprise the sense of self of PwD: the need to be meaningfully productive, the need to be independent, and the need for comfort and security. However although nurses strive to meet these core values, other challenges tend to prevent them from fulfilling these values such as organisational pressures.

Challenges in care – organisational pressures

Staff caring for PwD are faced with a range of challenges which appear to centre on balancing organisational pressures and the care of PwD. Research has found that staff feel restricted in the care they provide due to limited resources and activities (Baillie et al 2012a). The physical environment also provides problems for staff due to concerns of safety i.e. with open doors and stairs etc., which result in staff needing to be more restrictive with PwD in case they wander (Edberg et al, 2008). This impacts on the PwD independence and gives rise to uncomfortable feelings for staff for having to go against the PwD's will if safety is compromised (Edberg et al, 2008). This provides one example of the ongoing ethical dilemmas that staff are faced with. A decision making model has been developed to help staff working with PwD in this process by Bolmsjo, Edberg and Sandman (2006). However to the authors' knowledge there is no research into the efficacy of this model for staff who care PwD.

Staff often have to work according to routines rather than PwD needs due to time constraints (Ekman, Norberg, Viitanen, & Winblad, 1991). This can often result in the neglect of PwD who have difficulty expressing themselves as it would take too long to interpret body language (Byrne & Heyman, 1997). This can lead to moral stress (Lutzen, Cronqvist, Magnusson & Andersson, 2003) and powerlessness (Watts & Davies 2014), whereby staff believe they have limited control over situations to other pressures such as management factors, lack of support from other staff, inadequate trained for the job, service cutbacks, and lack of support from families (Dunn, Rout, Carson & Ritter, 1994; ADI & WHO, 2012; Watts and Davies 2014; Skovdahl et al, 2003).

The above highlights that organisational aspects are important to consider especially in relation to the emotional impact they have staff and their wellbeing.

Emotional impact and strain

The emotional impact on staff as well as the strain they experience when working with PwD has emerged consistently in literature related to dementia care. Research indicates that staff strain and burnout can be caused by the behaviours related to dementia (Evers, Tomic & Brouwers, 2002; Rodney, 2000; Coen, O'Boyle, Coakley & Lawlor, 1999). However, research highlights that the frequency of these behaviours has less effect on staff strain compared to the difficulty the experience in understanding the underlying reasons of the behaviours (Edberg et al, 2008; Hagen & Sayers, 1995).

Caring for individuals with dementia, brings with it a myriad of emotions, both positive and negative. Although staff experience positive emotions in relation to their role of happiness and pride (Baillie, Cox and Merritt, 2012b), these have been less reported in literature. The negative feelings however are referred to a great deal more. These include feelings of powerlessness (Norberg & Asplund, 1990), frustration (Almberg, Grafstroem, & Winblad, 1997), resignation (Hellzen, 2000 as cited in Rasmussen and Hellzen, 2013) and inadequacy (Ekman et al, 1991; Almberg et al, 1997), which are often transferred to the PwD (Athlin & Norberg, 1987).

Research suggests that emotional support to staff working in dementia care is very important in order to maintain a close relationship with PwD and improve

quality of care (Berg & Welander Hansson, 2000). The literature highlights the struggles that staff who care for PwD face and with numerous challenges it becomes difficult to think about the best way to resolve or lessen such challenges. However highlighting the main points of focus would not only impact staff wellbeing but also the quality of life for PwD.

Rationale

With dementia being a global 'public health priority', it is of absolute importance to have optimal service delivery and deliver the best possible care to PwD and their families to improve quality of life of those affected by dementia. However, the literature suggests this is a challenge to accomplish given the struggles that staff are faced with in their job roles as well as insufficient training (Royal College of Psychiatry, [RCP], 2011). Therefore collating a global experience of caring for PwD will aide service delivery in distinguishing what the main challenges are in providing the best possible care and where the focus of change needs to lie. However, the research to date has not yet been collated to provide this information. Given this the following metasynthesis collates original qualitative studies looking at staff experiences of caring for PwD.

Methods

Searching

A comprehensive search was conducted of six databases (PsychINFO, Medline, CINAHL, ASSIA, Embase and EThOS) all without time restrictions applied, to find peer reviewed journals and theses or dissertations. The key search terms used focused on the condition (dementia or Alzheimer), the participants (care$, support$, work$ and nurse), the method/approach (qualitative, interpretative phenomenological analysis, grounded theory, thematic analysis, narrative analysis, discourse or first person) and outcome (experience). Key search terms were used singularly or in conjunction as appropriate to the database.

Inclusion and Exclusion Criteria

The following inclusion criteria were applied:

- Population: Staff caring for PwD, in long term care or community settings. Studies that had other participant groups i.e. family, were also included if staff data was distinguishable. If so, only staff data was used.
- Design: Original research studies using qualitative methodologies to analyse first person accounts by carers were used. Studies that had more than one aim were accepted, however only data corresponding to aims related to staff experiences of caring for PwD were used.
- Study type: both peer reviewed journals and unpublished work were included in the search to obtain a broader account of experiences.
- No time restrictions obtain a broader account of experiences as mentioned above.
- Language – Only articles that were accessible in English were used.

The following exclusion criteria were applied:

- Studies that involved staff experiences but focused on specific concepts, i.e. experience of intramuscular injecting.
- Studies which focused on experiences of staff caring for PwD who also had comorbidities or other illnesses e.g. Down's syndrome, Parkinson's disease etc.
- Studies where raw data/first order constructs were not included.

These criteria were used initially during the search to assess study titles and abstracts and determine whether to retrieve the full article. Following full article retrieval, the criteria were strictly applied again to determine inclusion of the study. These criteria were strictly applied, to obtain a collection of homogenous studies from the literature that exclusively explored the experience of staff caring for PwD. Reference lists of included studies were searched using the same search terms for additional articles. The final search was conducted in June 2014. An overview of the study selection process is outlined in Figure 1.

Data Abstraction

The general characteristics and key themes were abstracted from each included study and are displayed in Table 1. The general characteristics includes Author(s)/year/country, research question, sample characteristics (role i.e. nurse, student etc., sample size, gender and location the sample was obtained from i.e. long term care home, hospital, community etc.), data collection and analysis method. Key themes were abstracted along with supporting raw data (quotations), however only the key themes have been referred to in Table 1, the raw data will be used in the synthesis stage.

Critical Appraisal

Studies that met the inclusion criteria were appraised for methodological quality. As no single standard has been identified for the appraisal of qualitative research this review used the Critical Assessment Skills Program ([CASP], 2006) tool for qualitative research. This tool was used to appraise each study to check for any excludable studies based on quality. The tool consists of 10 questions and each question has a list of considerations to inform the decision making process. The questions could be answered by three possible answers – yes, can't tell and no. This was adapted for the present review by changing 'can't tell' to 'partially', meaning the study partially meets the consideration points. The two initial questions of this tool are screening questions; following critical appraisal all 13 studies were included in the review on the basis that they had an answer of yes for the screening questions. Table 2 displays the methodological appraisal of each study using the CASP. Each question from the CASP has been summarised to form a heading for Table 2. However, the full questions along with the considerations can be viewed in Appendix l.

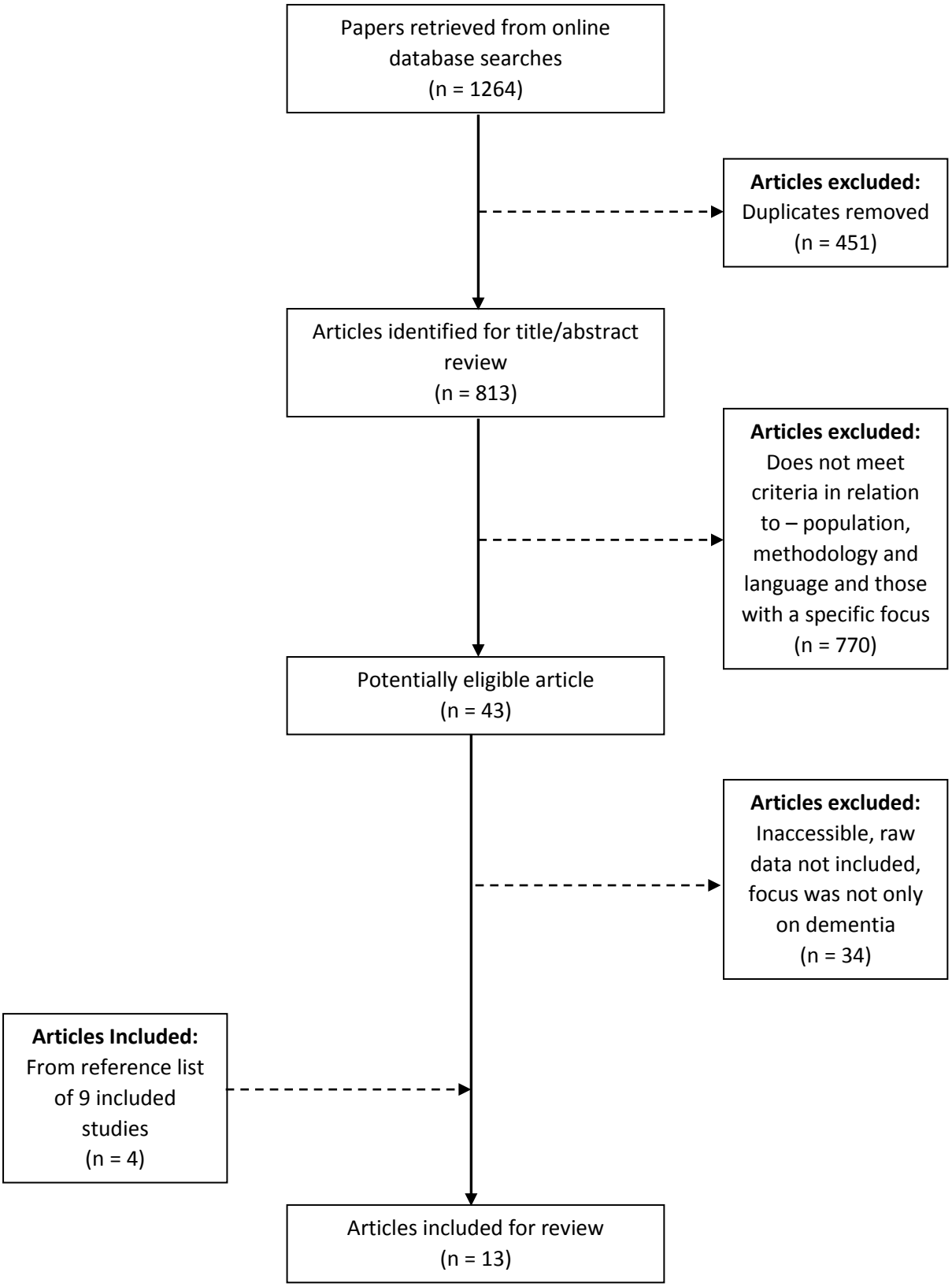


Figure 1. Quorum diagram outlining the selection process

Table 1. General characteristics of included studies

Author(s) (year), Country	Research Question	Sample Characteristics	Data collection method and analysis used	Key themes (subthemes)
Baillie,Cox and Merritt (2012a), England	To explore adult nursing students' experiences of caring for older people with dementia in hospital - challenges	**Role:** Nursing students (n = 20), **Gender:** Not stated, **Location:** Inpatient hospital setting	**Data collection:** Focus groups, **Analysis method:** thematically analysed (Patton, 2002)	1) Inappropriateness of the environment (Physical environment, organisational culture); 2) Deficits in knowledge, skills and attitudes of staff and students; 3) The struggle to provide care (nutrition, mobility, emotional needs and communication)
Baillie,Cox and Merritt (2012b), England	To explore adult nursing students' experiences of caring for older people with dementia in hospital - strategies	**Role:** Nursing students (n = 20), **Gender:** Not stated, **Location:** Inpatient hospital setting	**Data collection:** Focus groups, **Analysis method:** thematically analysed (Patton, 2002)	1) Getting to know the person and building a relationship; 2) Involvement of families; 3) Flexible and creative care approaches; 4) Comfort and communication
Beck (1996), America	What is the meaning of nursing students' experiences caring for cognitively impaired elders?	**Role:** Nursing students (n = 37), **Gender:** Not stated, **Location:** Care homes and hospital setting	**Data collection:** obtained written experiences, **Analysis method:** Colaizzi's (1978) phenomenological methodology	1) Nursing students experienced a myriad of emotions while caring for the cognitively impaired elderly people; 2) Caring for cognitively impaired elderly people presented difficult challenges for nursing students to overcome; 3) Because of the difficulties encountered in caring for cognitively impaired elderly people, nursing students utilised multiple nursing care approaches; 4)As a result of providing nursing care to cognitively impaired elderly people, negative consequences ensued for some nursing students: 5) The positive consequences that occurred in nursing students as a result of their providing nursing care to cognitively impaired elderly people far outweighed the negative consequences
DeWitt and Ploeg (2014), Canada	The purpose of this study was to describe health care professionals' experiences when caring for older people living alone with dementia.	**Role:** Healthcare professionals (n = 15), **Gender:** F-13, M-2 **Location:** community - client home	**Data collection:** semi structured interviews, **Analysis method: C**ontent analysis (Hsieh & Shannon, 2005).	1) Doing the best we can for them (Gentle realism, walking the tight rope, my hands are tied, it's my job it's not my decision, emotional struggle, believing I did the right thing)

Table 1. Continued

Author(s) (year), Country	Research Question	Sample Characteristics	Data collection method and analysis used	Key themes (subthemes)
Edberg and Edfors (2008), Sweden	To describe nurses' experiences of the difficulties and the possibilities in nursing people with dementia disease	**Role:** Nurses (n = 10), **Gender:** F-9, M-1 **Location:** Inpatient unit	**Data collection:** open interview - describe their experiences, **Analysis method:** qualitative latent analysis (Graneheim and Lundman, 2004) and manifest content analysis (Berg, 2001)	1) Difficulties relating to the behaviour (When inhibition and judgement fail, When anxiety is prevalent, When anger is out of control, When the ability to cope with physical needs is reduced, When the ego takes centre stage, Then dejection becomes uncontrollable; 2) Possibilities in nursing care (Being clear and consistent, being a step ahead, being flexible and seizing the moment, being close and building trust, being and doing things together, receiving continuous feedback and support
Edberg et al (2008), UK, Sweden, Australia	The aim of the study was to explore the experience of strain amongst nursing staff caring for people with dementia.	**Role:** nurses, social care workers and nurses aids (n = 35), **Gender:** not stated **Location:** care homes and hospital setting	**Data collection:** focus groups **Analysis method:** qualitative latent and manifest content analysis (Berg, 2001)	1)A desire to do the best for the residents to alleviate their suffering and enhance their quality of life (Experience of strain related to environmental factors, Experience of strain in relation to caring for people with dementia - Being unable to reach; Trying to protect; How to balance competing needs)
Eriksson and Saveman (2002), Sweden	The aim of the study was to describe nurses' experiences of difficulties related to caring for patients with dementia in acute care settings	**Role:** nurses (n = 12), **Gender:** F- 12 **Location:** acute inpatient hospital setting	**Data collection:** semi structured interview **Analysis method:** thematic content analyses	1) Ethically difficult situations, which can lead to abuse; 2)Difficulties related to disorderly conduct among patients with dementia; 3) Difficulties related to the organization of acute care as an obstacle to good nursing care of dementia patients
Nolan (2006), Ireland	The aim of this study was to illuminate nurses' experiences of caring for older persons with dementia in an acute hospital setting	**Role:** nurses (n = 7), **Gender:** F- 7 **Location:** acute inpatient hospital setting	**Data collection:** In-depth, non-directive conversational interviews **Analysis method:** thematic content analyses (Cohen et al, 2000)	1) Meeting the person as a person (Caring as an ethical way of being, Embracing each other – bonding, Working with relatives/carers in this process,

Table 1. Continued

Author(s) (year), Country	Research Question	Sample Characteristics	Data collection method and analysis used	Key themes (subthemes)
Nolan (2007), Ireland	The aim of this study was to explore nurses' experiences of caring for older people with dementia in an acute hospital setting.	**Role:** nurses (n = 7), **Gender:** F- 7 **Location:** acute inpatient hospital setting	**Data collection:** In-depth, non-directive conversational interviews **Analysis method:** thematic content analyses (Cohen et al, 2000)	1) Acute context as an environment for care (The reality of caring, Caring for people with dementia who are agitated or aggressive differs from caring for people with dementia who are not agitated or aggressive, The meaning of caring)
Rasmussen and Hellzen (2013), Norway	The aim of this study was to illuminate the meaning of caring for patients with FLD as experienced by health staff in a Norwegian nursing home.	**Role:** nurse, social educator, licensed practical nurse and social worker (n = 10), **Gender:** Not stated **Location:** nursing home	**Data collection:** narrative interviews **Analysis method:** phenomenological hermeneutic approach (Ricoeur, 2008)	1) Being aware of the relationship with the patients; 2) Being Insecure; 3) Being Safe
Robinson and Cubit (2007), Australia	The aim was to understand better students' experiences of providing care to people with dementia within these settings.	**Role:** nursing students and mentors (n = 37), **Gender:** Not stated **Location:** care home and hospital setting	**Data collection:** focus groups **Analysis method:** thematic analysis	1) nurse mentor's familiarity with dementia; 2) communication problems
Train et al (2005), England	To explore the positive and negative aspects of the experience of family carers, staff and people with dementia living in 24-hour long-term care settings and examined whether this varies between the different settings (hospital, nursing home, social care home)	**Role:** care assistants, nurses, manager (n = 30), **Gender:** Not stated **Location:** long term care setting	**Data collection:** semi structured interviews **Analysis method:** thematic analysis	1) Privacy, dignity and choice; 2) Relationships in the care settings complaints and protection; 3) Activities; 4) The physical environment; 5) The expectations of a care environment by family and professional carers, should they one day live in long-term care themselves

Table 1. Continued

Author(s) (year), Country	Research Question	Sample Characteristics	Data collection method and analysis used	Key themes (subthemes)
Watts and Davies (2014), Wales	The study sought to obtain in-depth insight into and understand final year pre-registration nursing undergraduates' (adult field) experiences of caring for people affected by advanced dementia so as to inform curriculum development and implementation.	**Role:** nursing students (n = 11), **Gender:** F - 11 **Location:** care homes and inpatient hospital settings	**Data collection:** in-depth one to one interviews **Analysis method:** thematic analysis (Green and Thorogood, 2004)	1) They can be quite challenging; 2) Dementia Patients are Seen as Hazards; 3) It's not all about doing stuff

Table 2. Methodological appraisal of included studies using CASP (2006)

	1. Aims	2. Qualitative method appropriacy	3. Research design	4. Recruitment strategy?	5. Data collection	6. Reflexivity in method	7. Ethical issues	8. Rigour and reflexivity in analysis	9. Findings	10. Discussion and conclusions
Baillie, Cox and Merritt 2012 C	Yes	Yes	Yes	Partially	Yes	No	Yes	Partially	Partially	Yes
Baillie, Cox and Merritt 2012 S	Yes	Yes	Yes	Partially	Yes	No	Yes	Partially	Partially	Yes
Beck 1996	Yes	Yes	Yes	Partially	Partially	Yes	Partially	Yes	Yes	Yes
De Witt and Ploeg 2014	Yes	Yes	Yes	Yes	Yes	Partially	Partially	Yes	Yes	Yes
Edberg and Edfors 2008	Yes	Yes	Yes	Partially	Yes	Partially	Yes	Yes	Yes	Partially
Edberg et al 2008	Yes	Yes	Yes	Partially	Yes	Yes	Partially	No	Yes	Yes
Eriksson and Saveman 2002	Yes	Yes	Yes	Yes	Yes	No	Yes	Partially	Yes	Partially
Nolan 2006	Yes	Yes	Partially	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Nolan 2007	Yes	Yes	Partially	Partially	Partially	Partially	No	No	Partially	No
Rasmussen and Hellzen 2013	Yes	Yes	Yes	Partially	Yes	Yes	Yes	Yes	Yes	Yes
Robinson and Cubit 2007	Yes	Yes	Partially	Yes	Yes	Partially	Yes	Partially	Partially	Yes
Train et al 2005	Yes	Yes	Yes	Yes	Partially	Yes	Partially	Partially	Partially	Yes
Watts and Davies 2014	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

Results

The 13 studies used as part of this review (Table 1) had a total sample size of 214. Any two studies using the same sample (Baillie et al, 2012a; 2012b) or query of the same sample being used was counted once in the total. There was query as to whether Edberg et al (2008) and Edberg and Edfors (2008) used the same Swedish sample and whether the same sample was used for the studies by Nolan (2006; 2007), however, this could not be confirmed as there was no return correspondence from authors when attempts were made. The total female to male (F:M) ratio of the studies that stated the gender of the sample was 52:3 (DeWitt & Ploeg, 2014; Edberg & Edfors, 2008; Eriksson & Saveman, 2002; Nolan, 2006; Nolan, 2007; Watts & Davies, 2014). The epistemological position and sample ethnicity position was not stated or discussed for any of the.

Methodological Quality

Methodological quality was assessed using the CASP (2006) tool. In relation to the 'research design', 'recruitment strategy' and 'data collection', two studies fully met the considerations outlined (Appendix l) (DeWitt & Ploeg, 2014; Watts & Davies, 2014). The limitations mostly appeared to be in relation to 'recruitment strategy', whereby studies failed to explain and provide discussion around their recruitment strategy (Baillie et al, 2012a; 2012b; Beck, 1996; Edberg & Edfors, 2008; Edberg et al, 2008; Nolan, 2007; Rasmussen & Hellzen, 2013).

Minimal reflexivity (the degree to which researchers take into account their own role and biases and reflect upon how these impact the research process and findings) was demonstrated in the formulation of the research questions and data collection with four studies failing to make any reference to it (Baillie et al, 2012a; 2012b; Eriksson & Saveman, 2002; Watts & Davies 2014). Those that demonstrated reflexivity in these parts (Beck, 1996; Edberg et al, 2008; Nolan, 2006; Rasmussen & Hellzen, 2013; Train et al, 2005) did this through transparency of their views and biases throughout the process.

Rigour (the thoroughness of processes whilst conducting the study) and reflexivity within the analysis stage were present in all but two of the studies (Edberg et al 2008; Nolan, 2007). Those that demonstrated both gave thorough accounts of how they conducted the study and analysis including a reference for the analysis and thorough consideration of reflexivity (Beck, 1996, DeWitt & Ploeg, 2014; Edberg & Edfors, 2008; Nolan, 2006; Rasmussen & Hellzen, 2013; Watts & Davies, 2014). Some studies failed to provide enough detail by not taking into account reflexivity and failing to describe the analysis process (Baillie et al, 2012a; 2012b; Eriksson & Saveman, 2002; Robinson & Cubit, 2007; Train et al, 2005).

Ethical issues were taken into consideration to some degree in all the studies, however, some provided more detail. Those rated a no were studies that only referred to informed consent but failed to mention any other aspects (Beck, 1996; DeWitt & Ploeg, 2014; Nolan, 2007). The findings were adequately discussed in all studies, however, some studies provided minimal raw data and failed to discuss the credibility (the trustworthiness of the findings through e.g. triangulation, respondent validation or using more than one analyst) of the

findings (Baillie et al, 2012a; 2012b; Nolan, 2007; Robinson & Cubit, 2007; Train et al, 2005). Only one study failed to discuss the findings and draw conclusions from the study (Nolan; 2007). This was also the only study that demonstrated consistent limitations in all areas of CASP (2006) minus the screening questions.

Key Findings

Five themes emerged from the synthesis of the data: Impact of organisational culture on nursing care; Emotional experience, staff struggles and management strategies; Relationship building; Understanding and approach to symptoms of dementia; Importance of staff support.

Theme 1: Impact of organisational culture on nursing care. The organisational culture refers to the responsibilities staff have to the service and the various other aspects of their role apart from caregiving.

Time constraints appear to be the biggest factor negatively impacting on nursing care. There was a general consensus of having limited time to spend with PwD due to other tasks needing to be completed (Baillie et al, 2012a; Edberg et al, 2008; Eriksson & Saveman, 2002; Nolan, 2007; Train et al, 2005; Watts & Davies, 2014). Respect, privacy, dignity and choice all appear to be compromised because of time constraints and a busy environment (Baillie et al, 2012a; Train et al 2005; Eriksson & Saveman, 2002). However, there is a desire to give the respect, privacy and choice to PwD but this is unmanageable with the amount of responsibility staff have and due to limited resources.

The limited resources impact on PwD stimulation and activity. Staff working in long-term care settings described there being a lack of stimulation for PwD (Baillie et al, 2012a; Train et al, 2005; DeWitt & Ploeg, 2014; Watts & Davies 2014). Train et al (2005) described open walking facilities which staff found helpful to stimulate and encourage activity, but staff also viewed activity more broadly than in the other studies "Even if I hold [their] hand and talk to [them] … everything is activity" (Train et al, 2005, p. 123). However this study followed the general consensus that not being able to carry out activities with PwD was not only down to limited resources available but mostly as a result of time constraints (Baillie et al, 2012a; Train et al, 2005; DeWitt & Ploeg, 2014; Watts & Davies 2014).

Theme 2: Emotional experience, staff struggles and management strategies. A range of emotions were experienced by staff in relation to PwD and the symptoms of dementia. Feelings of powerlessness were described across most studies (Baillie et al, 2012a; Beck, 1996; Edberg & Edfors, 2008; Edberg et al, 2008; Eriksson & Saveman, 2002; DeWitt & Ploeg, 2014), especially in relation to the confusion experienced by PwD, the fear the PwD have in relation to that confusion as well as the inability to effectively communicate with PwD to help console them. One staff member from Edberg et al's (2008) study described the feelings not only being present in the moment but the memories attached to those feelings stayed with him.

"And then one day, he waved at me and said, ''Do you know Johannesson?'' and I said, ''No''. He said, ''He was my neighbour'', and I said, ''No, I don't think I

know him''. He said, ''Well do you think you could call him?'' I said, ''Yes, was it anything special?'' And he answered, ''Well you know, he has a dammed good gun, could you phone him and ask if he could come over and shoot me?'' There was, sort of, nothing more to add. It happened about ten years ago, maybe more, but I still remember...'' (Edberg et al, 2008, p. 239)

Staff felt powerless for having to do things despite the fear expressed by PwD (Edberg et al, 2008; Eriksson & Saveman, 2002; Rasmussen & Hellzen, 2013). This made them feel as though they were 'crossing some limits' (Rasmussen & Hellzen, 2013, p.not stated). Although staff described feelings of fear in relation to aggressive behaviour (Beck, 1996; DeWitt & Ploeg, 2014, Rasmussen & Hellzen, 2013), the feeling of guilt experienced by staff for doing something they did not want to was more difficult to deal with (Edberg et al; 2008; Eriksson & Saveman, 2002; DeWitt & Ploeg, 2014; Rasmussen & Hellzen, 2013). Staff also experienced sadness and empathy as they tried to imagine what PwD are going through (Beck et al, 1996; Rasmussen & Hellzen, 2014; Robinson & Cubit, 2007), as well as physical and mental exhaustion (Beck, 1996; DeWitt & Ploeg, 2014; Edberg et al, 2008; Rasmussen & Hellzen, 2014). Two studies described strategies used to manage the negative emotions experienced. These strategies included building resilience, coping using desensitisation and through staff support (DeWitt & Ploeg, 2014; Rasmussen & Hellzen, 2013).

Only one participant described positive feelings in relation to being thankful and having a greater appreciation for life (Beck, 1996).

Theme 3: Relationship building*.* The importance of relationship building with PwD was evident in all the studies. A number of strategies were referred too to facilitate relationship building. Getting to know them to understand them better was regarded as highly important in establishing rapport (Baillie et al, 2012b, DeWitt & Ploeg, 2014; Nolan, 2006; Nolan, 2007; Rasmussen & Hellzen, 2013; Watts & Davies, 2014) to better meet their needs. Staff described various strategies and creative ideas to establish relationships i.e. various communication, understanding body language and doing tasks together (Baillie et al, 2012b; DeWitt & Ploeg, 2014, Edberg et al, 2008; Edberg & Edfors, 2008; Rasmussen & Hellzen, 2013). For example, one student nurse described singing opera with an individual she was caring for while she waited for him outside the shower "He's singing his opera and I'm going, "ooh, ooh", we're doing it together, he was having a lovely time." (Baillie et al, 2012b, p. 24).

Building a relationship through the knowledge and experience of the family was also important, especially when PwD have limited ability to verbally communicate (Nolan, 2006; Baillie et al 2012b; Watts & Davies, 2014). Positive emotions were experienced in relation to building relationships with PwD (Rasmussen & Hellzen, 2013; Baillie et al, 2012b),

Theme 4: Understanding and approach to symptoms of dementia. Nursing students described observing qualified staff as seeing the dementia rather than the person (Baillie et al 2012a; Watts & Davies, 2014) "she would scream out and they would say 'oh no it's just her dementia'" (Watts & Davies, 2014, p. 1151). Only in one study did staff attempt to make sense of the PwD

behaviour, in relation to whether it was the individual or the dementia (Edberg & Edfors, 2008).

However, a number of studies explained how they managed or approached the behaviours ranging from those that were effective to those that were viewed as abusive. Being clear and concise when confronting behaviours staff found challenging appeared to have good effect (Edberg & Edfors, 2008; Nolan, 2007). Staff described becoming desensitised to behaviour or took on a "task-oriented" (Beck, 1996, p. 996) approach, to help them get through the routines of the day (Beck, 1996; Robinson & Cubit, 2007; Edberg & Edfors, 2008; Train et al, 2005). Some strategies used with PwD were useful in the short-term but caused more problems in the long-term (Edberg & Edfors, 2008; Watts & Davies, 2014). "They're just brought back and 'you have to sit there' put back in the chair and then 10 minutes later 'sit back down there' you know it's not the best way is it?" (Watts & Davies, 2014, p. 1152), which was used to be able to get on with other jobs. Only one study described staff observing abusive strategies being used to manage symptoms of dementia (Train et al, 2005).

Theme 5: Importance of staff support. Staff support was found to be important for a variety of reasons which included; dealing with work related stress, reassurance, emotional wellbeing and cohesion (Rasmussen & Hellzen, 2013; Edberg & Edfors, 2008; Eriksson & Saveman, 2002). In addition to this staff support through supervision and feedback was found to be helpful for their roles, whereby staff felt safer having a forum to discuss what they were going through and receive feedback in relation to it. (Rasmussen & Hellzen, 2013; Edberg & Edfors, 2008). The guidance allowed staff to manage the emotional distress that they experience. "Through the guidance we have learned that it's not our fault when patients get aggressive. It is not personal; it is an expression of frustration. I was very grateful for the guidance" (Rasmussen & Hellzen, 2013, p. not stated).

Discussion

Quality Appraisal

The CASP (2006) tool was used to appraise the quality of the studies used for this review. The findings from the quality appraisal suggest improvements need to be made in relation to qualitative research on experiences of staff working with PwD. Improvements need to be made in description around the design, recruitment and data collection of study whereby the detail in these sections was found to be insufficient. A particular improvement needs to be made in terms of discussion of reflexivity throughout the methodology and analysis. The majority of studies failed to provide enough detail with regards to reflexivity making it difficult to assess how researcher bias within the studies was controlled for. This was also the case for the credibility of the research, which would have been beneficial in determining the trustworthiness of the findings. Rigour was one aspect that was present in most of the studies.

Metasynthesis

This review looks at staff experiences of caring for PwD. The findings from the review highlight the complexity of the role of staff who care for PwD. The themes

from this review provide a glimpse into these complexities and particularly capture the impact of time constraints and the impact on staff emotional wellbeing in different aspects of their job role.

The findings highlight the importance of staff approach to the care of PwD. When faced with difficulties especially in relation to behaviour they found challenging they took on a task-focussed approach by tending to the physical needs of PwD (Beck, 1996; Robinson & Cubit, 2007; Edberg & Edfors, 2008; Train et al, 2005). Given that all the studies that reported this apart from one (Beck, 1997) were conducted after Kitwood's (1997) notion of personhood, it was surprising to see minimal change away from a medicalised task-oriented approach to a more holistic one. Although some studies demonstrated that staff built relationships with PwD through getting to know them better (Baillie et al, 2012b, DeWitt & Ploeg, 2014; Nolan, 2006; Nolan, 2007; Rasmussen & Hellzen, 2013; Watts & Davies, 2014) and using family as a way of relationship building (Nolan, 2006; Baillie et al 2012b; Watts & Davies, 2014), this was not prioritised as suggested by previous research (McCormack et al, 2010; Nolan et al, 2004; Edvardsson et al, 2008). This was mainly due to time constraints and difficulty managing behaviour. Although this reinforces the need for staff to provide more person-centred care, it also highlights the demands placed on staff that compromise the ability to provide person-centred care. This is also reflected by the restrictions in the environment which highlight the need for more stimulating activities for PwD. Although this is not directly linked to staff experience, more stimulating activities for PwD may result in better quality of life for PwD and therefore a likely reduction in the negative emotions experienced or resulting behaviours presented by PwD, which could result in staff experiencing less negative emotions and promote relationship building.

A difference was apparent between staff that viewed PwD as a person and those that only saw the illness, in relation to the symptoms experienced (Baillie et al, 2012a; Watts & Davies, 2014, Edberg & Edfors, 2008). These differences appeared to be mainly between nursing students' perceptions of qualified staff's approach and perceptions of the qualified staff. One explanation of the difference could be that nursing students have more time to understand PwD behaviour and build stronger rapport, whereas qualified staff are unable to do this due to other responsibilities and time constraints. Due to communication difficulties, struggles were evident in understanding PwD, resulting in staff being unable to meet their needs (Baillie et al, 2012a; Beck, 1996; Edberg & Edfors, 2008; Edberg et al, 2008), which supports previous literature (Holst, Edberg, & Hallberg, 1999). This suggests a need for more in-depth training in behaviours present in dementia and the importance of person-centred care. This also supports the outcome of an audit by RCP (2011), which found that the training for staff in dementia care is insufficient. The core values identified by Harris and Sterin (1999) to comprise the sense of self of the PwD appeared to be minimally met in the experiences identified in this review. This highlights the impact that staff have on the PwD and possibly suggests that the sense of identity and self of PwD are further diminished due to lack of relationship with staff (Kitwood, 1997).

The review supports previous literature on distressing emotions that occur as a result of the lack of understanding (Rodney 2000; Skovdahl et al, 2003),

however the review highlights the intensity of these emotions. For example, memories laden with emotion being carried with staff for years (Edberg et al, 2008). The intense emotion of feeling powerless and guilty are emotions that are highly damaging for individuals and impact not only on their own life but the wider systems they are part of (Astrom et al, 2004; Livingston et al, 2012). These emotions were mostly present when staff experienced ethical dilemmas at work. The review found that ethical dilemmas mostly occurred in relation to organisational culture and the care of PwD (Edberg et al, 2008; DeWitt & Ploeg, 2014; Rasmussen & Hellzen, 2013), however, no staff referred to managing these dilemmas through the use of decision making models i.e. Bolmsjo et al (2006). This demonstrates that although these models are present, they are not being used. This may again reflect shortcomings of training and the need for more training in the management of ethical dilemmas. Staff support played a key role in the management of emotions that occurred as a result of these ethical dilemmas, however only staff from three studies referred to staff support (Rasmussen & Hellzen, 2013; Edberg et al, 2008; Eriksson & Saveman, 2002). Although this may not mean that staff from other studies did not receive staff support, it signifies that the staff support is not a key aspect of their experience of caring for PwD, whereby previous research including the three studies from this review, highlight the importance and impact of staff support on staff wellbeing (Berg & Welander Hansson, 2000).

As mentioned above the review highlighted the huge impact of time constraints on the experiences of staff. However, realistically time constraints will continue to be present with the growing demands on services and the current economic climate e.g. funding cuts, however other factors in relation to time constraints for example the emotional struggle staff experience can be reflected on for future clinical practice. The emotional experience of staff is likely to impact on many areas of staff life e.g. home life, motivation at work, staff satisfaction, burnout, therefore it is essential that staff are able to manage, understand and reflect on their own emotions in order to better manage them and help to prevent the negative impact they have on their work and subsequently on PwD. This will also empower staff to feel that they have influence over their work situation.

Future Research

Implications for clinical practice and service related implications have been referred to within the discussion. The review also highlights areas where further research is needed. Three areas for future research have been highlighted as a result of the review. Firstly the review draws on the importance of staff understanding behaviours related to dementia. Future research would benefit from looking at staff experiences of behaviour in dementia, to gain a more in-depth understanding of how they make sense of the behaviours This could help inform future training which has also been suggested. Secondly, previous research and the outcome of this review appears to focus hugely on the negative experiences of caring for PwD with only minimal reference to the positive experiences. Future research would benefit from exploring the positive experiences of staff caring for PwD and 'what works', which again would help to inform future training. Lastly, the review highlights the magnitude of the impact that distressing emotions have on staff, mostly in relation to ethical dilemmas.

Given that there are decision making models (Bolmsjo et al, 2006) for such ethical dilemmas, future research would benefit from investigating the efficacy of these models in relation to dementia care. This would help to provide staff with better management techniques when they are faced with ethical dilemmas. Also, as mentioned above, the review highlights the need for more robust qualitative research in this area.

Limitations

Although the review has helped to identify a number of implications for clinical practice and research, there are a number of limitations of this review which limit the conclusions that can be made. The review only used six data bases in the search, more research may have been found if more databases were searched, however time restrictions prevented this. The review intended to use both peer-reviewed literature as well as unpublished literature i.e. (theses and dissertations). Although unpublished literature was found the authors were unable to gain access to it. This limits the findings of the study in that the unpublished work may have provided a different perspective through different experiences. The studies used for the review did not fully meet criteria on quality appraisal (in particular poor reflexivity and credibility) and were included on the basis that they met the two screening questions on the CASP. This was a very lenient screening process and could have been made stricter to ensure studies included were of higher quality. However, this would have meant a decrease in data and subsequently findings that were less informed. A further limitation was in relation to the usage of the data extracted from the studies. The review could have given more attention to the differences in experience between different locations the staff worked at and between job roles, which may have highlighted a difference in experience. The data extracted however allows future researchers to make use of it.

Conclusions

The review has highlighted a number of important findings. Staff caring for PwD particularly appear to be struggling with the time constraints due to other pressures and the impact that this has on the quality of time they are able to spend with PwD and build rapport with them. The review also highlighted the impact of the emotions experienced on staff wellbeing e.g. the stress of dealing with ethical dilemmas, and on their job role e.g. some staff coping by becoming desensitised. The findings highlighted a number of implications both for clinical practice e.g. the need for more in-depth training as well as more stimulating activities for PwD, and for research. Although a number of limitations were evident in the review, the review enables services to get a global overview of how staff experience dementia and furthers our understanding. The experiences of staff across the globe have common themes which need to be addressed. Given that dementia is a global 'public health priority', the experience of PwD and their quality of life lies in the hands of their environment and their carers, who require support and guidance in working with such a vulnerable population.

Declaration of conflicting interests

None declared

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JOURNAL PAPER[1]

[1] Links to the extended paper will be shown by ^{EP} followed by the section number it corresponds to in the extended paper

How do inpatient psychiatric nurses make sense of and respond to behaviours in dementia: An interpretative phenomenological analysis

Vidya Fatania[1], Danielle De Boos[1], Anna Tickle[1], David Connelly[2]

[1] Trent Doctorate in Clinical Psychology, University of Nottingham, Nottingham, UK

[2] Nottinghamshire Healthcare NHS Foundation Trust

Abstract

Objectives: There is existing literature demonstrating that the perceived understanding nurses have of behaviours in dementia influences their response to persons with dementia. However, there is limited research on the psychological processes involved in making sense of behaviours and how this impacts on their response. There is specifically a dearth of literature from inpatient acute dementia settings. The aim of the study was to explore how inpatient psychiatric nurses make sense of and respond to behaviours in dementia.

Method: A qualitative method of Interpretative Phenomenological Analysis (IPA) was employed for this study. Eight inpatient psychiatric nurses were recruited from two inpatient services within the National Health Service. Semi structured interviews were conducted to gain an in-depth understanding of their experience. Transcripts of the interviews were then analysed using stages outlined for IPA.

Results: Four interrelated themes were identified: 'Effort to sense make', 'Pressures of the organisation', 'Balancing personal and professional selves: The underlying emotional connection', and '"Looking back on it…"'.

Conclusions: The study highlighted that sense making is a dynamic process which occurs through a range of psychological processes and can change moment-by-moment dependent on the influences on and around the nurse. It demonstrated that nurses need to be supported to move flexibly through a range of emotional connections, which were found to underlie the negotiations made at work and its subsequent influence on sense making and responding. Resulting clinical and research implications are also discussed.

Keywords: *Nurses, behaviours, dementia, interpretative phenomenological analysis*

Introduction[EP1]

Dementia is a global public health priority[EP1.1]. The demands that caring for persons with dementia [PsWD] makes on health care systems are increasing significantly, alongside an increase in prevalence (Alzheimer Disease International & World Health Organization [ADI & WHO], 2012; Prince et al., 2013). This contributes to the impact on professionals providing care to PsWD (Kings Fund, 2016). The National Health Service (NHS) provides a range of inpatient and community services for PsWD. Currently, PsWD have higher rates of hospital admissions than those without dementia (Pinner, Hillam, Branton & Ramakrishnan, 2011). The guidelines provided by the National Institute for Heath and Care Excellence ([NICE], 2016) advise that inpatient dementia care should only be considered if the individual is 'severely disturbed and needs to be contained for his or her own health and safety and/or the safety of others' (NICE, 2016, p.37).

One major contributory factor for inpatient care is difficulty in managing behaviours (Bianchetti et al., 1995; NICE, 2016; Linde, Pening, Matthews & Brayne, 2014; Finkel, 2000; Milano, Saturnino & Capasso, 2013). These behaviours include aggression, wandering, and disinhibited sexual behaviour (Department of Health, [DoH], 2009; NICE, 2012; Hellzen, Kristiansen, & Norbergh, 2004; Boyd, 2001; Eriksson & Saveman, 2002; Ballard, Lowery, Powell, O'Brien & James, 2000). Through his work on personhood, Kitwood (1997)[EP1.2] suggested that behaviours displayed by PsWD do not solely indicate cognitive deterioration, but are influenced by, and indicative of, personal histories, interaction and social context (Hughes, Louw & Sabat, 2006). However, if the latter is not considered within relationships, it can lead to feelings of fear, confusion, anger and uncertainty (Hammar, Emami, Engstrom & Gotell 2010; Hain, Touhy & Engstrom, 2010), which can present as behaviours that are difficult to manage (Talerico & Evans, 2000). These behaviours are hypothesised to function as a communication from PsWD[EP1.3] (Smith & Buckwalter, 2005; Feast et al., 2016), although interpreting their needs and wishes can be difficult (Duxbury, 2002), due to impaired verbal communication and cognitive deterioration (Kitwood, 1997). This particularly highlights the importance of nurses 'knowing' the PWD (Cooney et al., 2014; Cohen-Mansfield, Golander & Heinik; 2013) and looking beyond verbal communication to understand how personhood is embodied (Kontos, 2005; Matthews, 2006).

The way in which behaviours are perceived has been found to impact on the response of nurses (Hantikainen, 2001; Dupuis, Wiersma & Loiselle, 2012). Attribution literature[EP1.3.1] within dementia research suggests that when behaviours that challenge are attributed to cognitive deterioration, and PsWD are seen as having no control over them, carers are more accepting of the behaviours and

subsequently more willing to help (Dupuis et al., 2012; Paton, Johnston, Katona & Livingston, 2004). However, Paton et al.'s (2004) study used family members and informal carers, who may not have the professional training and knowledge a nurse may have, and hence may understand behaviours differently (Cohen-Mansfield et al., 2013). Other research has found that staff responses can exacerbate or be the cause of behaviours that challenge[EP1.4.] (Enmarker, Olsen & Hellzen, 2011; Hellzén et al., 2004; Duxbury, 2002; Somboontanont et al., 2004; Skovdahl, Kihlgren & Kihlgren, 2003). Absent from literature is the psychological process nurses go through to make sense of and respond to these behaviours, which could help to provide comprehensive knowledge of the complexities involved. The way in which PsWD are cared for has a significant impact on their experience of the dementia and its progression, through either adding to the difficulties (Beck, 1996; Robinson & Cubit, 2007; Train, Nurock, Manela, Kitchen, & Livingston, 2005; Watts & Davies, 2014) or helping to lessen them (Edberg & Edfors, 2008; Nolan, 2007), through a reciprocal process (Todd & Watts, 2005).

Nurses caring for PsWD are faced with a range of challenges, which appear to centre on balancing organisational pressures[EP1.5] and patient care (Strech, Mertz, Knuppel, Neitzke & Schmidhuber, 2013; Stacey, Johnston, Stickley & Diamond, 2010; Ramussen & Hellzen, 2013; de Witt & Ploeg, 2014), which can lead to high levels of burnout (Edvardsson, Sandman, Nay & Karlsson, 2008; Todd & Watts, 2005). This can impact on staff quality of life and their perception of the quality of care they are delivering, as well as the development of distressing feelings[EP1.5.1] (Edberg et al., 2008; Eriksson & Saveman, 2002; de Witt & Ploeg, 2014; Rasmussen & Hellzen, 2013; Hayajineh & Shehadeh, 2014; Edberg & Edfors, 2008; Train et al., 2005). However, these challenges in turn have been found to lead to more reactive and intrusive responses[EP1.5.2] (Todd & Watts, 2005; Erikkson & Saverman, 2002; Dupuis, 2012), such as increased administration of antipsychotic medication (DoH, 2015).

To deal with these challenges, nurses adopt a range of strategies which includes depersonalisation, a task-orientated approach, and staff support (Kitwood, 1997; Menzies Lyth, 1960; Robinson & Cubit, 2007; Edberg & Edfors, 2008; Train et al., 2005; Rasmussen & Hellzen, 2013). However, only one study focuses on nurses in acute inpatient settings (Eriksson & Saveman, 2002), where the nature of the environment is very different to long term care settings, as staff have less time to build relationships. The strategies and responses used by nurses can have a consequence on various aspects of the PWD's life[EP1.5.3], i.e. their personhood (MacRae, 2010; Hain et al., 2010; Caddell & Clare, 2009; Kitwood, 1997) and their quality of life (Logsdon, Gibbons, McCurry & Teri, 1999; Burgener & Twigg, 2002; Hoe, Katona, Orrell & Livingston, 2007).

Existing literature suggests that perceived understanding of behaviours in dementia can influence nurses' responses, which are likely to subsequently impact on PsWD. Given this, a qualitative study will aim to answer the research question: How do inpatient psychiatric nurses make sense of and respond to behaviours in dementia?[EP1.6]

Method[EP2]

Design[EP2.1]

Interpretative Phenomenological Analysis (Smith, Flowers & Larkin, [IPA], 2009)[EP2.1.2] was used to address the aim of this study.

Participants[EP2.3]

IPA adopts an idiographic approach and therefore studies are conducted with small sample sizes (Smith et al., 2009), to allow for a detailed case by case analysis (Smith & Osborne, 2008). The aim of IPA is to comprehensively elicit the perceptions and understandings of a specific group through recruiting a homogenous sample, rather than making more generalised claims (Smith & Osborne, 2008). Given this, eight participants were recruited. The participants were qualified nurses, working in inpatient, acute, short term assessment wards with PsWD. The sample consisted of five females and three males, and recruitment occurred from two different wards (four participants from each) within an NHS Trust.

Ethical considerations[EP2.4]

Approval was obtained from the appropriate local research ethics committees. Written informed consent was gained from each participant, and confidentiality was maintained through anonymising all data from the outset using pseudonyms. Therefore, the true identity of the participants is only known by the primary researcher. All confidential information and study data was stored in locked filing cabinets within the researchers' base.

Data Collection[EP2.5]

Following ethical approval, contact was made with the sites to begin recruitment. All those who were interested and met the inclusion criteria were interviewed. Data was collected through audio recorded semi structured interviews conducted by the primary researcher. These lasted 45-90 minutes. Prior to the interview, participants were introduced to the research and informed about

their right to withdraw. The aim of the interview was to gain in-depth knowledge into how nurses made sense of behaviours in dementia and the responses corresponding to these. The interview schedule was developed to reflect this, and to capture any complexities or additional factors within this process.

Data Analysis[EP2.6]

Each interview was transcribed verbatim by the primary researcher and analysed using the IPA stages of analysis guidance provided by Smith et al. (2009). Line-by-line coding was used to analyse the experiential claims, concerns and understandings of the participants (Larkin, Watts & Clifton, 2006). This process broadly consisted of reading and re-reading data, providing initial exploratory notes on descriptive, linguistic and conceptual factors and then developing initial themes from these notes. The initial themes were then collapsed to form superordinate and sub themes. This process was completed for each transcript. Following this, patterns across all cases were identified from the developed themes and these were organised and combined to make overall themes.

An important aspect of IPA is to embed the self within the subjective experience of others, which requires reflexivity[EP2.7] and the ability to bracket (Finlay, 2004). A reflective diary was kept throughout the research process to remain mindful of this.

Quality Assurance[EP2.8]

Qualitative research has been criticised for being open to researcher bias, difficult to replicate and generalise, and too subjective (Koch & Harrington, 1998). This has resulted in the validity and quality of qualitative research being questioned (Elliot, Fischer & Rennie, 1998). Smith's (2011) criteria for assessing the quality of IPA research was used, as well as additional methods for qualitative methods outlined by Vicary, Young and Hicks (2016) to add to the rigour.

[2]Results[EP3]

Characteristics of the wards

The two wards had the following characteristics: They were overseen by the same consultant psychologist and also had trainee psychologists on the ward; under pressure due to staffing levels; admitting patients from across the area; mixed gender wards.

[2] Extended paper is available with the full set of results on request from the authors.

Themes

Four interrelated superordinate themes were identified, and titled 'Effort to sense make'; 'Pressures of the organisation', 'Balancing personal and professional selves: An underlying emotional connection'; and '"Looking back on it…"' These results are grounded in the context in which the participants are working: acute, inpatient, short term stay assessment wards for individuals with dementia, who are likely to present with complex difficulties.

Effort to sense make $^{EP3.1}$

This superordinate theme captures the effort participants make in order to make sense of and respond to behaviours. This effort occurs through active processes that influence sense making and responses to behaviours. Deka makes sense of restless behaviour of a patient when approaching bedtime through engaging in the process of trial and error.

Deka: 'I said to the staff "give him his supper quick and then I'll… take him to bed" … but he didn't settle. We thought maybe by getting rid of him and putting him in bed would help but that wasn't it… sat down with him and had a chat… "What time do you normally go to bed?" "Oh, I don't go to bed until midnight" … so we knew he would go last and it was fine. We forced him into bed when actually he didn't want to sleep.'

Deka has a thought of what might be helpful and responds accordingly, but then modifies the response based on the patient's reaction and subsequent information gathering about the patient's prior routine. As Deka's sense making develops, the emotional tone of her account shifts. She moves from frustration and wanting rid of the patient, to a position in which she can acknowledge that his preferred routine was being overridden by her attempts to manage his behaviour. This same process of trial and error through the outcome of the response was demonstrated by Jill and Jan. In contrast, they were unable to find a helpful response, which left them feeling there was '*no choice but to go down the medication route' (Jan)* and to *'withdraw' (Jill),* highlighting that both of these strategies were last resorts for them when helpful sense making and responses were unachievable. Sense making and responding appear to be flexible processes and subject to review dependent on the outcome, demonstrating recognition of an active relationship between 'understanding' and 'responding to' behaviours.

Participants also apply existing knowledge in an effort to make sense of behaviours *(Deka, Romy, Mel, Paul, Ayo and Jan)*. For example, Jan described an experience of verbal aggression towards other patients when sitting in the ward by drawing on her existing knowledge of dementia, which subsequently influenced her response.

Jan: 'if she wasn't dementing she would see the same situation everybody else did… We just distract… how can I have expectations of her to understand when I know her brain is dying? … However, I've got to protect my patients because they also don't realise what they're doing'

Jan's acceptance of the aggression appears to be fuelled by attributing loss of control and insight to the aggression. There is a sense of diminished responsibility in the patient, where the patient is possibly viewed as blameless, due to misperception, as a result of dementia. This appears to influence her response of distraction and also how she positions herself in the interaction, where she feels responsible for the safety of all the patients.

Participants also engage in the process of perspective taking (*Paul, Jill, Jan, Mel, Ali, Romy and Ayo).* Romy describes an experience of aggression from a patient whilst bathing him.

Romy: 'he was scared… it's not nice if you're washing and dressing somebody and you just go behind and you take their clothes down and just start washing… it's wrong … I wouldn't want somebody to start undressing me without telling me what they're doing… I tried to explain… used gentle holds''

Romy makes sense of the aggression by attempting to understand how she would feel in the patient's place. This helps her understand the behaviour as being a result of fear experienced by the patient and subsequently her response is more empathic. Developing empathy through *'putting* [themselves] *in* [patients'] *shoes' (Mel),* appeared to aid participants' sense making and responses.

This superordinate theme highlights various processes in which participants engage in order to make sense of and respond to behaviours that they are presented with. These processes include drawing on existing knowledge, trial and error through response modification, and perspective taking. Through engagement in these processes, an iterative sense making and responding process is demonstrated, where sense making influences the response and then the outcome influences further sense making.

Pressures of the organisation $^{EP3.2}$

This superordinate theme reflects how the restrictions of the professional context impact on participants' sense making and responses to behaviours. Ayo describes how pressures on the ward influenced his response to a patient who was continuously pulling an alarm.

*Ayo: '…the ward is a busy ward… she does it and she wants to entertain it because she is getting the attention… If you're lead shift, and on that shift, you happen not to be fully staffed… you have her and other patient to look after… wash and dress, medication diaries, so I didn't want one patient to you know to take all my attention or all my care that particular morning… [*I*] administered PRN* [because] *she was becoming unsettled… taking her out of that situation for her safety… putting her in a different environment… She was not happy about it…* [but] *that behaviour that was challenging to myself.'*

Ayo makes sense of the behaviour as the patient wanting '*attention'.* There is a sense that the presence of this patient is making the whole shift unmanageable, as his attention is already stretched by multiple responsibilities. There is possible frustration in relation to this and Ayo's response appears to have the purpose of demand minimisation. Ayo's responses and sense making appear to be influenced by the pressures and responsibilities he is trying to balance within the system he is working in. The pressures of the organisation influencing sense making and responses to behaviours is reflected in the experiences of all of the participants.

Balancing personal and professional selves: The underlying emotional connection $^{EP3.3}$

This superordinate theme highlights the fragile balance participants need to strike between their personal (beliefs and values) and professional (standards, duties and responsibilities) selves, whilst also managing the emotional connection to the patient. It discusses how congruence or incongruence between the professional duty and the personal self/emotional connection can impact on sense making, the response and the outcome. This theme reflects the experience of 6 participants (*Ali, Paul, Mel, Jan, Jill, and Romy*). Ali speaks about his experience of being faced with aggression by a newly admitted male patient.

*Ali: '[*I said to the manager] *"look you can't leave me with these three staff… I'm the only man… the other two are old ladies" ... he was a really big guy, a strong guy… he punched the staff… I went and tried and grabbed the other arm to kind of restrain him… fighting with this guy… restrained him.'*

It appears Ali's sense making is influenced by what seems to be an emotional reaction of fear towards the patient. Ali's sense making is reduced to assessing his own physical strength against that of a *'man'* rather than a vulnerable patient. The professional context is lost and therefore the skill/training of staff appears forgotten and the female staff available are seen as '*old ladies'* and less valuable. Ali describes feeling '*proud*' of how he managed the situation, which may be due to his response being congruent with his sense making and the connection he formed with the patient. Ali's sense making and response appear to be primitive and driven by a threat reaction in relation to the fear. This also true for Jan, who similarly lacked quality sense making following the experience of fear towards a patient, and for Paul, who also abandons professional standards when a negative emotional connection is formed.

Alternatively, experiences are described where there is incongruence with the personal self (*Mel and Jan)*. Mel speaks about aggression from a patient when attending to personal hygiene.

Mel: '…it was as if you were going to attack and kill him, rape him or something like that… No amount of reassurance is going to do anything because he's in the moment, he's so frightened and confused… We had to restrain him because of his level of anxiety… It can touch you but you have to focus on the task… you build up a wall to manage your emotions and to be able to get on with a task and then that leads to guilt of having to do.'

Mel understands his behaviour as driven by a fear of staff, due to dementia related disorientation. Mel empathises with the patient, which appears to increase her understanding of the behaviour. However, she consciously disconnects from him in order to fulfil her professional responsibilities. The need to abandon her personal beliefs means she is having to take on an undesirable role, leading to unpleasant feelings and subsequent distressing memories *'*[the patient] *probably would have forgot the incident… I'm the one left with the memory' (Mel).* Unpleasant feelings were also experienced by Jill, who felt she had '*failed*' and had '*dehumanised*' a patient when needing to continue with physical hygiene care while the patient was visibly distressed.

Following this experience of disconnection succeeding incongruence with the personal self, Mel describes a desire to reconnect emotionally with the patient.

Mel: 'He used to pace off… as if he was running away… I used to give him a few minutes and then he'd come and I'd give him a cuddle. And he'd just hold on tight and I'd say "It's fine, it's ok, it's ok, don't worry, everything's alright now, you're alright."'

Mel's desire to reconnect with the patient seems to be driven by the guilt of persisting with her job despite the patient's distress. Reconnecting acts to alleviate guilt for Mel, as well as perceived patient reassurance. This need to reconnect was also experienced by Jan and Romy.

This theme highlights the fragile balance of different aspects of the self that participants negotiate when making sense of and responding to behaviours. Furthermore, when conflict is present between responses guided by quality sense making and professional responsibilities and restrictions, this appears to lead to a need to emotionally disconnect from patients and neglect the sense making. The theme further highlights that participants may need to flexibly move through a spectrum of emotional connection in order to survive and fulfil the duties of their role. The data showed that this spectrum ranges from connection, whether it is conscious or unconscious, to disconnection or rejection of emotional connection when participants felt there was no hope of improvement e.g. Jill, as well as reconnection. Mel's experience in particular, reveals movement around the spectrum within one experience, which highlights that a staff member may need to occupy different positions as part of their negotiations between their personal and professional selves.

"Looking back on it…"EP3.4

This superordinate theme describes how space to reflect on experiences during the interview process impacted on sense making and response ideas. Paul reflected on a patient who presents with '*nonsensical*' and repetitive behaviour, which he initially interpreted as '*attention seeking*' and responded by *'ignoring'* the patient.

Paul: I just need to maybe… give them a little bit more time and to give them a response… They obviously, they have issues which is why they're acting the way they are and I think it's useful to maybe remember that. They may be different to other people's needs but they're still issues that need dealing with so… it may be interesting to try it.

There was a shift in Paul's attributions of control and intention, which allowed him to think about an alternative response. The questioning style, which promoted reflective thinking, was felt to be a contributing factor to this shift. This theme highlights the potential power of reflective space in

processing experiences and the emotions corresponding to them, whilst also making opportunity to develop different ways of thinking about behaviours and subsequently more helpful ways of responding. This was also evident for Ayo and Ali.

Discussion[EP4]

The current research aimed to explore eight inpatient psychiatric nurses' experiences of making sense of and responding to behaviours in dementia. Four interrelated superordinate themes were identified: 'Effort to sense make', 'Pressures of the organisation', 'Balancing personal and professional selves: The underlying emotional connection' and '"Looking back on it…"'. Participants make a conscious effort to make sense of behaviours they are presented with through a number of active processes. However, the restrictions imposed by the professional context can hinder a quality and comprehensive sense making process and influence the response of staff. Participants sensitively balance their personal and professional selves as well as manage the emotional connection with the patient. They move flexibly through a spectrum of emotional connections in their sense making and responding process in order to fulfil their duties. When given the space during the interview, participants reflected on their experience, which enhanced the quality of their sense making, leading to alternative responses to those experiences where they felt unhappy/unsure with their response.

Participants made an effort to make sense of behaviours through engaging in different processes: drawing on existing knowledge, perspective taking and trial and error[EP4.1.1]. Previous research has suggested the occurrence of these processes (Edberg et al., 2008; Gilmore-Bykovski & Bowers, 2013) but had not specifically highlighted what they were. Literature suggests that 'willingness to help' is influenced by sense making (Weiner, 1995; Todd &Watts, 2005; Dowding et al., 2016; Dupuis et al., 2012; Paton et al., 2004), however the current findings identified more complexities within this. As well as 'willingness', 'helplessness' in not knowing how to respond also surfaced when sense making was unachievable. This is particularly true when an increased and comprehensive understanding of the patient and the behaviours is not available (Cooney et al., 2014; Kitwood, 1997).

A further influence on sense making and responses to behaviours was a backdrop of organisational pressures[EP4.1.2]. Consistent with existing literature (Todd & Watts, 2005; Erikkson & Saveman, 2002; Dupuis et al., 2012), responses appeared to have the function of making the shift more manageable for the participants. Additionally, quality sense making of behaviours was, at times, quashed and the individual/behaviour was seen as deviant. This could be due to the broader context hindering a

psychological understanding developing (Dupuis, 2010; Dupuis et al., 2011). It can be argued that the context spans further than the organisations themselves, to the whole system, which is reflected in the impact of national challenges and subsequent recommendations (e.g. Francis, 2013; Behan, Paterson & Forrest, 2014).

Although sense making and responding is impacted on by the organisational context, there is additionally a complex interplay with the participants' personal values and beliefs (Dowding et al., 2016). However, this is underpinned by an emotional connection with the patient[EP4.1.3]. Although dissonance might be created between the staff and the patient (Moore, 1999) due to task-orientated and distancing responses as a result of professional duties (Enmarker et al., 2011; Duxbury, 2002; Menzies Lyth, 1960; Kitwood, 1997; Eriksson & Saveman, 2002; Stacey et al., 2010; Kitwood, 1990), dissonance was found within the self for the participants. This dissonance was driven by the incongruence staff encounter between their professional duties and personal beliefs and emotions, all of which impacts on making sense of and responding to behaviours.

When an empathic connection was formed, it helped to make psychological sense of behaviour. This could be considered using the process of empathic identification (Wiseman, 1978), which describes the ability to identify with one another. When this occurred, it did so through understanding and bringing together a range of knowledge of the patient and their emotions, as well as drawing on their knowledge of dementia, which led to increased quality in sense making. This is consistent with psychological formulation, which uses theoretical knowledge as well as individual factors to comprehensively conceptualise behaviour and emotions in order to guide intervention in an informed manner (Johnstone & Dallos, 2014).

However, when duties needed to be fulfilled that went against quality sense making, personal beliefs and/or the emotional connection, participants rejected or disconnected from the emotion to fulfil professional roles. This elicited a range of difficult emotions for nurses, such as guilt and feelings of failure, which fuelled the need for some participants to reconnect with the patient to alleviate these feelings. Attachment theory postulates the importance of an attachment figure in order to feel safe and secure (Ainsworth, 1969; Bowlby, 1979). In inpatient settings, nurses deliver 24-hour care and hence become the default attachment figure for patients (d'Elia, 2001; Petersen & Koehler, 2006), especially given the loss of their loved ones (Magai, 2008) when in such a setting. Attachment literature emphasises the importance of repairing ruptures in relationships in order to strengthen them and reinforce a sense of security (Kohut, 1984; Daniel, 2006). Wanting to reconnect with the patient can be considered to be a way of repairing the rupture caused by disconnection and emotional distancing. Given the nature of dementia, this is not simple to do, as demonstrated by

Mel. Interestingly, some participants showed no evidence of existing empathic emotional connections or attempts to make such a connection

Reflective space to process experiences and feelings in relation to the behaviours and responses was found to be particularly important[EP4.1.4], especially for those who did not form an empathic connection. When given this reflective space as part of the interview, conceptualisation of the behaviour became more empathic for some and alternative, more informed responses were suggested. This is consistent with the limited literature available on effective reflective space in nursing practice (review by Brunero & Stein-Parbury, 2008).

***Clinical Implications*[EP4.2]**

The findings from this study contribute to extant literature by providing a more comprehensive understanding of the complex processes that nurses go through to make sense of and respond to behaviours in dementia. However, it additionally gives a novel understanding of the underlying emotional processes that influence this.

Participants who made empathic connections were more likely to reconnect with the patient and therefore attempt to repair any ruptures made through disconnection. As mentioned above, psychological formulation aids this empathic connection through gaining a comprehensive understanding of an individual to better conceptualise behaviour and inform intervention/responses (Johnstone & Dallos, 2014). A more thorough integration of formulation (e.g. The Newcastle Model by James, Mackenzie, Stephenson & Roe, 2006) into nursing care would enhance these empathic connections, which subsequently is likely to improve patient wellbeing as well as nurses' wellbeing, through having a stronger relationship (Eels, 2011; Nezu, Nezu & Colosimo, 2015).

Findings suggested a need for nurses to be able to move flexibly through a spectrum of emotional connection, disconnection and reconnection to fulfil their professional role. In a time where there is national reinforcement of compassionate care within the NHS, particularly following recommendations from the Francis Report (Francis, 2013) and other investigations into neglect in services, disconnection can lead to feelings of guilt and blame. However, too much compassion can lead to burnout (McQueen, 2004). Nurses need to be able to emotionally detach and reconnect in order to do their job, which does not mean uncompassionate care. In acknowledging the existence of this spectrum, practitioners will more likely be able to manage these distressing emotions in a healthy and effective manner. One way to do this is through clinical supervision.

Clinical supervision gives nurses time to reflect on difficult caring situations, especially those that result in an internal conflict (Berggren, Barbosa da Silva & Severinsson, 2005). The findings of the present study demonstrated the importance and impact of reflective space, which is an important aspect of clinical supervision (Rainey, 1997). Given the importance and wider impact of clinical supervision, there is a need for management at a higher organisational level to acknowledge and implement this.

It can be proposed that the novel findings of this study, i.e. the process that nurses go through, can be extended to other inpatient settings. Nurses working in other clinical settings such as learning disability and adult mental health, describe similar emotional experiences and also describe the need to disconnect from patients in order to do their job (Bonner, Lowe, Rawcliffe & Wellman, 2002; Hawkins, Allen & Jenkins, 2005). This initial understanding of the complex processes involved for nurses in inpatient settings can help to guide future research and promote practice that will enhance patient and nursing staff wellbeing.

Future Research[EP4.3]

As discussed, integration of clinical/reflective supervision and formulation in inpatient nursing care is essential, however there is limited research looking at either within inpatient dementia care settings. For example, a specific formulation model has been developed for dementia care, The Newcastle Model (James et al., 2006). However, there is no evidence for the use of clinical formulation in nursing care (Crowe, Carlyle & Farmer, 2008; Smith & Grant 2016), highlighting a need for further research as well as a more comprehensive integration of formulation into nursing care. It would be helpful to look into why neither might be occurring and how they can be promoted further in inpatient dementia settings.

In the current study, only a few nurses spoke about the impact of their personal lives and experiences on their understanding. Psychologically this is likely to have a significant impact as early or significant experiences influence our appraisals of situations, consistent with cognitive theory (Beck, 1979). Furthermore, it would be especially helpful for future research to further explore the emotional connection underlying staff experiences, given the impact it was found to have on the nurses and the patients.

Limitations[EP4.4]

One limitation of this study is participants' retrospective recall, making it unclear whether processes described were as experienced at the time or altered by retrospective sense making (Smith, 1996).

However, the interview questions and prompts were developed to elicit accounts as close as possible to the experience. The findings from this study are specific to this particular sample of participants. The study did not set out to make generalizable claims about all nurses working in inpatient dementia settings, as this would not be congruent with the idiographic nature of IPA (Smith et al., 2009). However, through comparison with previous literature, transferability of some of the findings has been suggested. The findings provide initial thoughts about the importance of psychological understanding for nurses as well as the complexities involved in sense making and responses to behaviours in PsWD.

Conclusions EP4.5

Making sense of and responding to behaviours is a dynamic process, which can be negotiated moment-to-moment within interactions with patients. It is more complex than some of the literature promoting 'compassion' or attachment literature suggests (Francis, 2013; Loboprabhu, 2006). This study demonstrated that understanding and responding are driven by both emotional connections and cognitive processes. Divergence within a spectrum of emotional connection appears to be healthy for staff, in order to survive their professional role. However, it is encouraged that staff reconnect following disconnection, as this was found to reduce difficult emotions experienced.

It would be beneficial for nurses to have clinical/reflective supervision space and formulation sessions, which are likely to benefit their own wellbeing and the patients'. Future research needs to focus on the use of supervision and formulation in nursing practice, with a focus on their impact and integration.

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EXTENDED PAPER

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1. Extended Introduction

1.1 Dementia and national policies

Dementia is a global public health priority, with a projected 85% proportionate increase in prevalence worldwide, from 2010 to 2030, among people aged 60 years and over (ADI & WHO, 2012; Prince et al., 2013). PsWD are a vulnerable population (NICE/Social Care Institute for Excellence [SCIE], 2007), due to the progressive nature of dementia resulting in increased levels of confusion, causing them to become less familiar with their surroundings (Hammar, Emami, Engstrom, & Gotell, 2010). Dementia is defined by NICE (2012, p.4) as 'a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function.' As it progresses, PsWD can experience progressive decline in a number of areas, such as memory, communication, and loss of self and identity. These symptoms can result in a high level of emotional distress, which can leave them feeling frightened and scared (Hinton & Levkoff, 1999; Hammar et al., 2010), highlighting the vulnerability of this population (NICE/SCIE, 2007).

Within the UK, the National Dementia Strategy (DoH, 2009) and the Dementia Challenge (DoH, 2012a) outline key objectives, which include: Improving quality of care for PsWD, identifying any gaps in evidence or knowledge that need to be filled, and improving public and professional awareness and understanding of dementia through better education and training for professionals. These are especially important following recent reports of neglect in the country e.g. the Mid Staffordshire NHS Public Inquiry Report (Francis, 2013), which highlights the importance of making the quality of care as important as the quality of treatment for vulnerable individuals.

1.2 Personhood

Kitwood (1997, p8) defined personhood as 'the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being'. Kitwood (1997) proposed the notion of personhood or person-centeredness as an approach to care when working with PsWD. This approach reinforces person-centred care as moving away from a medical, task orientated approach, towards holistic personalised care that focusses on the individual (Edvardsson, Winblad & Sandman, 2008; McCormack, Karlsson, Dewing & Lerdal, 2010). Kitwood (1997) suggests that the interpersonal processes that occur between people when someone has dementia can result in personhood being lost or retained. However, the concept of 'personhood' has been criticised, as it does not take into consideration the person as who they are in that particular moment in time (Post, 2006). Post (2006)

speculated that there is a fear in western cultures of extreme forgetfulness and, essentially, a cultural belief that people need to have cognition to be considered and responded to as people. The way in which healthcare professionals understand and perceive PsWD would need to consider how the PWD perceives their own dementia, and whether they are accepting of their deterioration and who they are becoming. If there is acceptance, present 'personhood' could be perceived differently to the premorbid 'personhood'. Nonetheless, the concept of 'personhood' has encouraged more meaningful relationships with PsWD and has encouraged staff to value and respect their rights, dignity, and self-worth as part of their everyday role (Edvardsson et al., 2008; Kitwood, 1997; McCormack et al., 2010).

1.3 Making sense of behaviours in dementia

Some research has identified that carers make sense of behaviour in dementia through knowledge of the PWD's prior routine and personality (Cohen-Mansfield, Golander, & Heinik, 2013; Garand, Buckwalter & Hall, 2000; Cooney et al., 2014). Furthermore, there is a belief that these behaviours are a way of communicating unmet needs (Smith & Buckwalter, 2005; Feast et al., 2016; Stokes, 2000; Colling, 1999; Dupuis et al., 2012). Behaviour can be interpreted by nurses through different lenses. For example, Cohen-Mansfield et al., (2013) looked at how carers (informal and formal) perceived hallucinations and delusions in dementia. This was an interesting concept as it looked at a medical vs non-medical conceptualisation and, when given the space to think about the behaviours presented, participants appeared to break away from the medical understanding, i.e. that behaviours were due to boredom or environmental triggers. This reframing of the meaning of behaviour was also evident in the work of Talerico and Evans (2000), who reconceptualised aggression seen during activities involving touch as an action of self-protection, and therefore the communication of fear of staff behaviour. In contrast, research by Dupuis et al. (2012) found that staff understood behaviour that was challenging as part of the cognitive deterioration occurring in dementia and, although this alleviated blame, it also impacted on their response where the communicated need and personal history was not considered, but rather attempts were made to redirect or distract.

Emotional impact on staff

Staff working with PsWD who present with various different behaviours experience a range of emotions, for example, feelings of guilt, blame and powerlessness in relation to behaviours signifying confusion and fear (Beck, 1996; Eriksson & Saveman, 2002; Edberg & Edfors, 2008). This is

further exacerbated by barriers in communication and, subsequently, difficulties in consoling PsWD (Edberg et al., 2008; de Witt & Ploeg, 2014).

1.3.1 Attribution Theory

Weiner's attributional theory (Weiner, 1985) provides a model of interaction between attributions, emotions and behaviour. The model suggests that individuals' attributions about the cause of an event, as well as the evoked, corresponding emotion and the individual's belief of whether they can influence the event in the future, will determine their behavioural response. Weiner (1985) suggests that individuals are more likely to help if they make the attribution that the cause of the behaviour is outside the person's (i.e. PWD's) control and likely to be causal in the future (Stanley & Standen, 2000).

Attribution literature is important in understanding how nurses make sense of behaviour. The limited research available in dementia care indicates that the attributions that staff make of behaviours in dementia can influence their willingness to offer help or support. For example, through qualitative research, Dupuis et al. (2012) found that nurses experienced difficulty accepting behaviour they considered not to be dementia related, and that challenging behaviours were those that had a higher level of threat attributed to them and crossed social boundaries. Paton et al. (2004) found that carers are most likely to assist PsWD if they believe the behaviour (mainly forgetfulness and aggression) is a result of dementia and therefore out of the PWD's control. This is consistent with the research mentioned in the previous section.

1.4 Staff responses and behaviours in dementia

The approach and response adopted by nurses has been found to have a contributory effect in triggering behaviours that staff may find difficult to manage (Enmarker et al., 2011; Somboontanout et al., 2004; Skovdahl et al., 2003; Hellzén et al., 2004; Duxbury, 2002). For example, quantitative and observational studies have found that the approach adopted by professional carers e.g. ineffective communication, invalidation of experiences, rushing jobs or not giving verbal prompts during interventions, can have an impact on the levels of aggression from PsWD (Somboontanont et al., 2004; Skovdahl et al., 2003). However, it was also found that the emotions elicited as a result of the behaviours can impact on the type of response. For example, Draper et al. (2000) found that nurses who felt frustration, anxiety and anger towards vocally disruptive residents, had a desire to distance themselves from the resident. When staff are faced with behaviour they find difficult to manage, some research suggests that a task-focussed approach is adopted to enable them to meet

the physical needs of PsWD (Beck, 1996; Robinson & Cubit, 2007; Edberg & Edfors, 2008; Train et al., 2005) over other needs that might be present, i.e. emotional. When this occurs, small cues that might alert staff to what the PWD is communicating, e.g. grimaces as a result of pain, can be missed (Cohen-Mansfield et al., 2013; Graneheim, Isaksson, Liung & Jansson, 2005). However, when a more person-centred approach is taken, the level of aggression has been found to reduce significantly (Sloane et al., 2007; Chen, Ryden, Feldt & Savik, 2000; Putman & Wang, 2007) and higher levels of interaction have been noted between staff and patient (Keatinge et al., 2000). This could possibly have been due to knowing the patient more personally, which is consistent with personhood (Kitwood, 1997).

1.5 Organisational Pressures

Organisational pressures include the external pressures that seep through systems into the working environment, in addition to those within the environment. There is an increased prevalence of individuals with dementia, which is projected to increase further (ADI & WHO, 2012), however service provisions within the NHS for dementia patients are not currently increasing or expected to increase (Kings Fund, 2016).

1.5.1 Impact on nurses

The conflict between balancing organisational pressures and caring for PsWD can lead to a high level of stress and burnout (Edvardsson, Sandman, Nay & Karlsson, 2008; Todd & Watts 2005). Stress exacerbating factors can include: limited resources and activities (Baillie, Cox & Merritt, 2012), restrictions within the physical environment (Edberg et al., 2008) and time constraints (Rasmussen & Hellzen, 2013; de Witt and Ploeg, 2014). Staff may feel as though they are failing when they are unable to meet the standard of quality of care that they desire, resulting in distressing emotions such as shame, guilt and feelings of powerlessness (Eriksson & Saveman, 2002; de Witt & Ploeg, 2014; Hayajneh, 2014; Evers, Tomic & Brouwers, 2002; Rodney, 2000; Coen, O'Boyle, Coakley & Lawlor, 1999).

Time constraints is one of the biggest factors in eliciting these feelings. Staff often have to work according to routines rather than the PWD's needs due to time constraints (Ekman, Norberg, Viitanen, & Winblad, 1991). This can often result in the neglect of PsWD who have difficulty verbally expressing themselves, as it would take too long to interpret non-verbal communication (Byrne & Heyman, 1997). There is a desire to give respect, privacy and choice to PsWD, but this is compromised because of time constraints and a busy environment (Train et al., 2005; Eriksson &

Saveman, 2002). This has been found to make staff feel as though they are crossing a boundary when attending to the PWD's needs, e.g. personal hygiene (Rasmussen & Hellzen, 2013). Although staff experience feelings of fear in relation to aggressive behaviour (Beck, 1996; de Witt & Ploeg, 2014, Rasmussen & Hellzen, 2013), the feeling of guilt experienced by staff when not meeting their standard of care has been found to be more difficult to manage (Edberg et al; 2008; Eriksson & Saveman, 2002).

1.5.2 Staff responses and management of difficult emotions

Research has indicated more reactive strategies being used by staff when under a high level of organisational pressure. For example, Eriksson and Saveman (2002) found that staff tended to administer sedatives to calm agitated patients in order acquire time to see other patients. Furthermore, due to time constraints, staff feel they are unable to build a relationship (Eriksson & Saveman, 2002; Cooney et al., 2014) or have time to understand what PsWD are trying to communicate through their behaviours, leading to responses such as 'ignoring' (Todd & Watts, 2005). However, such responses lead to distressing feelings and conflict for staff as mentioned in the section above.

Specific strategies have been found to be used more commonly when staff experience difficult emotions or challenges. These strategies include; depersonalisation (Kitwood, 1997; Menzies Lyth, 1986; Eriksson & Saveman, 2002), task-orientated approaches (Robinson & Cubit, 2007; Edberg & Edfors, 2008; Train et al., 2005) and staff support/guidance (Rasmussen & Hellzen, 2013; Edberg & Edfors, 2008). Menzies Lyth's (1960) early work on nurses' defence against anxiety has been supported considerably by subsequent research in dementia care (Kitwood, 1997; Eriksson & Saveman, 2002, Todd & Watts, 2005). Menzies Lyth (1960) proposed that the difficulty in building a nurse-patient relationship due to the organisational factors meant the patient was seen decreasingly as the person they were, but more in line with their symptoms or environmental aspects, such as bed numbers. Evidence also suggests that staff will detach from patients in order to do their job (Todd & Watts, 2005; Lopez et al., 2006; McQueen, 2004; Dupuis et al., 2012).

1.5.3 Impact on client

Due to limited research for both quality of life and self and identity for PsWD in inpatient hospital settings, this section collates wider research looking at PsWD who are no longer living in their home but in another facility.

Quality of Life (QoL)

Studies have suggested that quality of life in dementia is influenced by mood and environmental factors independent of dementia severity (Thorgrimsen et al., 2003; Hoe et al., 2005). Research highlights that a negative/stressful emotional climate on the ward, and staff being unable to effectively meet the patients' needs, were associated with lower levels of QoL (Barca, Engedal, Laks, & Selbaek, 2011; Nakanishi, Hanihara, Mutai & Nakaaki, 2011; Gonzalez-Salvador et al., 2000; Ballard & Fossey, 2008). Conversely, higher levels of social contact, increased staffing levels, and increased time with the patients were associated with higher ratings of QoL (Hoe et al., 2005; Missotten et al., 2008; Banerjee et al., 2009; Zimmerman et al., 2005; Reimer, Slaughter, Donaldson, Currie, & Eliasziw, 2004). However, research has found that those factors that improve the QoL in PsWD, cannot always be facilitated due to time constraints and low staffing levels (Banerjee et al., 2009; Bredin, Kitwood & Wattis, 1995; review by Jing, Wilis & Feng, 2016).

Self and Identity

The way in which carers respond to behaviours in dementia can have an impact on the PWD's sense of identity (Hellzen, Asplund, Sandman & Norberg, 1999; Caddell & Clare, 2010). PsWD experience many losses that can create feelings of incompetence and worthlessness (Harris & Sterin, 1999), which subsequently decreases their sense of control, autonomy, and independence (MacQuarrie, 2005). Harris and Sterin (1999) identified three core values that maintain a sense of self in people in the early stages of dementia: being meaningfully productive, feelings of independence, and experiencing comfort and security. Echoing this, Steeman, Godderis, Grypdonck, De Bal & De Casterie (2007) suggested that cognitive deterioration should come second to enhancing personhood, to increase the feeling of being valued and the individual's wellbeing. However, these values tend to be overshadowed by organisational pressures as they require time and adequate resources (Drageset, Normann & Elstad, 2015; Edberg et al., 2008; Bolmsjö, Edberg & Sandman, 2006).

1.6 Rationale revisited

Rationale for an inpatient service

PsWD have higher rates of hospital admissions, whereby 6% are inpatients in hospitals compared to 0.65% of over 65s without dementia (Pinner et al., 2011). PsWD living in the community experience a better quality of life than those living in long term care services (Hoe et al., 2005). This is unsurprising as PsWD living in the community are in an environment that they find familiar, with familiar people around them, which provides a feeling of safety and security (Logsdon et al., 1999;

Burgener & Twigg, 2002). However, those living in residential/inpatient settings are in an environment and with people that are unfamiliar to them, which is likely to increase their sense of insecurity and loneliness (Ready, Ott, Grace & Fernandez, 2002; Thorgrimsen et al., 2003). Quality of life and wellbeing in inpatient settings in particular has been found to decrease for PsWD (Hoe et al., 2005). The care provided can help to alleviate those feelings of insecurity and loneliness in inpatient services. There has been a great deal of research conducted in long term care settings (e.g. Paton et al., 2004; Edberg et al., 2008) and in community services (e.g. de Witt & Ploeg, 2014) and, therefore, the studies referred to in the extended introduction have been those investigating long term care settings. However, there is a gap in literature for inpatient acute psychiatric settings (Eriksson & Saveman, 2002), where staff see more complex presentations and are restricted in terms of time in the relationship and the knowledge they can build about the patient. As such, this study has looked at inpatient acute settings in particular.

Behaviours in dementia

The same behaviour can be interpreted differently by different staff members, which can lead to dissimilar responses (Cohen-Mansfield et al., 2013; Roper, Shapira & Beck, 2001). Many studies have focused on the experience of challenging behaviours in dementia (e.g. Cohen-Mansfield et al., 2013; Garand et al., 2000). However, the present study did not want to limit the experiences shared by the participants, as the process of sense making can occur with any behaviour, not just those deemed challenging. The participants were specifically asked about any dementia related behaviour and were later asked more specifically about those that they found challenging.

Rationale for sample population

Inpatient psychiatric nurses have been chosen in particular as they are considered to be influential in frontline inpatient care. Furthermore, the setting in which they are working may provide a barrier to relationship building (short term assessment), making this process of sense making time limited when literature has indicated that knowing the patient is crucial in care (Cooney et al., 2014).

Rationale for study

It is particularly important to better understand the sense making process for nurses, given that current research indicates that the way behaviours are understood and perceived has an impact on responses and outcomes for both the nurses and the patients (Cohen-Mansfield et al., 2013; Talerico & Evan, 2000). Furthermore, research highlights that the frequency of the behaviours has less effect

on staff strain compared to not being able to understand the underlying reasons of the behaviours (Edberg et al., 2008; Hagen & Sayers, 1995).

Given the above rationales and the information provided in the extended sections to the journal introduction, the research aims to answer the question: How do inpatient psychiatric nurses make sense of and respond to behaviours in dementia?

2. Extended Method

2.1 Design

Qualitative vs Quantitative

This study adopted a qualitative design due to its exploratory nature. Qualitative and quantitative designs differ in relation to the researcher's perspective of reality (ontology) and what can be known of this reality (epistemology). The position the researcher intends to take determines the design to use. The goal of quantitative research is to determine whether the predicted generalisation of a particular concept or theory holds true (Punch, 2013). This is underpinned by the assumption that there is an objective reality which can also be studied objectively. Given this, hypotheses are tested within a cause-effect framework, with an aim to contribute to existing theory through generalisation (Goertz & Mahoney, 2012). Alternatively, qualitative research attempts to make sense of phenomena in relation to meanings people give to them. Rather than an aim of generalisation, qualitative research aims to expand on the understanding of human behaviour or the phenomena at hand from multiple perspectives (Smith, Flower & Larkin, 2009). In addition to this, a qualitative methodology allows for reflexivity within the research process, through taking into account how the researcher makes sense of their world, whereas quantitative research does not consider this (Koch & Harrington, 1998).

Methods used in previous quantitative research looking at nurses' experiences of behaviours in dementia (e.g. Todd & Watts, 2005; Cohen-Mansfield et al., 2013) have restricted participants to pre-defined categories, which fails to capture the intricacies of how staff make sense of behaviours and respond to them. Qualitative data allows new knowledge to surface without the restrictions of existing theory. This has been demonstrated through a number of qualitative studies looking at staff experiences of working with PsWD (e.g. de Witt & Ploeg, 2014; Nolan, 2007; Watts & Davies, 2014). However, only few of these studies have looked into how behaviours in dementia are made sense of (e.g. Dupuis et al., 2012; Eriksson & Saveman, 2002). Given this gap in literature, a qualitative design

was chosen to better understand the psychological process of sense making and responding to behaviours.

Epistemological Position

Epistemological positions fall on a spectrum from positivist positions to constructionist positions. Quantitative research falls at the positivist end of the spectrum, where an objective reality is perceived. This is in line with a naive realist ontology. Qualitative research originally derives from constructionist philosophical positons, which fall at the opposite end of the spectrum (Barker, Pistrang & Elliott, 2002). Constructionist positions seek to explore individual experiences in line with their perceptions of the experience. As interpretation within research began to emerge and researchers were unable to fit neatly into a positivist position (Madill, Jordan & Shirley, 2000), other positions were developed, such as a critical realist. This position falls midway between positivist and constructionist. It postulates that there is a reality that science can study. However, it takes into account that we use socially constructed theories and methods to explore reality (Madill et al., 2000) and that there can be multiple meanings and perspectives within this reality (Fade, 2004).

How nurses make sense of behaviours will be subjective and shaped by various aspects of their life, i.e. their feelings, previous experiences, expectations etc. However, I am mindful that what the nurses may say is likely to be influenced by their perceptions, i.e. the behaviours 'happen' but it is their perception of the behaviour that will influence how they respond to the behaviour. I therefore adopted a critical realist position.

2.1.2 Interpretative Phenomenological Analysis (IPA)

IPA is informed by hermeneutics, which is the theory of interpretation. It recognises that the researcher needs to interpret or make sense of the participant's interpretations of their experience, which is referred to as double hermeneutics (Smith et al., 2009). IPA is a method which can be used to examine how people make sense of their life experiences. It uses language to examine phenomena within specific contexts and interprets them by exploring the particular meaning that people bring to their experiences (Denzin & Lincoln, 2000). IPA is idiographic as it aims to elicit in detail what the experience for the individual is and what sense they have made of it (Smith et al., 2009). The researcher is not searching for a single 'truth'; multiple plausible truths are acceptable and this is in line with a critical realist epistemological stance (Smith et al., 2009) and the exploratory research question of the present study: How do inpatient psychiatric nurses make sense of and respond to behaviours in dementia?

Phenomenology

Phenomenology is the philosophical approach to studying experiences, through considering how each individual experiences their world. Husserl (1927) suggested the adoption of a phenomenological attitude within the examination of human experience, by looking beyond objects themselves but instead at how this object is perceived and how this perception is arrived at. Husserl (1927) also introduced the concept of 'bracketing'. Within phenomenological enquiry he stated that it is important to move away from the 'taken for granted' and towards a broader phenomenological understanding, which he suggested occurs through reflection on the experience. Heidegger (1962) and Merleau-Ponty (1962) both added to Husserl's (1927) ideas and suggested that phenomenology is not as abstract as Husserl indicated. They suggested that the individual exists in a world full of objects, which may be difficult to look beyond, and therefore suggested that individuals' interpretations of the object are important to understand. It was further suggested that this interpretation is complex and is determined by the individuals' relationship and connection to the world or the object, i.e. worldliness (Heidegger, 1962), intersubjectivity (Larkin, Watts & Clifton, 2006) and embodiment (Merleau-Ponty, 1962). Within phenomenological enquiry, things that are absent are viewed as being just as important as things that are present, in understanding how we view the world and our relationship with the world (Sartre, 1974). The history of phenomenology highlights the importance of the focus on experience and the perception of it, as well as its relationship to it, which is captured in IPA (Smith et al., 2009).

Hermeneutics

Hermeneutics is the second theoretical underpinning for IPA and it refers to the theory of interpretation. The theory of hermeneutics focusses on the methods and processes by which an interpretation is arrived at. Theorists within this strand elaborate on the concept of hermeneutics by suggesting that the careful process of interpretation, in line with existing psychological understanding, can lead to a more meaningful insight than the original participant interpretation (Schleiermacher & Bowie, 1998). Subsequently, new meaning and understanding is brought to light (Heidegger, 1962, Dreyfus, 1991) through this hermeneutic circle. The hermeneutic circle (Smith et al., 2009) is key to the process, as it allows understanding of the whole experience as well as parts of the experience, and to understand one you need to understand the other. This is particularly important for the current research, whereby the aim is to bring the underlying psychological understandings to light.

IPA rationale

There are few studies looking at how nurses make sense of behaviour. For example Dupuis et al.'s (2012) study looked at how staff make sense of behaviours in long term dementia care, however it only drew on challenging behaviour, the impact of the behaviour, and staff response. The findings did not provide a deeper understanding of the underlying process. Evidence suggests that the way nurses respond to behaviour is influenced by how they perceive or frame the behaviour, e.g. attribution literature around control (Todd & Watts, 2005; Paton et al., 2004). In order to understand a participant's interpretation of their experience and how they have made sense of it at a deeper level to create new meaning and insight, I would need to consider the phenomenological aspects discussed above and engage in a hermeneutic process. Furthermore, IPA is in line with my epistemological position of critical realism, whereby nurses can experience the same event but interpret it in different ways and this could be underpinned by their individual beliefs and expectations (Willig, 2008). Given this, IPA was chosen for this study.

Rejected Qualitative Designs

Grounded theory

The aim of grounded theory is to generate theory that is grounded in the data (McLeod, 2011). Dupuis et al. (2012) used interpretative grounded theory (Charmaz, 2006; Daly, 2007), which has the additional aspect of interpretation. However, Dupuis et al. did not engage in a hermeneutic process, as interpretation stopped at the participants' interpretations. This meant the data lacked the additional level of analysis that IPA offers of bringing in a psychological understanding. Furthermore, the interview schedule used in Dupuis et al.'s (2012) study did not allow for detailed exploration of experiences, but rather offered broader and general understanding. Detailed exploration is likely to allow more discussions i.e. about the context, environment, emotions elicited and personal values. All of these elements help to consider unconscious and conscious processes which may be occurring for the individual. This would allow for the development of a higher level of meaning from the data through interpretation that is connected to theory, which is not captured by grounded theory.

Common to all approaches within grounded theory is an exploratory, inductive nature which focuses on theory generation. The aim of my research was to explore the unique lived experiences of nurses' experiences of behaviours, not to develop a theory on this process.

Discourse Analysis

Discourse analysis aims to use language to understand how concepts, identities or relationships are shaped (Starks & Trinidad, 2007). It draws on language to understand the construction of individuals' worlds. Although linguistics is taken into account in IPA, it was not solely my aim for the research. I wanted to look at more than language, i.e. at the connection between the emotional responses to their experience and how the experience is embodied and made sense of.

Thematic Analysis

Thematic analysis aims to identify themes within research. Although it is similar to IPA, thematic analysis does not stem from a typical theoretical underpinning (Braun & Clarke, 2006) and rather than a method in itself, it has been described as a 'tool' that can be used across different qualitative methods (Boyatzis, 1998). Although latent analysis within thematic analysis has been claimed to be similar to IPA, IPA was felt to be more appropriate given its phenomenological and hermeneutic roots, which play a key role in understanding the process of meaning making. Although other qualitative approaches take into account the role of the researcher, IPA explicitly acknowledges the hermeneutic process in all the stages of the study (Smith et al., 2009).

IPA critique

The initial stage of analysis requires it to be broken down into three factors: descriptive, linguistic and conceptual. However, there is a likelihood that an element of depth can be lost given the breadth covered within the analysis, especially with novice IPA researchers (Smith, 2004), whereas with more experienced researchers this is less likely to be the case. Although I am a novice IPA researcher, I felt IPA was the most appropriate method for the research question and, furthermore, I felt the theoretical underpinnings of IPA allowed detailed focus to be given to the lived experience of the participants.

2.3 Participants

Sample size rationale

Given IPA is an idiographic approach, studies that use this method tend to have small sample sizes. Recent publications that have applied IPA to research with a similar area of focus to the current study have had sample sizes of 6-8 (e.g. 6 participants in Johnson, 2016; 8 participants in Ali & Bokharey, 2015; 6 participants in Gill, 2014; 8 participants in Talbot & Brewer, 2015). I chose 8 participants in order to take into account that initial interviews by novice IPA researchers may not hold enough data, as advised by Smith et al. (2009).

Homogenous sample

A homogenous sample was recruited through purposive sampling, which is theoretically consistent with IPA, as it provides insight into a particular experience (Smith et al., 2009). It is also consistent with the epistemological position, as the particular sample chosen would be exposed to similar situations but are likely to hold different perceptions and interpretations of these experiences.

Inclusion Criteria

The sample recruited were inpatient psychiatric nurses, who work with individuals with dementia within an NHS Trust. Requirements for inclusion were:

- To be formally qualified and on the nursing register
- Have a good level of spoken English

Participant recruitment

Participants were recruited from two inpatient dementia services across one NHS Trust. Initial contact took place by attending a team meeting at each location to inform potential participants of the study and to hand out information sheets (Appendix II). Following this, an email was sent to all staff nurses asking them if they would like to take part in the research (Appendix III) and an information sheet was also attached. Potential participants were then identified from those who showed interest through observing whether they met the inclusion criteria. The participants were contacted in order of those who made contact.

2.4 Ethical Considerations

Ethical approval

The study was approved by the Faculty of Medicine & Health Sciences Research Ethics Committee (Appendix IV) and sponsorship was agreed with the NHS Research Ethics Committee (Appendix V). Due to initial difficulty recruiting, which appeared to be as a result of pressures on staff at the sites, following discussions with my supervisors, I submitted a Minor Amendments form to the ethics committee to include a £20 incentive for participation, which was approved by the ethics committee (Appendix VI).

Other considerations

Informed Consent

Given the nature of the study, participants may have felt they were being asked questions that were personal to them and their work and therefore they were made aware from the outset of their right to withdraw their data. I emphasised to each participant that consent regarding study participation may be withdrawn within a week of interview completion. Written consent (Appendix VII) was obtained from participants who took part in the study and participants were informed both verbally and in a written format, via the information sheet, about confidentiality and anonymity, the right to withdraw, the storage of information, and the risks and benefits of taking part. The participants received a copy of the signed and dated consent form and another copy was retained in a locked filing cabinet at the University of Nottingham (UoN). A debrief was held at the end of the interview and the participants were given the opportunity to ask questions.

Confidentiality and Anonymity

Names of participants were not used in the transcripts. Each transcript was given a pseudonym and only I am aware of which pseudonym has been allocated to which participant. The pseudonyms/participant allocations were stored on a password protected document and this was deleted following the one week time period for withdrawal of data. Locations referred to during the interview were removed from the transcripts.

It was stated from the outset that the interviews would be kept confidential unless I considered the participant to be at risk of harm to or from themselves or others. It was made clear that any information from the interview that I felt needed to be shared with others would be discussed with the participant first where possible.

Storage of Information

I endeavoured to protect the rights of the study's participants to privacy and informed consent, and adhered to the Data Protection Act (1998). All audio recordings and any other materials used were stored in a locked filing cabinet at the UoN as stated in the UoN Research Data Management Policy (UoN, 2013). Any electronic files were password protected, saved on a memory stick and also stored in a locked filing cabinet at UoN. The audio recordings will be destroyed after seven years from the date of any publication which is based upon them, as per the UoN Code of Research Conduct and Research Ethics (UoN, 2013).

Risks and Benefits of taking part

Participants were asked about professional experiences and, although it was not felt that they would become upset and distressed, it was still a possibility. To take this into consideration, participants were advised that they could stop the interview at any point. Numbers and email addresses for the researcher and the research supervisors were included on the information sheet for participants to contact for support, if they were affected by any aspect of the interview, or if wanted any further information. Participants were also informed that if they appeared distressed at any point during the interview, they would be given the option to terminate the interview and withdraw their data. If this had happened, they would have been supported by the researcher and directed to numbers and email addresses of supervisors and the researcher.

Taking part in the study gave the participants the opportunity to openly talk about their experiences and a chance to reflect on their professional practice in more depth, which is an opportunity that is unlikely to arise often outside of their workplace, and sometimes even within.

2.5 Data collection

Semi structured interview

Smith et al. (2009) suggest the use of a semi structured interview schedule to guide the interview, however this is suggested to be used as a guide and not as a prescriptive method (Biggerstaff & Thompson, 2008), given each participant will have a different experience and will require individualised tracking of that experience. The aim of the schedule was to ensure the participants felt comfortable during the interview and were given enough structure, as well as enough freedom to explore their experiences. Whilst developing the schedule, I kept in mind the findings of existing literature, as well as thinking about the gaps in the literature. I also consulted guidance provided in literature for interview questions in IPA (Smith et al., 2009; Smith & Osborn, 2007). A copy of the interview schedule can be found in Appendix VIII.

The schedule was used flexibly to allow for individual exploration dependent on what participants discussed. Open ended questions were used (i.e. descriptive, evaluative and comparative questions), as well as prompts. An information sheet summarising the findings of the research will also be developed and offered to participants of the study. Permission to hold contact details of the participants for the purpose of distribution was sought through the consent form.

Procedure

As participants who met the inclusion criteria were identified, they were contacted to arrange a time for interview. The interviews took place at the participant's place of work. When the participant arrived, I talked them through the consent form for the interview process and the information sheet to ensure they understood what the study was about and what to expect. The interview process lasted 45–90 minutes. After the interview, participants were given a verbal debrief. Participants were also given some time at the end of the interview to ask any further questions about the study. This process terminated once the sample size had been reached. I transcribed the audio recordings verbatim, using transcription guidance provided by Smith et al., (2009). This involved transcribing all semantic content but only using the main prosodic features (e.g. sighs, laughs, interruptions, overlaps, ums and ahs). (An example of a transcript can be found in Appendix IX).

2.6 Data Analysis

Data analysis was conducted through guidance provided by Smith et al. (2009); reading and re-reading—immersing self into the original data, initial noting—examining semantic content and language on an exploratory level, developing emergent themes through breaking up the narrative flow of the interview, re-organising the data, searching for connections across the emergent themes, moving on to the next case and repeating, and then looking for patterns across all cases. The following section provides more detail on this process. The process aimed to look at the transcripts in parts and then as a whole, as discussed previously.

Step 1: Reading and re-reading

This step involved immersing myself in the original data. Whilst going through the transcript the first couple of times, I also listened to the audio recording, which is recommended by Smith et al. (2009). During this stage, I also ensured I recorded and made notes of my own most powerful recollections of the interview, in order to get my initial thoughts down and help to bracket these before the initial noting stage. The reading and re-reading of the data also aims to provide a narrative of the transcript as a whole.

Step 2: Initial noting

This step involved examining semantic content and language at an exploratory level, with the aim of producing comprehensive notes of the data. Line by line analysis was used to consider the claims, concerns and understandings of each participant (Larkin et al., 2006). This process required me to maintain an open mind and note anything of interest within the transcript. As part of this stage, I

placed the transcript within a table which had three other columns (emerging themes [for the next stage of analysis], line numbers, and coding). I used the guidance provided by Smith et al., (2009) to help me with my coding by conducting three levels of coding: descriptive (green text), linguistic (red text) and conceptual (purple text) (Appendix X provides an example of part of a coded transcript).

Descriptive notes were developed to capture the phenomena within each unit of the data. This was done through staying close to the nurses' accounts. This helped to capture the key object in the participants' lives and what the meaning of these objects were for them (Heidegger, 1962; Merleau-Ponty, 1962). Due to feeling overwhelmed by the amount of data, I used a more guided approach of object-descriptor coding to help me stay focused (Smith et al., 2009).

The linguistic comments were recorded through exploring participants' use of language. This helped to provide a deeper meaning to the data through identifying what might not be captured at surface level. For example, I recorded the changes in how a PWD was addressed throughout the recall of an experience, e.g. 'gentleman' to 'lovely man'. This allowed me to reflect on why this change might have occurred, whilst also taking into account the other notes.

The conceptual comments allowed for interpretation to occur. Through drawing on the descriptive and linguistic comments, I was able to move away from the more explicit claims made by the participant and develop a more abstract level of coding. This process required me to also think about what was not being said (Sartre, 1974) and reflect on this. For example, in Ali's account there were several times where he commented on being the *'qualified nurse on shift'*, *'I should have to guide others'* and '*never got into any trouble'* highlighting a need to be the expert or to be seen as competent. It was further noticed that he was unable to recall an experience which he felt he could have handled differently and instead drew on how others could handle their experiences differently. In this instance, I wondered if there was a reluctance to share this experience, as it may taint the self-image he desires of being an expert and competent. This stage took a great deal of time to reflect on and refine my ideas. Examples of my coding were taken to supervision to ensure my conceptualisations were not too far removed from the data. This process also allowed for a 'dialogue' to occur between me and the account and to engage in the hermeneutic circle (Larkin et al., 2006; Smith, 2004; Schleiermacher & Bowie, 1998; Heidegger 1962) through bringing in my psychological knowledge and reflecting on my own experiences and feelings that were evoked in this process—the reflexive process (Finlay, 2014). (Reflexivity will be discussed in more detail at the end of this section.)

Step 3: Developing emergent themes and Step 4: Searching for connection across themes

Step 3 required careful synthesis and reduction of the large and comprehensive coding through the development of emergent themes. This meant engaging in a process of fragmentation of the transcript as a whole into parts. Smith et al. (2009) acknowledge that this can be an uncomfortable process to engage in, which is a feeling I experienced at this stage. Step 4 required breaking down the chronological order the themes were in, i.e. in line with the narrative, and mapping them out to see how they fit together. I attempted different ways to capture this stage, which is in line with Smith et al., (2009) who refer to this stage as innovative rather than prescriptive. My concern at this stage was missing something important within the participant's experiences, through fragmentation and also through further interpretation.

Again, due to the large amount of coding produced, I made a table for each participant of all the objects and descriptors (Appendix XI). This then helped me narrow the data down further whilst being able to look at divergence and convergence within the data table and develop themes further (Appendix XII). I also produced mind maps (Appendix XIII) for each participant, to think about the themes' relatedness. I was able to use supervision to make sure there was a clear audit trail. Furthermore, I produced a table for each experience of each participant, to track any particular processes (Appendix XIV) and help me think further about the best possible way of capturing the data.

Step 5: Moving to the next transcript

This stage repeated all of the above steps with the next transcript and so on. Although I tried to bracket my ideas from the previous transcript, I understand that this is not entirely possible. To ensure I was focussing on the individual's experience with limited influence from the previous transcript(s), I wrote reflective notes of two kinds: 1) reflective notes on where I felt there was similarity with other transcripts, and 2) reflection on aspects within the transcript, to ensure focus on the particular individual's experience.

Step 6: Looking for patterns across transcripts

This step required the development of patterns across the transcripts. For this step, I laid out all of the maps that were developed to establish what connections or themes occurred across transcripts. After completing individual mind maps, I had an initial idea of overarching themes, which I changed around a few times. I took a mind map of the overarching theme to supervision and, through several discussions and debates, the final superordinate themes and subthemes were developed. A table showing the final themes and the participants within each theme can be found in Appendix XV. This

was part of the hermeneutic cycle where the parts were then understood as a whole (Smith et al., 2009)

2.7 Reflection and Reflexivity

A reflective diary was used throughout the research process to help me with my decision making. The reflective diary allowed me to reflect on difficulties during the research process and think about how to overcome these. Reflexivity is especially important in IPA, as the essence of the analysis is to understand the participant's version of their experience (Smith, 2007). The reflective diary was also used to consider the process occurring between me and the participant and subsequently me and the data. This allowed me to remain aware of the influence of my own views and social constructs during interpretation of data, through bracketing my ideas and views and not assuming commonality in experience (Finlay, 2006). I have included reflective sections at the end of each part of the extended paper with excerpts from the reflective diary, in order to critically appraise my research journey. Although there were many reflections and decision making processes throughout the research journey, only some have been discussed.

2.8 Quality Assurance

There has been a wide debate about what classifies as good quality guidelines for qualitative research (Chamberlain, 2011; Kaptein, 2011; Todorova, 2011). Smith (2011) developed criteria to assess quality of IPA research in particular, which has been used to assess the quality of this research.

In writing my paper I have employed the seven factors outlined by Smith (2011) that demonstrate quality in IPA research. These are:

1) The paper should have a clear focus

2) The paper will have strong data

3) The paper should be rigorous

4) Sufficient space should be given to the elaboration of each theme

5) The analysis should be interpretative and not just descriptive

6) The analysis should be pointing to both convergence and divergence

7) The paper needs to be carefully written

Smith (2011) acknowledges that there is likely to be room for improvement in all guidelines assessing quality of qualitative research given the subjectivity of it, and therefore suggests the use of other resources alongside these in ensuring the above. Quality in the current research was achieved through the following:

During the study planning and writing stage

During the planning stage and writing of the study, I ensured I kept revisiting the research question to ensure the research findings were in line with this and that the study itself held a clear focus throughout. IPA requires careful selection of the sample and construction of the semi structured interview schedule to allow for detailed answers in relation to the phenomenon in question, as well as flexibility in discussion. This process has been described in sections 2.3 and 2.5 respectively. This helped to provide focus and rigour as well as allowing for rich data. IPA also requires commitment to care with analysis of each case, which was achieved by following Smith et al.'s (2009) process of analysis and consulting with IPA experienced supervisors in the process.

In the results section, interpretations are provided after each account and both convergence and divergence are drawn on. Verbatim extracts from participants are included to support interpretations being made (Elliot et al., 1999; Smith et al., 2009). Furthermore, I believe the paper has produced novel findings, as well as clinical implications deriving from them.

Reflective diary

Quality in qualitative research can also be achieved through reflexivity, reflection and journaling (Vicary, Young & Hicks, 2016). Given this, as mentioned above, a reflective diary was kept. Additionally, I endeavoured to be true to the double hermeneutic, through capturing the participants' sense making and then my interpretation of their sense making, which also demonstrates quality in IPA research (Chamberlain, 2011; Shaw, 2011).

Audit trail

Smith et al. (2009) emphasise the importance of an audit trail in demonstrating validity in qualitative research. This can be done by filing all the data chronologically to show the chain of evidence that leads from the initial documentation through to the final report (Yin, 1989, as cited in Smith et al., 2009). For an IPA project this may consist of initial notes on the research question, an interview

schedule, audio tapes, tables of themes, drafts, and the final theme tables. The appendices demonstrate the chain of evidence, which helps to increase this study's validity. The validity was further increased by having my supervisors look at the annotated transcripts with the initial codes and themes to ensure they were not far removed from the participant's account (Smith et al., 2009).

Supervision

Supervision from my research supervisors and my field supervisor has been used throughout the research process. This has been referred to throughout the extended paper. Supervision helped to achieve credibility of my interpretations as mentioned above.

2.9 Reflective section

Through the planning, recruitment, interviewing and analysis stages, there were a plethora of reflections. Given I am a novice using IPA, there were dilemmas and reflective debates throughout the process. This section highlights some of these reflections. Further reflections and examples of reflexivity can be found in the appendices related to analysis.

Why I chose to do research on this particular area

I was particularly interested in doing a piece of research on dementia care. My interest in this area was fuelled following an experience I had a few years ago, whereby my neighbour spent a whole night outside in the winter due to confusion and loss of memory related to dementia. Although I tried to help him the best I could at the time by speaking to him and also calling the police, it was to no avail. The dementia had progressed to a point where he was unable to recognise me or orient himself to time. I felt helpless and powerless during this experience, just as the participants in the current study described feeling. The feelings this experience elicited in me was one of the reasons dementia care had been at the forefront of my mind during the time research projects were chosen.

Planning

Smith (2007) highlights a need to bracket, from the outset, any preconceptions you may have in line with the research area before any other process begins, and, although I may return to these preconceptions later in the research process, it will be with the new knowledge from the current research at hand. The research area of dementia was chosen due to an interest in this area as mentioned above. At the time of research selection, there were several cases in the media around neglect of dementia patients in care settings. My views at that time around dementia care were

largely based around the lack of good quality care in dementia services. Reactively, I felt there was a need for more education for staff that work with dementia patients. Given the need to bracket these views and preconceptions from the outset, in order to allow for open mindedness, I used my reflective diary to document my views and also allow further reflections. The following passage is an excerpt from my reflective diary during this time.

'I can't even begin to imagine what it must be like to lose all sense of familiarity and surrounding, to lose the world as you know it and be thrown into another world. It frightens me just to think about it. But what's worse and frustrating is how these people are treated by those who are meant to be looking after them. How can people be so cruel, as to hurt those that are vulnerable? To ignore them and treat them as though they are invisible. What drives that? There has to be something happening for them that is so awful to be able to do that, otherwise it just doesn't make sense why you would be in a caring role.'

Although I understood that there were many other factors at play, the emotional reaction was nonetheless strong. Through reviewing literature in the area further, I tried think about the perspective of the staff in relation to the current economy and subsequent pressures on services. Reflecting on my own feelings, and understanding the biases that this could cause within the research process, allowed me to bracket these ideas and pursue the research in a more open-minded manner.

Recruitment and ethics

There is wide discussion in the literature about the use of incentives within research (Head, 2009; Russell, Moralejo, & Burgess, 2000; Singer & Kulka, 2002). Being aware of the drawbacks and the impact an incentive can have (e.g. interviewee bias) developed a dilemma for me. I felt torn between needing participants quickly and also not wanting to use an incentive in case it only drew attention from specific people. Given this dilemma, I had a conversation with my field supervisor working within the services. Using this space within supervision to reflect on what the pros and cons might be and ways to overcome the bias was beneficial and helped me to arrive at the decision of including incentives.

Interview

The interview process was very interesting and thought provoking. Although my first couple of interviews gave some good data, I noticed that as the interviews went on, and I became more comfortable with the process, participants also gave richer data. I felt this may have been because of

the questions becoming more familiar for me and, due to this, I was able to move more flexibly between them in line with the participants' account. For example, below is an excerpt from my reflective diary, when listening back to one of my first interviews.

'*There were so many missed opportunities in this interview. He spoke about behaviours as a result of hallucinations and alternatively behaviours as a result of dementia. But what might have been the difference for him? How might he have distinguished between the two in practice? I should have probed further to understand his experience better.'*

However, this also allowed me to better my interviewing skills thereafter and make use of opportunities that arose to gather richer data.

Consistent with my epistemological position of critical realism, I was aware that participants would hold different beliefs and perceptions from one another about behaviours they see in dementia, which would reflect their own experiences and their relationship with the world as they know it (Heidegger, 1962, Merleau-Ponty, 1967). I was also aware that their perceptions were likely to be different to mine. The interview process required a great deal of reflexivity, where I needed to ensure that I was able to bracket my ideas and perceptions and not influence the interviewees' answers. However, this was a difficult process, which required active reflection and reflexivity during the interviews, thus engaging in a metacognitive process.

There were several interviews which elicited a number of emotions in me in relation to what was being said. For example, during Paul's interview I could feel myself becoming frustrated due to the lack of sense making and the distancing approaches that he spoke about when describing a specific experience.

'I could feel myself becoming frustrated when Paul spoke about ignoring the patient and described her behaviour as attention seeking. I remember thinking at the time to calm myself down as these were the reactions I described before the study. I remember having an urge to challenge this narrative he held but kept telling myself to reframe what I wanted to say to gather information rather than challenge. He later described his sense making as 'it sounds a bit flimsy, I appreciate that', which makes me think I may not have been as discreet as I perhaps thought I was and maybe he picked up on this. At times, it felt I was in a supervision session with him rather than interviewing him and maybe that in itself highlights the strong feeling I had of wanting him to think about behaviours differently?'

Although the reflective diary entry was following the interview, during the interview I was aware of myself becoming frustrated and recognised that these were the reactions I wrote about at the outset. I recall taking deep breaths to relax myself during the interview and remind myself to remain non-judgemental in this process. Although some of the emotions elicited were undoubtedly still present, I was able to remain aware of my questioning style and attempt to reduce the influence it may have.

3. Extended Results

Figure 1 shows all of the superordinate themes and subthemes developed from the full set of data

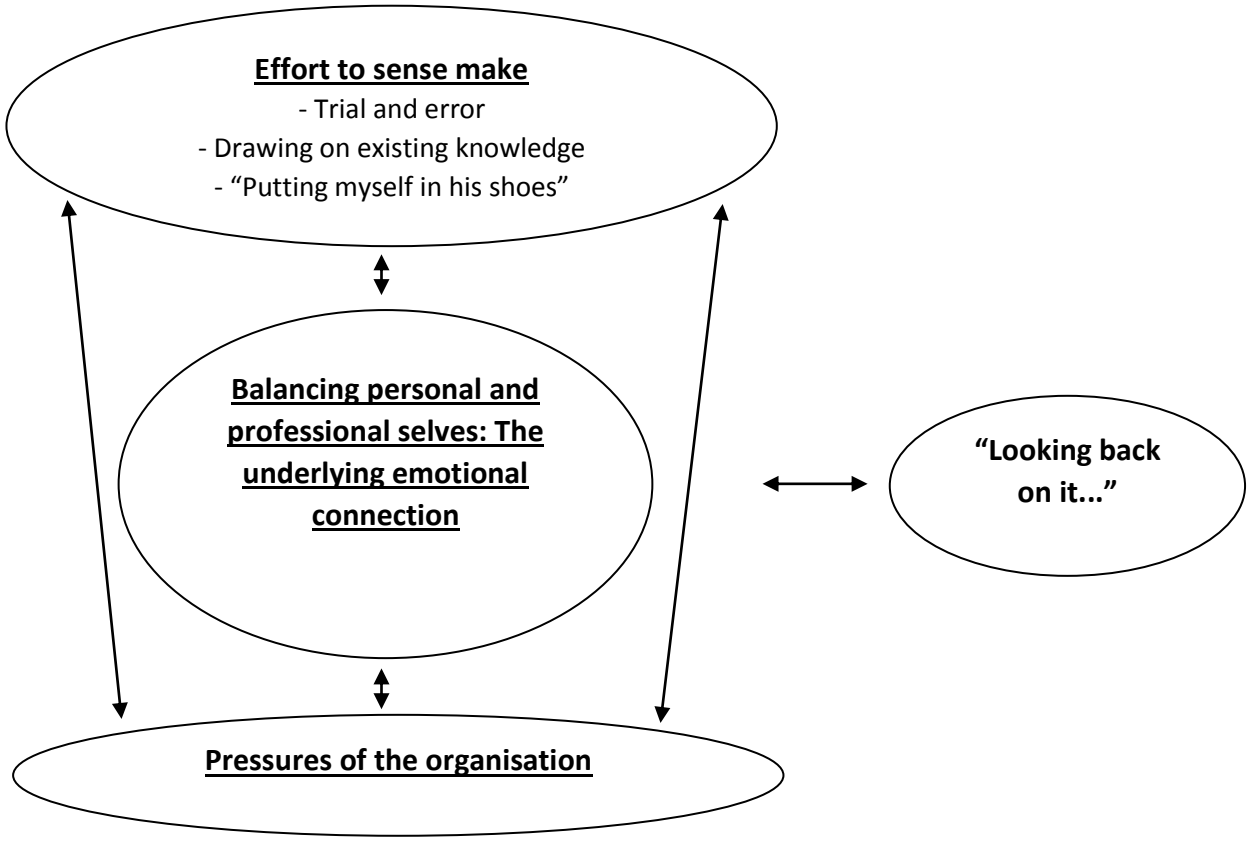


Figure 2. Interrelated superordinate themes and subthemes.

3.1 Effort to sense make

This superordinate theme encapsulates three themes. However, for the purpose of the journal paper this was collapsed into one theme due to word constraints. The three themes are 'Trial and error', 'Drawing on existing knowledge' and '"Putting myself in his shoes"'.

3.1.1 Trial and error

This theme captures a process where participants give meaning to a behaviour through a process of trial and error with response modification based on outcome.

Jill, Jan and Deka all draw on the use of trial and error in their responses in order to make sense of patients' behaviours. Jill discusses her experience of making sense of aggression:

Jill: 'The honest answer is I couldn't tell you [why he was aggressive] *because we try and rule out the agitation that could be there, we try and give him emotional support, we make sure that he's clean, fed and appropriately watered. We try and meet all of his basic needs, we've tried to rule out every sort of possibility and when there's nothing left you're not really a 100% sure on what to do which at times you think, should we withdraw and see if that is better or should we continue to give him full support. I think we've tried both approaches and neither work (laughs)… So it really can be quite hard with things like that when you've exhausted every avenue that you can go.'*

Jill appears to be relying on the outcome of the response to help her make sense of the function of aggression, hence there is an assumption that the behaviour depicts either a physical need or a surface level emotional need that could be reduced through emotional or physical support. Jill appears to convey a feeling of despair in not being able to help despite her attempts. This feeling of despair could be associated with the need to want to help through providing care in line with what she may feel is the desired role of a nurse. Jan and Deka also experience similar feelings when unable to makes sense of a behaviour through this process. Jan also attempts to make sense of aggression through trial and error.

Jan: 'Sometimes it will be a walk in the garden. She likes flowers. Sometimes it will be a cup of tea. Erm sometimes it will be just "can you come and help me do this?" Erm and often she does respond to those things… If she doesn't respond to reassurance, low stimulus, diversion, cups of tea, biscuits, I go through the whole big long list, take her for a walk, exercise, if she doesn't respond to none of that you have no choice but to go down medication route…. you have no choice. Because you have to keep her safe and other people safe.'

Similar to Jill, Jan's responses appear to be reactive, with the purpose of calming the patient in the moment, rather than a proactive strategy of understanding the behaviour. There is a suggestion within her account that medication is a last resort which she would prefer not to use.

This theme particularly captures the difficulty for the participants when they are unable to make sense of patients' behaviours as well as their efforts in their attempts to sense make. When sense

making is unachievable, it seems to have an emotional impact on participants and they also tend to resort to reactive responses.

3.1.2 Drawing on existing knowledge

This theme refers to the process of using existing knowledge as part of sense making. There is a range of knowledge which participants draw on, which includes medical, biological, experiential, knowledge of the patient and relational. However, only some have been discussed.

Knowledge of patient

In some instances, participants' sense-making of behaviours seems to be influenced by their existing knowledge of the patient. Ayo and Deka both spoke about their experiences of a patient who was an ex-soldier and was displaying aggression. Deka's example has been used:

*Deka: 'He was so aggressive—he was an ex-soldier so he would guard his territory all the time. And he used to sleep during the day and was awake at night like a soldier. So each time you approach him or you see him walking, you want to go and find out whether he wants something his fist would be clenched… it was to fight… [*I know] *from the history… I will just pull my pin for others to help … I was alright but you just think one day he will get me'.*

Deka makes sense of aggression as being related to his previous role as a soldier and him still perceiving himself to be one. There is a sense that having this perception and knowledge from the outset appears to have placed fear in Deka, which has impacted on how she responded to the anticipated aggression, i.e. pulling her pin point. This contrasts with how she reacted in another experience of anticipated aggression, where the patient did not have a similar history and Deka used de-escalation and supported isolation to respond.

Paul also uses pre-existing knowledge as part of his sense making process of a patient's behaviour of hanging '*on to his wee'*.

Paul: 'it was just the start of the admission process, they just stumbled across the fact that he got a full bladder which is unusual. So erm, he was re-catheterised—it was the first time this guy had been catheterised —so I took it on myself to speak to the family and found out interestingly enough that this chap— for years has hung on to his wee. So the behaviour in fact was normal for him. Because of

that the catheter was removed because it was decided that it might not be a medical problem but more a personality.'

The behaviour of holding on to his urine was initially seen as a medical problem and problematic for staff, and the intrusive method of catheter insertion was used due to the understanding that staff came to, consistent with the assessment process and routine. However, after finding out more from the family about this behaviour being *'normal'* for the patient, the behaviour appears to be more accepted. There is a sense of acceptance of the behaviour if it is put into the context of premorbid personality.

Control

Another process evident was in relation to participants' attributions for behaviours. Romy describes an experience where she perceived a patient to have a level of control over their behaviour, which appears to have influenced her response.

Romy: 'We had a lady who was very repetitive. She just kept saying the same thing, the same statements, the same questions… Sometimes people forget, don't they? I don't think she'd forgotten that she'd asked. She just needed reassuring… she could realise that [her husband] *needed to know to come and fetch her. So to me erm, she'd got some reasoning, you know she couldn't just forget because she wanted me to reassure that he knew to come at such and such a time to fetch her… and after several nights of this... I thought I'd ignore what she's saying… I was thinking of children really, I don't know why I thought that. I just thought if I ignore this negative behaviour.'*

Romy initially makes sense of the behaviour as the patient being '*anxious*' and needing '*reassurance*'. However, the persistence of the behaviour appears to evoke feelings of frustration, which seems to be reflected through Romy calling the behaviour 'negative'. Her response of '*ignoring*' and withdrawing from interaction with the patient appears to be informed by drawing on knowledge of interacting with children. Romy thinks about how to respond to similar behaviours in children, which seems to guide her response. However, feelings of guilt are then evoked for Romy when the patient calls her *'nasty'* because of her response and the patient's behaviour and anxiety subsequently increases. Similarly, Paul describes an experience of a patient being in control of repetitive behaviour.

Paul: 'I think attention seeking in this case to get staff time… a degree of control unlike the majority of our patients who are a slave to their confusion if you like. That doesn't seem to be the case with this other patient… I have been known to ignore. That's probably the normal response.… When you

get the impression that somebody knows what they're doing, I have problems with that… I can deal with confused people but not people who are aping confusion.'

Through attributing a higher level of control over the behaviour, there is an implication that the behaviour is deliberate and intentional, leading to Paul ignoring the patient as a '*normal*' response, implying regularity. There is a sense that Paul is expecting specific behaviours of individuals with dementia to be unintentional, however when he feels unable to manage the behaviour and there is a perceived level of control over the behaviour, his views regarding the individual change and subsequently his response. This pattern is also consistent with Mel's experience, where she describes a patient she believes to have control over his aggression as *'premeditated'.* As with Paul, this led to a disengaging response in comparison to responses for behaviours Mel perceived the patient to have less control over.

Relational knowledge

Romy uses her knowledge of relationships to make sense of aggression.

Romy: 'I know it's a hospital ward, but the patients don't always know that, so sometimes we're the intruders in the patient's home… they misidentify some of the patients as being their wives or husbands… it's difficult when we've all got the same need whether you've got dementia or not… the basic need to touch or to feel wanted… but it causes aggression sometimes if you try to distract… it's not inappropriate is it if you're in your own home to want to touch somebody or hold hands, but here it is inappropriate, it's difficult… distraction I think is the main thing and erm just guiding people away.'

Romy also draws on the idea that patients are misinterpreting their surroundings because of the dementia. Romy uses her knowledge of both dementia and of relationships, in particular intimate relationships, to make sense of aggression. She appears to understand the behaviour as logical and universal, in relation to intimacy and the '*basic need to touch'*. Romy therefore feels the aggression is a result of taking this '*basic need*' *away* and patients not understanding why this is happening because of the dementia. There is possibly a sense of guilt in relation to this and, similarly to Jan, when the aggression is viewed as acceptable in line with the sense making, the response appears to be less intrusive.

This theme captures a number of ways participants use existing knowledge and understanding to help them make sense of behaviour. In particular, it highlights how this knowledge contributes to

and is influenced by their own experiences. Furthermore, the understanding that participants draw on appears to impact on their perception, and subsequently the response.

3.1.3 "Putting myself in his shoes"

This theme captures the processes involving perceptions that the participant holds of the patients and their behaviours, as well as the influence on and of these perceptions. Paul draws on his own life experience to tentatively make sense of why a patient was aggressive.

Paul: 'I remember once 40 years ago, I had some LSD and that just sent your head just totally stupid and everything seems real, although it was twisted and, when I look back, I often imagine if this is what's going on in these guys' heads… there's wires crossed, nothing's getting through in one piece.'

Paul appears to be making sense of the aggression as a result of individuals with dementia experiencing the world as a distorted version of the reality we experience. Jan also draws on a personal experience.

Jan: 'You know, how tired I am, I have a disabled child at home as well as here so.
Vidya: … it seems like that personal experience as well has an impact? On work?
Jan: Well yeh because I always try to treat everybody the same way as I treat my own disabled child at home. And I give them the care I give her at home. So I know that people get good care… That is a big ethic running through me.'

Jan makes a personal connection to individuals with dementia because of her role in caring for them having some similarities to her role in caring for her disabled child. It is interesting that Jan says *'as well as here',* which could suggest she views individuals with dementia as being similar to children who require a high level of care and nurture, and also a view of individuals with dementia as having a loss of a function, which makes them less able. What also stands out here is her empathy towards individuals with dementia because of the experience of having a family member who is vulnerable and requires care. Through this process of perspective taking, Jan describes a need to behave towards and treat patients she works with as she does her disabled child, where there appears to be a sense of treating individuals with respect and giving *'good care'*. This identification of a patient with a child is also evident for Jill and Deka. It highlights a parent/child relationship as an influence on the participants' response to patients and behaviours. Jill, Mel, Ayo, Romy and Ali also use perspective taking to better understand behaviours.

This theme captures a variety of perspective taking methods that participants engage in. It places importance on participants' needs to respond in a way in which they would want to be responded to, or the way they would want their families to be treated, and how this shapes their view of care.

For some, their sense making is linked to how the behaviour or the individual is perceived e.g. like a child. Some participants place themselves in the position of the patient, with a possible desire to understand what dementia feels like through thinking about their own personal experiences; at times, this was through making sense of behaviours as a result of difficult emotions patients may have felt.

3.2 Pressures of the organisation

This section provides additional examples to the ones in the journal paper.

Ayo describes how staff responses can be influenced by the context and staff can act as triggers to the patient's behaviours.

Ayo: 'For example I'm in bed, it's a natural thing, I'm in bed in the morning sleeping. Probably in my lifestyle or through my life I wake up between the hours of 9 and 10 in the morning. This is when I wake up if I'm not working any shift. Then you come to me in the morning by 7 o clock 'oh Ayo, time to wash and dress'. Well how do I'm meant to react. You, it's a trigger, you're a trigger in the aggression, you're a trigger in the challenging behaviour. So you wouldn't expect me to respond to you like 'ok can you come and wash and dress me' you wouldn't. So the approach goes a long way.'

Ayo reflects on his lifestyle in relation to the routine on the ward to put into perspective how the staff approach can be a trigger to aggression. There is a feeling of acceptance of the behaviour as a result of the sense making, as well as empathy towards the patient in relation to the behaviour. His sense making is related to his understanding of the pressures within the environment and his role in relation to them. However, this approach still needs to be used due to the pressures that are mentioned in the journal paper—*'19 other patients to look after'*—which causes a conflict between knowing he is the trigger and having to continue to be that trigger to manage the shift. Several other participants also discuss their responses as a result of shift management (*Ali, Mel, Deka).* Ayo further emphasises the pressures and impact of staffing levels in relation to patient behaviour.

Ayo: 'If we were getting the staffing level right for individuals with dementia, most of the challenging behaviours I think would, you know, would reduce.'

Mel describes the influence others have within the professional environment. Mel describes a situation where a patient will constantly put herself on the floor.

Mel: '…it's also like, how relatives see what we're doing. Like, we feel like we have to justify ourselves sometimes, they say "Oh that patient's on the floor there, did you know?" But sometimes they just

keep repeatedly putting themselves to the floor because that's where they feel safer… So, it is difficult and it's open to criticism quite a bit, when people who don't realise and don't have any insight into dementia criticise the way that we're caring for patients.'

Mel appears to be in conflict where she tries to negotiate the response and whether it should be tailored to meet the patients need or be tailored to prevent criticism of her care. It appears she feels there is a sense of attack against her caring role which she feels the need to defend against. The pressures of the organisation influencing sense making and responses to behaviours is experienced by all of the participants.

3.3 Balancing personal and professional selves: The underlying emotional connection

This section provides additional examples from the data.

Paul describes verbal aggression from a patient in relation to the death of her husband.

Paul: It's as though the death had escalated—it was clear that she was in denial, but now and again you have to bring her into reality and talk about what's actually happened. She wanted to phone him up to make sure he was dead. Erm, and because—we didn't want to sit her down with the telephone and she didn't know what the phone number was, erm, she'd just get angry. I guess she couldn't process that. She got very angry — "I'm going to call the police"— and then that went on to "you've killed him." I don't know it must be the process of the—the denial— the not being able to deal with it. I guess because we couldn't help her as much as we wanted to help her.'

Paul conceptualises the behaviour as a process of grief/bereavement, which everyone goes through. His sense making appears to be driven by his own personal experience of losing his mum to dementia a couple of months prior to this experience and having gone through his own experience of loss recently, which he mentioned in the interview. An emotional connection appears to be formed through empathy and a shared understanding.

Paul: 'I remember wanting just to help her and sometimes you—you try and put yourself in their position if you like and if you'd lost somebody close to yourself and how that could sort of screw your head up. Just not being able to get on with that. To accept it. And that's how I saw her, erm and I just wanted to try and help the best way I could. Not just give her a blue pill and, erm and get her to sleep for an hour. Erm, realising as I say it that it would be very short lived because you can't just cure things like that with a chat, but for now it just gave her that peace I suppose.'

There is clearly a high level of emotion felt within this account and also as he was saying it during the interview. There is a feeling captured here of wanting to rescue this patient from the loss she is experiencing. This emotional connection is driven by empathy, which seems to strengthen this connection and influence his response to the behaviour. He describes not wanting to *'give* [the patient] *a blue pill'*, which again is removed from the medical/biological model of thinking, which earlier in the interview he was strongly in favour of. Instead, he responds by sitting and talking with her and providing emotional support as a response.

In this example, Paul's personal and professional selves are congruent, where his response to the patient is consistent with his sense making and the emotional connection. However, Paul also describes an experience where his personal and professional selves were in conflict and driven by a more negative emotional connection. Paul describes a situation where he felt anger and frustration towards a patient that he believes has control over her repetitive questioning behaviour. He makes sense of the behaviour as '*attention seeking'* and *'it's a game for her',* again implying intention. Paul appears to abandon the professional context and appears to be purely driven by a negative emotional response to the patient, which has influenced his response of '*ignoring'*. He goes on to specifically comment on the difference in his response and reaction to both patients

Paul: 'There's no pain, there's no hurt. Erm, just—it's—it's like it's a game for her, you can't compare the two. It's easy to get involved as well as you can with that amount of emotional pain that, you know… the first lady was very troubled erm and you just—it just tugged at you to try and take away some of the obvious emotional pain that she's got I guess. So that's easy—that was easy for me to engage with that. Erm, the second patient, erm the behaviour she presents with she'll present with a smile on her face. Nonsensical sort of requests and—so it was the emotional aspect of the two'.

For Paul, his experience with the second patient appears to be a result of not being able to make sense of her behaviour. There appears to be conflict between Paul's personal and professional worlds, where he is unable to take on the role of a containing carer because the patient does not meet the pre-determined role of vulnerable patient. This appears to cause him frustration and impacts on his sense making, where control is attributed to the behaviour and the response in relation to this is punitive/detached: *'I have been known to ignore yes. Erm, that's probably the normal response.'*

Similarly, as discussed in the journal paper, some participants described a conflict between their professional role and their emotional experience, which led to guilt if the professional role overruled the personal belief. For example, Jill talked about her response to a patient who constantly

screamed and pulled at her hair. Jill made sense of this behaviour as the patient reliving a previous traumatic event. Jill commented on using several different responses but to no avail.

Jill: 'I think because I never got any positive feedback from her in any or form, I loathed it. And it wasn't because I don't like her, it was again going back to the hopelessness because I couldn't do anything and just watching someone being so tormented and knowing nothing you do will make a difference and still trying anyway… I'm in a job because I want to help people. But then when you can't help somebody you get annoyed that you can't help them and so then it becomes—it's like an argument with yourself like I don't want to see her because I can't help her. I suppose that's really what it boils down to. I don't really want to get involved because I can't do anything. And I know that sounds really horrible—but it's just this human response is like well, I've done everything I can, we've done everything we can and it's still not good enough, and so I suppose you feel like you've failed in a way... So I suppose in a way it was a failure and so because I couldn't help her, I didn't really want to know. That sounds so harsh.'

There is an element of wanting to gain a positive reward and *'to help'* which is in line with the dominant narrative given to nursing/medical care staff. However, when this narrative cannot be lived, and these values and beliefs that are held cannot be met, Jill appears to reject any form of emotional connection as the inability to help is too painful for her. It highlights a need for some form of reward or good feeling through the caring role. A reduction in motivation and increase in avoidance is present when Jill thinks about not wanting *'to get involved',* however, there could possibly be a feeling of guilt here as she feels the need to justify her response as a '*human response'.* This self-justification does not appear to placate her, as she goes on to talk about feeling '*like* [she has] *failed'* and also a feeling of having '*dehumanised*' the patient.

As with Mel, who wanted to reconnect with a patient she had to disconnect from to fulfil her professional duties, Jan also describes an experience of wanting to reconnect with a patient, following disconnection, whilst attending to personal hygiene.

Jan: He used to try and get out of the holds and kick you, stamp on your feet, try and shin you, anything he could. We'd talk to him really calmly, saying "We're really sorry we're having to do this. It's because this has happened and it's because we need to". But of course, he wasn't getting that—because of course if he did understand he would be going and washing himself… You do feel bad. Erm, but then you just have to say "ok—we did—that happened", apologise and say "I'll try to never make that happen again". But you can't always say you wouldn't have let that happen again, because you don't know if you're coming on another shift and there's two people again.'

Jan makes sense of the behaviour as a result of confusion and disorientation as well as a communication barrier due to cognitive impairment. It is clear that Jan feels bad for having to do what she is as part of her role, which is demonstrated through her apologising whilst she is attending to the patient's personal hygiene. Jan seems desperate to want to reconnect with this patient as he is angry with her and the staff; this desperation is sensed through using verbal apology despite knowing the patient is unable to understand what she is saying. This again highlights a constant battle between emotion related to the patient and having to do a role due to the professional duties.

This also occurs for Romy in relation to an experience mentioned in another theme. She speaks about her experience of a patient who was presenting with repetitive behaviour, which she conceptualised as a presentation of anxiety and worry.

Romy: I just thought if I ignore this negative behaviour. So, I did do that and I mean, I knew it was wrong really but I was in the room and I was doing somebody's medicine and I came out and she asked me the same question and I didn't answer and I went to get the next medication, came to the next patient (speaking fast). So, it must have been about 10 minutes, which was bad… She said "you're nasty—you're being nasty to me". And when I came out I thought oh I am being aw— it's awful. You know and I did feel bad because I could have just said "yes your husband's coming" and left it at that as I've always done… when she asked me again I just answered her then... It's awful I feel awful now.'

Romy appears to unintentionally disconnect from the patient due to the factors occurring around her. This disconnection is presented through her response of ignoring the patient. Her reaction when she is called '*nasty*' seems to come as a surprise for her and there is a sense that the disconnection is broken due to the feeling evoked in her when she is faced with the impact of her response. The emotions evoked in Romy appear to lead to her wanting to reconnect with the patient again. As with Jan and Mel, this reconnection has an underlying need to placate herself from the guilt she appears to experience. It was evident during the interview that recalling the experience brought back the same feelings— '*I feel awful now*'—which could suggest that she is still struggling to process this experience.

The superordinate theme highlights the fragile balance between participants' personal and professional selves that they need to consider when caring for PsWD. It further highlights that participants appear to move through a spectrum of emotional connection in order to fulfil their job role.

3.4 "Looking back on it…"

This superordinate theme highlights changes in sense making and the development of alternative responses during the process of the interview. A change in sense making as the interview progressed was demonstrated by Ali when describing an experience of a patient being physically aggressive during admission.

Ali: 'He was hallucinating wasn't he? He was hallucinating… he probably got some paranoid thoughts in his head towards that staff or towards all of us actually and he was aggressive… There was no way I could have talked to him, I had to restrain him. Simple as that.

Vidya: And he reacted to your response by becoming more aggressive it seemed?
Ali: No I don't think—he was aggressive as it is but obviously, he would have been more resistive because he did not want to get restrained I'd assume… Obviously, he was yeh resistive to what we were trying to achieve or do. He probably wanted to—possibly wanted to leave the ward as well. Probably didn't want to be there either.
Vidya: Why do you think he didn't want to be there?
Ali: I mean for example, I don't know if I put it to you bluntly, if I lock you in here in this locked environment what would you do would you try and leave, would you, could be compliant? Not everybody's compliant. I think that might be the reason, because it was a locked door anyway. He couldn't leave, so.'

Initially Ali conceptualises the behaviour as being a result of hallucinations and paranoia and describes having only the option of restraint to use. However, as the interview progressed Ali was able to empathise with the patient through perspective taking. His sense making changes from considering the aggression to be a result of hallucinations to understanding it as the patient wanting freedom from a locked environment. He appears to normalise aggression and non-compliance through this process and seems to adopt a non-blaming stance. An additional example is from Ayo. As referred to previously, Ayo described a difficult experience of a patient constantly pulling an alarm and his initial sense making was that it was *'attention seeking'* and his response was the use of PRN (as needed) medication and isolation. During the interview, he reflected on this further.

Ayo: 'I managed it in a way that up till now I said ok, even though I was managing it for her safety, I should have managed it differently, because she wasn't on one to one but I would have that morning advised one to one and put her as a priority, but I didn't manage it that way. I used another mentor which like I said I'm still reflecting on it and I learnt from it that I wouldn't go that route again.'

It can be assumed there that there is an element of guilt in relation to his management of the situation, whereby this guilt is present because of his response and subsequently the patient's reaction to the response, where '*she wanted to come out'* of the room she had been isolated to. However, it is particularly significant how reflection on his experience brings an element of change in how he would respond in the future. Interestingly, as the interview progresses and Ayo is prompted to reflect more on his experience, his sense making of the behaviour changes from *'attention seeking'* to *'childlike behaviour',* which he conceptualises as a result of the dementia symptoms of *'confusion'* and '*loss of memory'*. His perception of the intention of the behaviour also changes from an intentional perception to '*She doesn't know what she was doing',* which particularly highlights the power of reflection on beliefs and feelings towards patients following a shift in sense making.

This theme highlights the power of reflective space in processing experiences and the emotions corresponding to them. It highlights the benefits of appropriate reflective space in enabling different ways of thinking about behaviours that are presented and, subsequently, new ways of working and responding in line with sense making.

3.5 Reflective Section

This stage was by far the most difficult stage for me and is also highlighted by Smith et al. (2009) as a challenging process.

Coding

Whilst coding the data, I found myself making interpretations that were removed from the data, which meant that, even though I had a clear process in my mind of how I had come to an interpretation, this was not evident through my coding, meaning this would affect the quality (Smith et al., 2009). Through supervision I was able to reflect on my interpretations and how I came to them. Through describing the difficulty I experienced in this phase, my supervisor recommended I use an object descriptor approach to help me to stay close to the data. Furthermore, I joined an international IPA group/forum, which allowed me to have a support network from a range of backgrounds and experience. I emailed the network to gain ideas about how people have tried to stay close to the data and received a very helpful response from one of the more experienced IPA researchers. The email conversation can be found in Appendix XVI. I found this to be extremely helpful in in the coding stage and this also helped me to increase quality of the data (Smith, 2011).

Clustering theme

There was an abundance of data from the analysis, which made me feel very overwhelmed when it came to condensing it. I found this process frightening, exhausting and eye-opening. Smith et al., (2009) acknowledges that this stage is a difficult process of trying to capture the data in its new form with limited overlap in the themes (Smith et al., 2009). Through reading various different IPA papers and research books to find out what makes a good study, I wanted to ensure that my themes were not mapped on to my interview schedule, which would highlight a lack of quality in the data as it would suggest limited novelty and innovative ideas. My first table I developed of emergent themes (the object and descriptors) appeared to be partly mapped on to the interview schedule and it was difficult to see beyond this, eliciting feelings of hopelessness. The following excerpt from my reflective diary outlines my reflections at this time.

'*There is so much information to restructure and organise, it's really overwhelming. It's difficult to know what to keep in and take out. I have a feeling of wanting to do it all again and reorganise everything, but it is difficult because of time. But to be able to think with clarity I need to take a step away from this.'*

I found writing down what I was going through slowed my thought process and decreased my anxieties. I made a decision at this point to take a break from the data and revisit it. This was extremely helpful as the space away from the data made me realise I needed to move my focus away from the 'objects' and think about the descriptors and the divergence and convergence within these.

4. Extended Discussions

4.1 Discussion of findings

This section will be used to expand on the findings outlined in the journal paper. It will critically draw on the findings in relation to existing theory and literature.

4.1.1 Effort to sense make

This section will discuss in more detail the findings outlined in the journal paper on the efforts to make sense of behaviours. The current study found that nurses engage in a process of trial and error through modifying their responses based on outcomes and what they assume might be the reason for the behaviour. Although research does not explicitly highlight a trial and error process in making sense of and responding to behaviour, there is some research that suggests this process occurs

(Edberg et al., 2008; Gilmore-Bykovski & Bowers, 2013). Edberg et al.'s (2008) findings highlight that nurses tried their best in responding to patients, but did not always know if it was best for them, highlighting an unknown element to their response, which, it can possibly be assumed, is due to not knowing the meaning of the behaviour. Existing research has identified difficulty in communicating with the patient (Smith & Buckwalter, 2005; Feast et al., 2016; Stokes, 2000; Colling 1999; Dupuis et al., 2012). Edberg et al. (2008) provided a deeper meaning to this by describing this phenomenon as 'being unable to reach' the patient, which suggests a desire to want to 'reach' the individual. The current study supports this, in that the initial focus and desire participants had was to reduce or eliminate the behaviour that some found challenging. However, following quality sense making of the behaviour (i.e. premorbid routine was not being followed), this focus changed to identifying (and responding in line with) the patients' needs. The difference here is particularly pertinent, as one is meeting staff needs and the other, when quality sense making is achieved, is meeting the patients' needs. Like Edberg et al. (2008), Gilmore-Bykovski and Bowers (2013) highlighted that nurses mostly made sense of changes in behaviours as being related to pain and therefore trialled a number of interventions to see what would bring the patient's behaviour back to what they conceptualised as normal for the patient. Again, although not explicitly stated, this highlights a process of trial and error, with a theory in mind about the behaviour, to develop a response to reduce the behaviour, which is supported by the current study.

The research also supports Weiner's Attribution theory (Weiner, 1985). The nurses in the current study who perceived the cause of the difficult to manage behaviour as external to the patient (i.e. as a result of the dementia), were able to sympathise with the patient, and felt they would be more able to manage the behaviour in the future (i.e. by applying premorbid routines) were more willing to help, which supports existing research (Dowding et al., 2016; Todd & Watts, 2005; Dupuis et al., 2012; Paton et al., 2004). Research also suggests that staff that attribute the cause of the behaviour to be from within the individual, and thus feel less able to influence the cause in the future, are less likely to help and are more likely to have negative emotions towards the patient (Paton et al., 2004; Todd & Watts, 2005). However, the current study identified more complexities in this process. At times, although the nurses were unable to identify a cause, and hence were not able to attribute the cause within or external to the individual or have an expectancy of future influence, they were still willing to help. In the current study, it was not 'willingness to help' that specifically stood out, but more the dilemma that they did not know how to help despite wanting to. Although sympathy was highlighted as a factor in influencing helping behaviour (Todd & Watts, 2005), the current study found that empathy built through perspective taking influenced both sense making and responding

by bringing the self into the process rather than staying external to it. The nurses tried to understand the individual's world through the information they had available to help them in their responding (Cooney et al., 2014; Cohen-Mansfield et al., 2013; Garand et al., 2000; Kitwood, 1997). However, some nurses within the study viewed the behaviour through the lens of dementia and cognitive deterioration, and so the concept of personhood appeared to be abandoned (Cohen-Mansfield et al., 2013; Dupuis et al., 2012).

This study added to current theoretical literature by identifying processes which led to sense making and responses: particularly acceptance through informed sense making and drawing on existing knowledge, e.g. the patients' premorbid personality. In particular, it highlighted the complex and dynamic nature of sense making and responses, which is not fully captured through existing theoretical models of behaviour.

4.1.2 Pressures of the organisation

There is a vast amount of literature in the evidence base about the impact of organisational pressures on staff wellbeing. In the current study, it was found that the pressures around staff in their working environment led to a change in sense making. For example, the behaviour might initially have been viewed as a result of anxiety, but with increasing pressure it was instead viewed as intentional. This supports existing research findings that burnout has an influence on sense making (Jenkins & Allen, 1998). However, Jenkins and Allen's (1998) study was conducted in care homes where staff are able to build a relationship over a longer period of time and are possibly exposed to different pressures than those of an inpatient psychiatric setting. The current study interestingly highlights the change in sense making within a very short period of time, and in line with the pressures around nurses. It additionally highlights how the change in sense making leads to a change in the response towards the patient, which at times exacerbated the behaviour and related anxiety. This is consistent with existing literature that suggests that patients and behaviours that are originally seen as conceptually appropriate can then be seen in a negative light due to the broader context hindering a psychological understanding from taking place (Dupuis, 2010; Dupuis et al., 2011). In the present study, although a psychological understanding was evident for some participants, it was rejected due to the high levels of pressure.

There are a number of systemic factors that impact on nursing care in dementia services. Within the past decade there have been numerous changes within the NHS, which resulted in financial pressures and a drive to carefully manage resources to meet wider government-based targets (Appleby, Galea & Murray, 2014; Behan et al., 2014). However, pressures from the NHS are not

solely impacting on nurses in inpatient care, there are also the indirect pressures from local authorities and social care, which are highly involved in patient transitions to community services (Appleby et al., 2014). With dementia care being one of the national priorities, a significant amount of funding has gone into research and training for staff (DoH, 2009; DoH, 2012a), however resources within services still appear to be limited.

There is a wider cultural narrative around care of vulnerable adults, encouraging respectful and compassionate care, which has been reinforced even more so by recent incidents of neglect, i.e. the Mid-Staffordshire inquiry (Francis, 2013) and the Winterbourne View serious case review (DoH, 2012b). This is likely to place extra pressure on nurses where they want to fit this narrative but are unable to due to the impact of the pressures from the organisation. Several participants described the feelings of guilt when responses were undertaken as a result of pressure, rather than in line with their sense-making, which positively correlates with existing literature (e.g. Eriksson & Saveman, 2002; de Witt & Ploeg, 2014; Robinson & Cubit, 2007; Edberg & Edfors, 2008; Train et al., 2005). It is evident that sense making is not carried out in isolation, but rather it is carried out over time with the influence of other professionals, the patient, and the organisational environment and culture (Dowding et al., 2016).

4.1.3 Balancing the personal and professional selves: The underlying emotional connection

This section will expand on the discussion from the journal paper.

Research has suggested a complex interplay between staff's personal values and beliefs and the organisational context (Dowding et al., 2016). Although Dowding et al.'s (2016) study was in relation to making sense of behaviours that might signal pain, they postulate that sense making cannot occur without this interplay and both are undoubtedly present within the sense making process. The present study highlighted this interplay, however it added to existing literature through emphasising the underlying emotional connection to the patient, which could be either conscious or unconscious. Participants' negotiations between their personal and professional selves were at times congruent or incongruent, where extreme conflicts led to the abandonment of one. Interestingly, the type of emotional connection developed with the patient had an impact on sense making, the desired response, the actual response, and on the staff member's wellbeing. When an empathic emotional connection was formed, the sense making appeared to be more psychologically informed. Identification derives from the Freudian school of thought, which considers it to be the original emotional connection with an individual (Freud & Strachey, 1922). Wiseman (1978) describes empathic identification as being able to identify with one but with 'aesthetic distance'. Through

empathic identification and trying to understand the patient's distress, participants were able to make better sense of the behaviour through attempting to understand the emotions experienced by the patient.

To ensure quality sense making of behaviours and enhance empathy, a comprehensive understanding of the patient and their background is essential. Coupling this with theoretical knowledge (Nayton, Fielding, Brooks, Graham & Beattie, 2014) helps the development of psychological formulation, which guides informed responses (Johnstone & Dallos, 2013; Chenoweth, Merlyn, Jeon, Tait & Duffield, 2014). Psychological formulation increases empathy (Eells, 2011), through making staff more aware of the patient and enabling conceptualisation of the behaviour in relation to this knowledge. This helps to build a stronger relationship between staff and patient (Nezu, Nezu & Colosimo, 2015). However, despite the development of a specific formulation model for dementia care, The Newcastle Model (James et al., 2006), there is no available literature on the use of clinical formulation in dementia nursing care (Crowe et al., 2008; Smith & Grant, 2016).

In this study, although psychological understanding was at times achieved, when professional responsibilities took precedent the personal beliefs of staff in line with their sense making and emotional connection were abandoned. This resulted in a number of different strategies being employed by participants in order to manage the disconnection or rejection of emotional connection they had formed. These strategies included taking on a task focussed approach, withdrawing from contact, and ignoring the patient. Kitwood (1990) speaks in-depth about these strategies in his work on social malignant psychology. The current research extends his work by considering the emotional connection formed and the complexities for the staff, especially in relation to the subsequent feelings of guilt, blame, hopelessness and helplessness. Previous literature in nursing care has identified that extended exposure to such feelings can at times lead to compassion fatigue (Boyle, 2011), which can impact on the ability to empathically identify with an individual and subsequently the psychological sense making which drives well informed responses (McQueen, 2004). This is also consistent with Moore (1999), who highlighted that dissonance is created between the staff and the patient as a result of strategies that staff might use to manage conflicts, which impacts on the therapeutic relationship. The current study extended this by highlighting that there is also a dissonance in the self, leading to difficult emotions being evoked in staff members.

Some participants spoke of wanting to reconnect with the patient following disconnection, which appeared to be driven by the desire to alleviate guilt. This can be understood within the concept of therapeutic ruptures described in psychodynamic and attachment literature. Attachment theory (Bowlby, 1979) has been extended to attachments in clinical settings. When an individual faces

illness and loss they will tend to seek an 'attachment figure' and interaction in a clinical setting between the patient and the professional becomes this relationship (d'Elia, 2001; Petersen & Koehler, 2006). However, there are likely to be ruptures within a therapeutic relationship and, in order to maintain safety around and within the patient, it is important to repeatedly repair therapeutic ruptures (Loboprabhu, 2006). Loboprabhu's (2006) work was, however, based on informal caregivers and long term care in dementia, which may not reflect the difficulties in repairing ruptures in short term acute assessment wards.

The findings from the study suggest that the repairing of ruptures within acute, inpatient, dementia care settings are more complex than that described in attachment literature. The findings of this study propose that the function of repair is more helpful in alleviating distressing feelings of staff rather than the patients, due to the symptoms of dementia. Furthermore, the pressures within a short-term, inpatient, acute setting are likely to make it difficult to build a secure relationship. Developing attunement with the patient can be hypothesised to be difficult given the difficulties participants described in relationship building due to time constraints and organisational pressures. Nevertheless, the present study highlighted that some participants felt the need to emotionally re-attune/reconnect with patients following disconnection, demonstrating the desire to build a relationship. This can be thought about in relation to Merleau-Ponty's (1962) theoretical ideas of embodiment. When staff need to emotionally disconnect and carry out a task which they may not want to, it may go against their perception of their self and their relationship with the world. The reconnection could possibly help to provide a feeling of self-equilibrium.

4.1.4 "Looking back on it…"

Reflection has been suggested to be the key factor of clinical supervision to help support and positively increase nurse-patient interaction (Van Ooijen, 2000). Brunero and Stein-Parbury (2008) conducted a literature review to assess the effectiveness and key factors of clinical supervision in nursing care in dementia. Although none of the studies they considered took place in an acute setting, highlighting a gap in literature, the findings were important to draw attention to the benefits and impact of clinical supervision. They found that clinical supervision served a range of functions, such as reflective space, peer support, stress relief, and development of skill and knowledge. However, there is a dearth of literature closely examining reflective space in particular, and the emotional and clinical impact of it. Although the purpose of the present study was not to examine the impact of reflection, when participants were given the space to think about their experiences, with relevant prompts and questions, they were able to increase the quality of their sense making.

Furthermore, the findings highlighted a shift in the responses that were subsequently suggested, from distancing to engagement/interaction. These findings support previous research (Cohen-Mansfield et al., 2013; Talerico & Evans, 2000).

Cohen-Mansfield et al., (2013) conducted an interesting study looking at medical vs. non-medical conceptualisations of behaviour when given the space to think about them compared to when given no space. Although this was not labelled as reflective space, when given the space to think about the behaviours, participants appeared to break away from the medical understanding, i.e. felt that behaviours were due to boredom or environmental triggers. This reframing of the reason for the behaviour was also evident in the work of Talerico and Evans (2000), who reconceptualised aggression seen during activities involving touch as an action of self-protection, and hence the patient possibly communicating fear during the staff interaction.

4.2 Clinical implications

This section builds on the clinical implications within the journal paper.

Formulation

Given that the findings indicate that participants who made empathic connections were more likely to want to reconnect with the patients and thus continue to build the therapeutic alliance, it would be beneficial to encourage and support empathic connections and reconnections. One function that psychological formulation serves is to build the therapeutic alliance (Eells, 2011) through having a shared understanding of difficulties.

One of the key competencies for psychologists is formulation (British Psychological Society, [BPS], 2007; BPS/Division of Clinical Psychology, [DCP], 2011). In a study comparing nurse and psychologist attributions of behaviours in patients with dementia (Todd & Watts, 2005), it was found that psychologists made a higher number of attributions compared to nurses. Additionally, nurses experienced a higher level of expressed emotions, in particular anger and sympathy. It can be suggested that the formulation skills that psychologists possess might help to explain this difference. Furthermore, formulation helps to increase acceptance of behaviours, as they are then underpinned by an informed understanding, which might explain the lower level of expressed emotions in the psychologists compared to nurses. Although these are only assumptions that are being made based on current understanding, they highlight a need for informed and effective sense making, which could help to develop more informed and empathic responses.

Clinical supervision and reflective practice

A review on clinical supervision in nursing care for dementia (Brunero & Stein-Parbury, 2008) found that nurses receive an inadequate level of clinical supervision (Butterworth, Bell, Jackson & Majda, 2008), despite research showing that it is beneficial for handling ethical dilemmas (Pearce, Phillips, Dawson & Leggat, 2013; Berggren et al., 2005), reducing levels of burnout (Edwards et al., 2006), improving nurse wellbeing (Begat & Severinsson, 2006), improving nurse–patient relationships (Edberg, Hallberg & Gustafson, 1996; Berg & Welander Hansson, 2000), improving quality of care (Berg & Welander Hansson, 2000) and increasing nursing confidence and empowerment (Gustafsson, Asp & Fagerberg, 2007). Although many theories in relation to sense making are cognitively driven (Dowding et al., 2016; Dowding & Thompson, 2004; Thompson & Dowding, 2009), this study demonstrated that emotional connections also occur, which impact on sense making and responding. From a psychological point of view, different approaches might be needed from management to promote a healthy emotional connection. This could also be beneficial in reducing difficult feelings that staff may experience, especially given the current findings and the findings from previous research, which suggest that these difficult feeling and memories can remain with nurses (Edberg et al., 2008). Nurses who are aware of how their own beliefs and values influence their relationship with patients are likely to have more informed care provision due to having an understanding of the nurse-patient dynamics (Harper & Jones-Schenk, 2012).

Effective and protected clinical and reflective supervision would be vital for this. The current study highlighted that distressing emotions in relation the conflict between personal and professional selves impacted on the quality of care the nurses would have liked to provide, suggesting that they do not operate in the way they best can as organisations do not always provide the environment and resources for this. Therefore, they resort to undesirable responses, which detracts from personhood (Kitwood, 1997). Furthermore, given the divergence of emotional connection that occurs, sometimes within a single experience, there would be a use for clinical supervision in helping nurses to accept that divergence through reflecting on their experience and gaining support to reconnect emotionally with the patient.

Transferability

This divergence in emotional connection and the process that nurses go through could be extended to other inpatient settings. The literature suggests that elements of the process occur in other settings, such as learning disability inpatient care (e.g. Fish & Culshaw, 2005; Hawkins, Allen & Jenkins, 2005; Ravoux, Baker & Brown, 2012) and inpatient adult mental health services (e.g. Bigwood & Crowe, 2008; Gelkopf et al., 2009; Bonner, Lowe, Rawcliffe & Wellman, 2002). Research

for both of these services highlighted staff experiences of distressing feeling following responding to behaviour using intrusive strategies, such as restraint (Bonner et al., 2002; Hawkins et al., 2005; Gelkopf et al., 2009). Staff described feelings of powerlessness, guilt and helplessness. However, they 'turned them off' in order to fulfil their duty (Gelkopf et al., 2009), which is consistent with the aspect of disconnection highlighted in this study. Furthermore, feelings of conflict between strengthening a therapeutic alliance and using intrusive responses which would damage it are also reported (Bigwood & Crowe, 2008). There are also aspects of wanting to reconnect with patients described in the literature of these services (Bonner et al., 2002). These similarities indicate aspects of the process identified in this study, occurring in other inpatient settings. However, further research would need to be conducted to explore this further.

4.3 Future Research

In the early 1990's there was literature suggesting that care provision for dementia patients needed to be holistic and have a hermeneutic understanding rather than a pathological perspective (e.g. Moody, 1992). However, despite the numerous recommendations and findings suggesting the need to better conceptualise behaviour, this is still limited within inpatient dementia settings and more widely. Clinicians will benefit from understanding where the difficulties arise when attempting to implement a more holistic and hermeneutic understanding within acute inpatient settings for individuals with dementia.

The research question covered a broad topic and produced a vast amount of data in relation to sense making and responding. There are many questions that arise from the findings of this study in relation to the interaction between sense making and responding, as well as the two separately. For example, the study highlighted both conscious and unconscious emotional processes that might influence sense making and responding. The study found a difference between the two, whereby a reconnection was sought when there was a conscious process of disconnection or use of an undesirable approach. However, this reconnection was not observed in the participants where there appeared to be an unconscious emotional process. Research looking in to the unconscious process in more depth could help strengthen the implications for these findings in particular.

4.4 Strengths and Limitations

This section will provide further strengths and limitations of the paper.

Limitations

There were several imitations of this study. Additional limitations to the ones highlighted in the journal paper have been discussed in this section.

Demographic data and contextual information

Demographic data are important aspects of a study (Connelly, 2013). However only a limited amount was collected from the participants in this study, which is a significant limitation. Gathering such data would have helped to contextualise the findings and also allow the data to be used for secondary research, e.g. looking at years of experience against sense making and responses, or ethnic diversity within sense making and responses. Furthermore, the data collection stage lacked participants' personal experience, which would have added depth to the contextual information (Mack, Woodsong, Macqueen, Guest & Namey, 2005). The participants spoke about themselves in the professional context but found it difficult to speak about themselves as a person (their personal worlds). It can be hypothesised that this could be due to wanting to keep difficult experiences and emotions related to work separate from their personal lives, hence finding it difficult to talk about the impact of their personal experiences. For example, Romy specifically stated during the interview that she keeps both her personal and professional worlds separate and forgets about her role as a nurse as soon as she leaves the workplace.

Location of interviews

The interviews for the study took place in the participants' workplaces. Research has found that an increased level of stress and pressure can reduce reflective ability (Kinman & Grant, 2011). During the interviews, many participants discussed the increase in pressures in their workplace due to low staffing levels. Therefore, holding the interviews in an environment where they felt high levels of stress may have reduced their reflective ability during the interview. However, the questions used within the interview were specifically developed to enhance reflections of their experiences Therefore, it is hoped that the location of the interview had minimal impact if any. Furthermore, participants did not comment or raise any concerns about having the interview in the workplace.

Wording of questions

The concept of 'behaviours in dementia' was kept open and participants were not specifically told to focus on challenging behaviours. This allowed them the opportunity to talk about all behaviours they observe rather than only challenging behaviours, which previous research has predominantly focussed on. Despite keeping the concept open, most experiences discussed were about behaviours that participants found challenging. Although this was not explicitly asked for in all of the questions, there may have been an implicit suggestion embedded in them due to the way they were phrased. For example, 'handled a behaviour' would imply that a behaviour needed 'handling' and

intervention. However, another explanation could be that there is a social and clinical context to the area of research, which could mean participants were more inclined to think about challenging behaviours. Nonetheless, this limitation helped me to reflect on the complexities and importance of the phrasing of interview questions.

Constraints of the topic

The topic area of this study focussed on how nurses made sense of and responded to behaviours in dementia care. The questions being asked were of a personal nature as they were about the individuals' responses to behaviours of vulnerable adults. Given this, participants may have felt anxious about speaking openly if they felt their behaviour was unprofessional, and hence there may have been a fear of dismissal or researcher judgement. This could suggest that participants might have given answers the researcher wanted to hear or concealed the whole truth (Lee, 1993). However, despite the sensitive nature of the topic, participants appeared to talk openly about their experiences, e.g. one participant spoke of his experience consuming LSD, whilst another spoke about 'hating' working with a particular patient, demonstrating honesty in their answers.

Missing quality checks

There are numerous debates about the assessment of the quality of qualitative research (Chamberlain, 2011). Assessing qualitative research is much more complex than quantitative research, whereby quantitative research is evaluated against validity and reliability criteria (Smith et al., 2009). However, this is difficult to evaluate for qualitative research and therefore various guidelines have been developed for assessing quality in qualitative research. Given the difficulties in assessment of quality, it is important to be thorough with quality checks. Although this study followed Smith's (2011) guidelines for quality of IPA research, as well as adding additional quality checks, there were some quality checks which were not used that would have increased the quality further. For example, I could have asked my supervisors to listen to the interviews against my transcript, which could have been an additional quality check for the transcribing stage. Furthermore, it could have aided reflection on the interview process, which may have informed and enhanced the quality of future interviews.

Novice IPA researcher

A final limitation of the study was that I am a novice IPA researcher. This meant that my coding of the data tended to be more descriptive than interpretative, which Smith et al. (2009) describes as common in novice IPA researchers. I was aware of this being a possible limitation from the outset and ensured I made use of supervision effectively to build on my interpretative skills. For example, I had two supervisors reviewing coding for parts of each interview.

Strengths

Novel findings

One strength of the study was that it produced novel findings, which resulted in various clinical and research implications. I felt the findings of the study provides a new understanding of the processes that nurses go through when they are making sense of the behaviours they are presented with. These findings may also be extended to nurses in other services, demonstrating transferability of the findings despite this not being an aim of the study.

Dissemination

The findings have been disseminated at the service's clinical effectiveness meeting, where it was received with a great deal of interest. Following the meeting, a subsequent meeting was requested by the Community Services Manager, who felt the results also reflected the difficulties arising for her nursing staff. The meeting was requested to think about the clinical implications and how best to support staff to reconnect (Appendix XVII displays the presentation used for the clinical effectiveness meeting). Furthermore, the final journal paper will be submitted for publication.

4.5 Conclusions

The findings of this study contribute to extant literature by highlighting the emotional connection to the patient that underlies the negotiations which occur between nurses' personal experiences and professional worlds. Moreover, it provides an initial understanding of how this can impact on their sense making and responses to behaviours, which the study found occurs through a range of processes and within the context of organisational pressures. The emotional connection forms a spectrum consisting of 'empathic connection', 'disconnection', 'rejection of connection', and 'reconnection', all of which can occur within one experience for one individual. The study specifically recognises the need for nurses to be able to move back and forth through the spectrum in order to deliver their professional duties, and therefore that there is a need for nurses to be supported in emotional reconnection with patients.

In conclusion, nurses are presented with different behaviours daily. The meaning making process is dynamic and occurs moment-by-moment, dependent on a number of factors that might be occurring at the time. Nurses are having to manage a whole barrage of emotions in every shift and terms such as 'burnout' do not fully capture the nuances and the personal processes that nurses go through as professionals within this context. The findings have various clinical and research

implications in relation to supporting staff in making sense of behaviours effectively in order to carry out well informed responses, given that previous research has found that staff responses impact on patient quality of life and their personhood.

5. Reflections

5.1 Write up

In the 'planning' reflections section (section 2.9), I mentioned the preconceived ideas I had at the start in relation to staff working in dementia care. The write up was a very interesting process for me, where my view at the beginning had been about nurses needing more education around dementia patients' care, experiences, feelings and the subsequent impact, but by the write up stage there was quite a big shift in this. I felt empathy towards the nurses working in the setting and a feeling of wanting to help them. I reflected on this change and it took my focus back to the analysis stage. The process of deconstructing within IPA, to break the whole interview into parts and then bring them back together through the theme development (Smith et al., 2009), opened my eyes to a new narrative and perception. This could easily have been missed if this in-depth process had not been carried out. Given that I had faced a range of challenges and difficulties in the analysis stage, as discussed in section 2.9, the true value of IPA stood out for me in the write up, where I was able to think about this 'new whole' with theoretical understanding.

5.2. Journal choice

As my themes started to emerge, I was able to think about the existing data in relation to my findings. Through my literature review I knew that it was not only nurses in dementia settings that experience the conflicts and the ethical dilemmas that arise in inpatient settings. There were also nurses in LD settings and mental health settings. This made me think about the difficult processes that many nurses working in positions of great responsibility and environments of high pressure go through. There was a dilemma about the impact of the research within a dementia journal as opposed to a broader journal. I consulted with my supervisors about this and, after some deliberation, we decided the findings would be helpful to a wider audience and not only nurses in dementia care. Therefore 'Ageing and Mental Health' was chosen.

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APPENDICES

Appendix I. CASP (2006) questions and considerations

1. Was there a clear statement of the aims of the research? (HINT: Consider - What was the goal of the research? Why it was thought important? Its relevance)
2. Is a qualitative method appropriate? (HINT: Consider - If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants. Is qualitative research the right methodology for addressing the research goal?)
3. Was the research design appropriate to address the aims of the research? (HINT: Consider if the researcher has justified the research design e.g. have they discussed how they decided which method to use?)
4. Was the recruitment strategy appropriate to the aims of the research? (HINT: Consider - If the researcher has explained how the participants were selected. If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study. If there are any discussions around recruitment e.g. why some people chose not to take part?)
5. Was the data collected in a way that addressed the research issue? (HINT: Consider - If the setting for data collection was justified. If it is clear how data were collected e.g. focus group, semi-structured interview etc. If the researcher has justified the methods chosen. If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? If methods were modified during the study. If so, has the researcher explained how and why? If the form of data is clear e.g. tape recordings, video material, notes etc. If the researcher has discussed saturation of data)
6. Has the relationship between researcher and participants been adequately considered? (HINT: Consider - If the researcher critically examined their own role, potential bias and influence during (a) Formulation of the research questions (b) Data collection, including sample recruitment and choice of location. How the researcher responded to events during the study and whether they considered the implications of any changes in the research design)
7. Have ethical issues been taken into consideration? (HINT: Consider - If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained. If the researcher has discussed issues raised by the study e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study. If approval has been sought from the ethics committee)
8. Was the data analysis sufficiently rigorous? (HINT: Consider - If there is an in-depth description of the analysis process. If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process. If sufficient data are presented to support the findings. To what extent contradictory data are taken into account. Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation)
9. Is there a clear statement of findings? (HINT: Consider - If the findings are explicit. If there is adequate discussion of the evidence both for and against the researchers arguments. If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst). If the findings are discussed in relation to the original research question)
10. How valuable is the research? (HINT: Consider - If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy? or relevant research-based literature? If they identify new areas where research is necessary. If the researchers have discussed whether or how

the findings can be transferred to other populations or considered other ways the research may be used)

Appendix II. Participant Information Sheet



Division of Psychiatry & Applied Psychology
School of Medicine

Participant Information Sheet[3]

Title of Study: A qualitative study looking at inpatient nurses' experiences of overt behaviours in dementia

Name of Researcher: Vidya Fatania
Research Supervisors: Anna Tickle and Danielle de Boos

We would like to invite you to take part in our research study. Before you decide if you would like to take part we would like you to understand why the research is being done and what it would involve for you. The researcher will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

Individuals with dementia present with a range of different behaviours which nurses work with on a day to day basis. These behaviours might be understood differently by each individual nurse depending on a range of factors. The purpose of this study is to obtain some knowledge and understanding from you about your experiences of working with behaviours that individuals with dementia present with. The study is being carried out as part of the researcher's Doctorate in Clinical Psychology.

Why have I been invited?

You are being invited to take part because you are a qualified nurse working in an inpatient dementia service. We are inviting 6-8 participants who meet the criteria to take part. The criteria to take part is: -

- To be a registered nurse.
- Work with inpatients with dementia.
- Speak English fluently.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are free to withdraw at any time during the interview or up to a week after the interview without giving a reason. This would not affect your legal rights.

[3] Vidya Fatania Participant Information Sheet Draft 3.2 Final Version 1.2 date 08.04.15

What will happen to me if I take part?

If you decide to take part in the study, you will be asked to attend one interview which will last 45-90 minutes. The interview will either take place in a quiet room at your workplace or in a room at the University of Nottingham, depending on which location you will feel more comfortable at to talk about your work. The interview will be audio recorded for the purpose of transcribing and analysing after the interview is complete. Before the interview, the consent form and the interview sheet will be discussed to ensure you fully understand the study and are happy to take part. The interview itself will consist of several questions which will give you the opportunity to discuss your experiences. There are no right or wrong answers with this interview and the emphasis will mainly be on exploring your experience in detail.

Expenses and payments

Participants will be paid £20 to take part in the interview and travel expenses will be offered for any visits incurred as a result of participation.

What are the possible disadvantages and risks of taking part?

As the interview will require you to talk about aspects of work and experiences within your work, it may cause a certain level of discomfort for you. However, if you do experience feelings of discomfort, please make the researcher aware of this and the interview will either be terminated or you will be supported to continue if you choose to do so.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help to provide further knowledge into nurses experiences of working with individuals with dementia and help to identify how better to support nurses. The interview will give you an opportunity to reflect on your professional work, which may be an opportunity that does not arise often outside of work for you.

What happens when the research study stops?

At the end of the research study you will be given the opportunity to ask any questions and you will be reminded of the numbers to contact if you think of questions at a later stage.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do so by then contacting the Research Ethics Committee Administrator, c/o The University of Nottingham, School of Medicine Education Centre, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: louise.sabir@nottingham.ac.uk.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

The report of the study will include quotes from interviews, but these will be kept anonymous. If anything you said in interview is quoted, it will not be possible for anybody to identify you as the source.

Your personal data (address, telephone number, email) will be kept until the end of the study so that we are able to contact you about the findings of the research (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Every effort will be made to maintain confidentiality, unless in the event that information is disclosed which may raise concern about you being at risk of harm to or from yourself or others. In such cases, it will be made clear that any information you first where possible.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you decide to withdraw at any time during the interview or up to a week after the interview your data can be discarded and will not be used, however if you decide to withdraw your data after the weeks period following the interview then the data collected cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?

This research study will be written up for a doctoral thesis. It will also be written into an appropriate format to be submitted to a journal and may be presented at appropriate conferences. To ensure that participants are not identified in any written or verbal dissemination of the findings of this study, pseudonyms will be used and any personal information will be changed. An information sheet summarising the findings of the research will be developed and be posted out to you which will require securely holding your personal

details until the end of the study in order to do this. Please let the researcher know if you do not want a copy sent out to you.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by Nottinghamshire Healthcare NHS Trust.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the University of Nottingham Research Ethics Committee.

What do I do if I want to take part?

If you would like to take part in this study please email me on the address below to arrange a time and date to meet for the interview.

Further information and contact details

Researcher – Vidya Fatania
lwxvf@nottingham.ac.uk
0115 8466646

Research Tutor – Anna Tickle
anna.tickle@nottingham.ac.uk
0115 8466646

Research Supervisor –Danielle de Boos
danielle.deboos@nottingham.ac.uk
0115 8466646

Appendix III. Email to staff

Email to Staff[4]

Dear All,

Following my attendance at your staff meeting on (DATE) to inform you about the study I am completing as part of my Doctorate in Clinical Psychology, I am writing to invite those who are interested to contact me to arrange a date for interview.

The study will be investigating your experiences of working with individuals with dementia. It aims to give nurses working in an inpatient setting an opportunity to talk about their experiences of working in an inpatient dementia setting. The data from this study will help gain a better understanding of your experiences in order to inform practice. Each interview will take 45-90 minutes and each participant will be paid £20 for taking part. Attached is an information sheet providing further information of the study. If you have any questions regarding the study, please do not hesitate to contact me.

Please email me if you are interested in taking part and we can arrange a time and date for the interview.

Many thanks,

Vidya

[4] Vidya Fatania Email to Staff Draft 1.1 Final Version 1.1 date 08.04.15

Appendix IV. Approval letter from the Faculty of Medicine & Health Sciences Research Ethics Committee

Direct line/e-mail

+44 (0) 115 8232561

Louise.Sabir@nottingham.ac.uk

Faculty of Medicine and Health Sciences

Research Ethics Committee
School of Medicine Education Centre B Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham
NG7 2UH

19th January 2015

Vidya Fatania

Trainee Clinical Psychologist

Division of Psychiatry and Applied Psychology Yang Fujia Building

Jubilee Campus Wollaton Road Nottingham NG8 1BB

Ethics Reference No: T11122014 14106 SoM PAPsych PhD – please always quote
Study Title: An interpretative phenomenological analysis looking at inpatient psychiatric nurses' experiences of overt behaviours in dementia.

Chief Investigator: Thomas Schroder, Director of Trent Doctorate in Clinical Psychology, Division of Psychiatry and Applied Psychology, School of Medicine.
Co Investigators: Vidya Fatania, Trainee Clinical Psychologist and PhD student, Anna Tickle, Academic Tutor for the Doctorate in Clinical Psychology, Danielle de Boos, Clinical Tutor and Lecturer in Clinical Psychology, Division of Psychiatry and Applied Psychology, School of Medicine.

Duration of Study: 12/2014-01/2016 13mths **No of Subjects:** 8 (+18yrs)

Thank you for submitting the above application which has been reviewed by the Committee and the following documents were received:

Nurses Experiences of Dementia:

- FMHS Research Ethics Application Form dated 20.11.2014
- NHS R&D Form IRAS Version 3.5 164561/700194/14/450
- Sponsorship Statement University of Nottingham dated 10 November 2014

- Evidence of Insurance – The University of Nottingham, Henderson, 30 July 2014.
- Protocol draft 5.0 Final version 1.0 date 20.11.14
- Consent Form Draft 3.0 Final Version 1.0 date 20.11.14
- Email to Staff Draft 1.0 Final Version 1.0 date 20.11.14
- Interview Schedule Draft 2.0, Final Version 1.0 date 20.11.14
- Participant Information Sheet Draft 3.0 Final Version 1.0 date 20.11.14
- Participant Information Sheet Draft 3.1 Final Version 1.1

date 11.12.14 These have been reviewed and are satisfactory

and the study is approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

1. You must follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).

2. You must notify the Chair of any serious or unexpected event.

3. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

4. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely



Dr Clodagh Dugdale

Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix V. NHS Research Ethics Committee Sponsor Letter

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Research and Graduate Services
University of Nottingham
King's Meadow Campus
Lenton Lane Nottingham
NG7 2NR

Our reference:
RGS 14106
IRAS Project ID:
164561

0115 9515679
Sponsor@nottingham.ac.uk

NHS Research Ethics Committee
Health Research Authority

Thomas Schroder
Yang Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

10 November 2014

Dear Chair of the Ethics Committee,

Sponsorship Statement

Re: An interpretative phenomenological analysis looking at inpatient psychiatric nurses' experiences of overt behaviours in dementia

I can confirm that this research proposal has been discussed with the Chief Investigator and agreement to sponsor the research is in place.

An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.*

Any necessary indemnity or insurance arrangements will be in place before this research starts. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

The duties of sponsors set out in the NHS Research Governance Framework for Health and Social Care will be undertaken in relation to this research.**

* Not applicable to student research (except doctoral research).
** Not applicable to research outside the scope of the Research Governance Framework.

Yours faithfully

Angela Shone
Head of Research Governance
University of Nottingham

Appendix VI. Minor Amendments Approval Letter

Direct line/e-mail

+44 (0) 115 8232561

Louise.Sabir@nottingham.ac.uk

Faculty of Medicine and Health Sciences

Research Ethics Committee
School of Medicine Education Centre B Floor, Medical School
Queen's Medical Centre Campus Nottingham
University Hospitals Nottingham
NG7 2UH

19th January 2015

Vidya Fatania

Trainee Clinical Psychologist

Division of Psychiatry and Applied Psychology Yang Fujia Building

Jubilee Campus Wollaton Road Nottingham NG8 1BB

Dear Vidya

Ethics Reference No: T11122014 14106 SoM PAPsych PhD – please always quote **Study Title**: An interpretative phenomenological analysis looking at inpatient psychiatric nurses' experiences of overt behaviours in dementia.
Chief Investigator: Thomas Schroder, Director of Trent Doctorate in Clinical Psychology, Division of Psychiatry and Applied Psychology, School of Medicine.
Co Investigators: Vidya Fatania, Trainee Clinical Psychologist and PhD student, Anna Tickle, Academic Tutor for the Doctorate in Clinical Psychology, Danielle de Boos, Clinical Tutor and Lecturer in Clinical Psychology, Division of Psychiatry and Applied Psychology, School of Medicine.
Duration of Study: 12/2014-01/2016 13mths **No of Subjects:** 8 (+18yrs)

Thank you for notifying the Committee of amendment no 1: 8th April 2015 as follows:

> Addition of an incentive to take part to improve recruitment: Participants will now receive £20 for participating.

and the following revised documents were received:

Nurses Experiences of Dementia:
Protocol draft 5.1 Final version 1.1 date 08.04.
Email to Staff Draft 1.1 Final Version 1.1 date 08.04.15
Participant Information Sheet Draft 3.2 Final Version 1.2 date 08.04.15

These have been reviewed and are satisfactory and amendment no 1: 8th April 2015 is approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

1. You must follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).

2. You must notify the Chair of any serious or unexpected event.

3. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

4. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

Dr Clodagh Dugdale
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix VII. Consent Form



CONSENT FORM[5]

Title of Study: An Interpretative Phenomenological Analysis looking at inpatient psychiatric nurses' experiences of overt behaviours in dementia

REC ref: ***T11122014 14106 SoM PAPsych PhD***

Name of Researcher: Vidya Fatania

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number ……dated..... for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that the data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

[5] Vidya Fatania Consent Form Draft 3.0 Final Version 1.0 date 20.11.14

4. I understand that the interview will be recorded and that direct anonymised quotes from the interview may be published ☐

5. I agree to take part in the above study. ☐

6. I would like a summary sheet of the findings from this study when it is complete. ☐

_____ _____

Name of Participant Date Signature

_____ _____

Name of Person taking consent Date Signature

2 copies: 1 for participant and 1 for the project notes

Appendix VIII. Semi structured interview schedule

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1) How do you find working with individuals with dementia?

2) What types of dementia related behaviours do you see in the people that you work with?

3) Are there some behaviours that you find are more difficult to manage than others? If so, tell me about those that are more difficult.

4) How do you make sense of these behaviours?

5) Tell me about an experience of when you felt good about the way you handled the dementia related behaviour of a patient

a. What sense did you make of it?
b. How did you respond to the behaviour?
c. How did you make sense of your response?
d. What other factors may have influenced your response?
e. How did the patient react to your response?

6) Tell me about an experience of when you felt you could have handled the dementia related behaviour of a patient differently

a. What sense did you make of it?
b. How did you respond to the behaviour?
c. How did you make sense of your response?
d. What other factors may have influenced your response?
e. How did the patient react to your response?

7) Can you tell me about an experience where you have found the dementia related behaviour of a patient challenging?

a. What sense did you make of it?
b. How did you respond to the behaviour?
c. How did you make sense of your response?
d. What other factors may have influenced your response?
e. How did the patient react to your response?

8) What do you feel are the main differences in these experiences?

a. (How do you make sense of the difference in your response in these experiences)

9) What factors do you think may have influenced your responses?

Prompts

Can you tell more about that?

What sense did you make of that?

What did this mean to you?

Appendix IX. Example of a transcript (Mel)

(54.15 mins)

Int Ok, erm, so I'll start off with more of an open question. How do you find working with individuals with dementia?

Mel I find it very challenging. Erm, mentally draining sometimes. Erm, and I also sometimes find that you can become complacent sometimes because you're exposed to it on such a regular daily basis and that sometimes you just automatically know how patients are gonna be. It can become quite complacent at times.

Int And what kinds of dementia related behaviours do you normally see on a day to day basis?

Mel Aggression, agitation, frustration, confusion, muddled speech, expressive dysphasia, erm, a lot of frustration which is based on them being disorientated, confused. Erm, aggre – fear not aggression that can be misinterpreted as aggression erm which is actual fear because they don't know who we are erm don't know where they are or anything like that. Erm, and I think a lot of the behaviours erm are linked up together they actually cause either the – agitation or aggression from it or fear.

Int Right ok, so it's quite a few there.

Mel There's a lot yeh.

Int Are there any that you find more difficult to manage than others?

Mel Erm, yes. I think – I think it's difficult when the patients become – gets insight and starts to get quite tearful because there's the barrier of communication and if they're hard of hearing and they're not able to understand our language properly because of the dementia. It's hard for us to sometimes give them that reassurance erm and some of them when they do get the insight they do become very very upset erm and they actually realise "this is my life". Erm, even though it might only be the odd time that they get that snippet, but that's difficult because of the barriers of them understanding and communicating. Sometimes you could make it worse because you could be giving them that support and reassurance but then they also can't really understand what you're saying and it can have a bit of a knock on effect. Although we don't come across it as much as the aggression and agitation, that seems to be the focus of the dementia. But when we do get patients that are very insightful sometimes and it does affect them, it can be quite difficult

Int Are there any other ones apart from that insight that you see that you find difficult to manage?

Mel Erm – we – we find difficulties with erm patient falls – it's a biggy, when they've got poor spatial awareness, where patients, walk into just walk into walls and bang their heads on like the windows thinking that that's a way through so their perceptions completely, you know wrong and they. Yeh they fall and it's difficult to manage that because we don't know when they're going to fall and we don't know how they're always perceiving, what they're perceiving and it's so difficult to manage that because they could be walking down the corridor and then they just bang into a wall and we can't really always stop, stop that, you know that's very difficult to manage. And when they've fallen on thein floor, what do we do to manage that behaviour, do we let them fall on the floor because that's where it feels safer, because that's probably one of the reasons why they do because of the sense of gravity, erm or to other people who come on the ward it looks wrong because we're actually, it looks like we're neglecting the patient because we're leaving them to crawl around on the floor. Or do we get them up? But then you know, change their sense of gravity again. I don't know that's difficult one as well, when they are crawling on the floor because – and it's also like, how relatives see what we're doing. Like, we feel like we have to justify ourselves sometimes, they say "Oh that patients on the floor there, did you know?" But sometimes they just keep repeatedly putting themselves to the floor because that's where they feel safer, but it's how to manage it and how to actually nurse that kind of behaviour, that always becomes quite challenging and how we deal with it. We try to take every patients, you know, behaviours individually but sometimes it comes down to what are we actually going to do to – are we going to keep sitting them down? Or are we going to let them crawl on the floor? Or are we going to put them in a room on their own where we can let them just you know mill around on the floor? So it is difficult and it's open to criticism quite a bit, when people who don't realise and don't have any insight into dementia criticise the way that we're caring for patients.

Int Yeh, how do you – What impacts on your response? So you mentioned a number of different responses that you could have when somebody is either on the floor or crawling on the floor, and the way you made sense of their crawling is that they feel safer because of the gravity and they're got more awareness I guess and more stability being on the floor.

Mel Yeh that's right yeh.

Int And you mentioned a number of different ways that you might respond to that, like either leave them there or pick them up or take them to a place

where they can stay on the floor or somewhere else. So how do you – what impacts on how you might respond to that behaviour?

Mel Erm, it depends on whether – how much they're at risk and whether others are at risk. Erm, so if we've got somebody that just tends to put themselves down on the floor from the chair, then we would probably – if that's – if they're safe and not causing anybody else any harm, then we probably would leave them there and then later on try and attempt to sit them down on the chair, but if then if they keep going to the floor – If it's repeated actions, we would probably leave them there because it's a repeated thing that they want to do and we're not really gaining anything by keep putting them on the chair for them to get back down again. Erm, but if a patient – obviously – if it was someone that was just rolling around on the floor and patients were walking – and we've got – it would also depend on the type of other patients that we've got. So we've got little ladies on zimmer frames you know, walking around and they're liable to trip over, then we'd have to assess those risks as well. So it depends on the patients that we've got at the time and also the patient that's actually on the floor that's having those behaviours. We would have to take that into consideration. We would discuss it at ward round obviously with the doctors, erm, and the ward doctors before ward round and kind of come up with some kind of plan to minimise – it's all about minimising risk. So that's what we would look at so that we wouldn't be causing any risks to the patients that are walking around the ward and also the risk to the patient on the floor because we do get quite a bit of erm – where the patient will go on the floor and then the other patients try to get them up. So then that's obviously putting them at risk because if that patient becomes aggressive when you normally try to get them up then they can then lash out at that patient. So there's all those kinds of risks that we have to take in to consideration and that's - that does depend on what response we use really.

Int Yeh.

Mel Erm, if we feel that they are high risk and they are causing high risk to other people that's probably when we would look at putting them in a room.

Int Right.

Mel On their own to try and take those risks away.

Int Yeh yeh.

KNOCK ON DOOR – RECORDING PAUSED.

Int Ok so you were saying about your responses, and how if – if it's going to be a risk to other people and if it's a high risk that's when you decide to take them to another room.

Mel Yes that's right.

Int Are there any other behaviours that you think are difficult to manage?

Mel Erm, the behaviours of when we get patient clashes, they're very difficult. If we've got a lot of – if we've got a lot patients with very difficult health needs, so we've got a lot of noisy patients and then we've got patients that don't like noise. We get a lot of personality clashes and we're – you know – you just happen to have one patient that just sits there screaming and then another patient that just does – gets that - his trigger is noise. So that's difficult to manage sometimes. Sometimes you'll be fine where you've got a lot of patients in that are just very confused, wandersome, don't seem to interact with each other and then other times you get patients that clash and just you know they just cau – trigger each other's behaviours so yeh. That's difficult and it's - and you can't always move them away. So you can't always move the patient that's doesn't like the noise away because then they'll get more agitated. So it can – that can be very difficult and that's sometimes when we tend to erm, put them on 10 minute obs and things like that. Or if it did get really bad where they kept targeting that patient that was screaming, we'd have to put them on high obs. But it's very difficult especially when you've got patients responding to other patient's behaviours and they – yeh then it causes more problems.

Int How do you make sense of the – screaming I guess. So when the patient is screaming, how do you make sense of that?

Mel (sighs) It's difficult. Because a lot of the time when they're so cognitively impaired that's when you find that they are – they ha – scream and things like that. So it's difficult to know what they're screaming about. They're not able - a lot of the time when they're screaming they're not able to communicate verbally erm, so a lot of it going through is it pain, erm, you know, is it hallucinations that are causing the screaming. Are they you actively hallucinating? Erm, it's difficult – and a lot of the time, sometimes we just don't know, because we just can't. There's not like a magic wand and we just don't know sometimes and it's difficult. And it's quite frustrating when we don't know erm because what can we do for that patient. You know and it's tri – a lot of the time it's trial and error. Erm, we'll discuss it with the consultant, they'll give their feedback what they think it may be. So it could be that they're in pain, so we'll try analgesics to see if it is pain and then if the screaming stops then we kind of think "oo maybe it's pain". So a lot of it's trial and error. Then they could try them on risperidone, see if it's hallucinations. If the screaming reduces then it could that they was responding. But sometimes we just don't - we don't know.

Int I guess that – I picked up on you saying you tell a – you might tell a psychiatrist exactly what you're seeing, erm so that they can make a bit of a

decision about what they think it might be. How might you distinguish, so if we stick with the screaming, how do you think you might distinguish whether you think it's pain that the screaming's about or hallucinations that the screaming's about?

Mel Erm, We – we've got an (a-??) pain scale which we try to fill in. Like I say it's very difficult when somebody is just screaming and they're not able to communicate. Erm, it's little things like communicating with the healthcare assistants. They do a lot of hands on, more than what we do and if they're wincing when they're getting up. Erm, also monitoring whether it's while they're sleeping or if it's ongoing or if it's intermittent. Erm, that kind of thing. And erm and then we always take that back to the consultants, then we leave them to make their clinical judgement from what we've gathered from observing the patient to what they think it may be. Erm, otherwise it's just constantly monitoring and observing and communicating and you know a staff may say "oo well he was quiet in the morning" but then it was - as the day progressed – erm you know and there could be a patient that's with what – for example one of our patient's well she was very noisy all the time and then we found that it was intermittent - they put her on pain relief but then it was intermittent. And it – and then when we used to take her to the toilet she'd be faecal incontinent. So then we'd got a pattern that every time she became faecal incontinent she started screaming. It took us a while to understand and to get that pattern to realise, but eventually we kind of worked out that oh she was screaming, took her to the toilet she was incontinent to faeces, we cleaned her up, attended to her personal hygiene and then she settled, and that is the pattern that we found. Sometimes we can find a pattern. It takes a while, it doesn't just take a day or you know what I mean, and that took a – it probably took a week or a couple of weeks just actually – for everybody to report back the same thing and then for us to figure out that it was this particular issue. And then sometimes we don't. We don't always know and that's the tragic bit about it because they're not able to tell us either, and it's frustrating, you know when its – yeh.

Int For both I'm guessing

Mel Yeh, yeh.

Int Yeh ok. So to help us think a little bit more about your experience in particular I've got a few questions just to help you talk about those experiences. So, can you tell me about an experience of when you felt good about when you handled a dementia related behaviour?

Mel Erm, there was one particular patient that erm, when – when you had to attend to his hygiene, he basically – it was as if you were going to attack and kill him, rape him or something like that. His fear and his anxiety was soo high. So so high, that he was so strong because he was literally – every time

that you attended to his personal care he was fighting for his life. Erm, and we wasn't able to sort out the agitation at the time of having to attend to his personal hygiene and that was really upsetting for all of us. But what we could do and what I did was after, he used to pace off like run off as if he was running away, but then give it – I used to give him a few minutes and then he'd come and I'd give him a cuddle. And he'd just hold on tight and I'd say "It's fine, it's ok, it's ok, don't worry, everything's alright now, you're alright". And then – and then he'd forget, because of his short term memory but he'd be fine and that reassurance and that comfort – and that used to make me feel that although we can't stop him from feeling - although we used to give him reassurance when we was doing his personal care, although we weren't able to get through to him because of his – you know his anxiety and his fear was so high, but at least after was able to – I was able to be there and to give him a cuddle and that reassurance.

Int And it made you feel better as well.

Mel It made me feel a lot better. There's a sense of guilt sometimes. You don't want the patients to feel like that but then you know you've got to attend to their personal hygiene because if you don't their going to end up getting sores, you know, skin conditions er, things like that. So you feel – there is an element of feeling guilty when you're having to do those – that personal care and you know exactly how they're going to respond but being able to reduce the anxiety just by supporting them and just giving them that extra attention – it does – it makes you feel better because it makes them feel and you can see that' you've brought them back into a settled mood. You know, and that is – it's – I wouldn't say it's rewarding but you do – you feel better about it all you know– and that it kind of sots better with yourself, that they then feel better and they're not going to continue that agitation of fear.

Int Hmm yeh, so how – I guess just going back to the beginning of what you said when he – when it's – when you're attending to his personal hygiene, it's literally like he's fighting for his life.

Mel He is yeh.

Int How did you make sense of that? Him behaving in that way.

Mel Erm – the – the sense is that (pause) he – he doesn't recognise any of us, he doesn't know who we are, he doesn't know – he's completely disorientated. So he's not able to remember any of us. He's not able to you know – he's totally disorientated to person so he's not able to know who we are and that it's putting like yourself in his shoes. That if we was not ab – if we woke – was in a room with random people that we didn't know who we are, it's taking on board and understanding what he's feeling erm and the – the emotions that he's experiencing are real emotions – and you know they're real to him and –

and that kind of you know you've got the empathy and the compassion there and it – and we just try to make it as quick as possible. You know just get what we've got to get done. No amount of reassurance is going to do anything because he's in the moment, he's so frightened and confused. So we just – it just helps us to understand you know like putting ourselves in his position. Erm and I think that kind of comes with experience erm you know. I've been a nurse for 12 years - qualified nurse and I think it just comes with experience of – yeh – getting in sync with your patients and knowing that what they're feeling is real and that you know – and trying to imagine and reflect how you would feel if it was you. And it's such an intimate thing that we do with them. The personal care. Erm and obviously with this particular patient he felt violated because you know people – he couldn't understand why we was doing it, he'd got no insight into that he'd actually been incontinent, or anything. But it's a;; about understanding that erm and getting your head around that to understand why he's acting like he is. But that's the only way really.

Int Hmm, yeh. How did you – I meant that's difficult being faced with something like that because you talked about the emotions that that comes with. His emotions and your emotions.

Mel Hmm. Yeh.

Int But how did you respond to that then?

Mel To respond to when he was being fearful?

Int Yeh. Yeh.

Mel Erm, it – the aim was to possibly do it as quickly as possible to get the intervention over with as quickly as possible in a timely way and still reassure him and that is the only way we could do it. Because no matter what we'd do he was going through this. So the longer we took the longer he endured the fear and the anxiety and it was basically just to focus on the end. To just get what we needed to do – make sure he was clean, make sure he was properly dressed and that was it, to do an action. Focus on the action. Erm, because you know the length of time that we're doing it obviously how long it takes us to do it is how long he is anxious and fearing you know. But it was just to – the aim is to get it done as quickly as possible. To all work together to you know do it, get everything out ready. So we used to pre prepare. So if he needed to change his bottoms, we used to get his bottoms ready, get his pad ready, so literally it was just in there as quick as possible and out.

Int Yeh, so when you were quick did it mean sometimes you might have had to restrain him or ..

Mel Yeh we had. We had to restrain him because of his level of anxiety. Because if – yeh. He didn't know why we were taking him into the toilet. Probably didn't even know it was a toilet you know because of his perception. Erm, and no matter what he was going through his anxiety was there and it was just to make it as short as possible. That that time that he had as anxiety was as short as possible.

Int And for you I guess that response of trying to make it as quick as you can, just focus on the end, try and get it over and done with – why was that important for you? How did you make sense of your response? Was it to get his anxiety over and done with quickly and yours? How did you make sense of it?

Mel I think it's both – I think sometimes things can go wrong – you know if they – if you're trying to get a pad on and then it falls on the floor so you get another one. Things do happen and it does take longer than expected so then – and the longer it does go on, of course it has an effect on us, but mostly it's the patient because we don't want them to be in that state for a long period of time. We'd rather it just be as quick as possible. When things do go wrong when you know it takes a bit longer, erm, than usual for whatever might be erm, whether it's that he's incontinent more than usual, or whether it's that he needs a full set of clothes changing. The more that it's prolonged it has more of an effect on staff erm, and it's not nice walking out after when that patient been really really highly anxious and you know so worried and breathing heavily and that. It's not nice. So that's why we do try for both us and the patient to just make it as short as possible.

Int You spoke about it having an effect on staff as well. What kinds of an effect does it have on staff?

Mel Erm, it just – it's just mental strain and erm just – there's feeling of guilt there but you've got to do it because you sometimes forget that if you didn't do it nobody else would because he can't do it for himself. But you tend to forget that sometimes and you do focus on you know "poor such and such" you know and it is upsetting, it's very very upsetting. But like I say when you go back to the – when you become complacent, I think when you've been doing it a long time, sometimes erm, I find with a lot of student nurses they get really upset, tearful. We have to kind of build a wall up to that erm, because if you don't you can't do your job. Erm, so you have to just – you learnt to just focus on the matter in hand which is getting them clean and dressed and that is how you deal with it. And if you do let your emotions get – I mean we all do – these particular patients that are absolutely brilliant, right little characters you know and sometimes it really does touch you. But you have to try and just focus on what you're doing and the task if you like erm because if you bring your emotions in too much if can affect – it can affect what you're doing.

Int You mentioned building a wall up. Can you tell me a bit more about what that means for you?

Mel Erm, building a wall. I feel that if you – it's like not letting your emotions get to you. Erm because I think when you let your emotions get to you, you overthink things and we can all overthink things and then look into it and you know and you make more of it, but if you keep it simple and try to dis-attach yourself, it enables you to do your job and if it enables you to do your job then you're benefitting the patient. If all your emotions come into it, you're not – you don't do your job as effective. Erm, they – it's like they need us to do that task and to do that you have to just try and keep your emotions separate erm.

Int Does that have an impact on you?

Mel Yeh. Yeh, lots pf wine (laughs). Yeh a lot of – I self-reflect a lot. Erm, and I find myself doing it and I don't know I'm doing it, but it's my way of making sense of everything. And also self-reassuring myself in a sense. Erm, but I do it all the time, I catch myself thinking about things and then – you know and then yeh. I do it a lot, I do self-reflect a lot. But I think it's just your way of processing everything, making sense of what you're doing, what you're experiencing, erm, otherwise I think you get burnt out. Especially with it being a daily job and if you work full time – I work full time so it's you know – sometimes you feel like you live here and it's all the time. But it's also nice that when you've got changes of staff, so some day you might not be as hands on as you might other day and that's good as well. It's about having that balance because it kind of gives you a bit of a step back from it all. So that you're not exposed to it constantly.

Int Yeh definitely. Absolutely. And the guilt that you talked about, how do you manage that guilt because that's a big emotion to have?

Mel Yeh. You try to – like I say you try to focus on "well if I didn't do that how would that patient be", you know we've done a good thing because they're dry, they're clean, they're not going to get pressure sores, you know that kind of thing. So you try to self-justify and look at the positives. Although dementia's a cruel thing, he's still clean, dry, you know everything, his skin integrity is being kept kept well. We're not adding to his problems, or the problems, we're not adding to – with pressure sores or moisture – skin moisture lesions or whatever. We're trying to keep you know everything under control. So that's – that's basically how you balance out the guilt – it's in trying to justify your actions and what you're doing and you have to always think to yourself that without us, these patients wouldn't be able to do it.

Int Hmm hmm. And it's like they're all linked, where you build up a wall to manage your emotions and to be able to get on with a task and then that

leads to guilt of having to do that and dealing with their confusion and anxiety, but then you use self-reflection to try and bring that guilt down and think about well what are the reasons that I'm doing this – It seems like it's a cycle and it's all linked together.

Mel Yeh. Yeh. And a lot of time erm was only saying earlier on today, sometimes you have to just use humour as well. Erm you know just humour, see the soft side of it you know and not just think of the harsh reality of the dementia. Erm, it's about having a sense of humour as well and trying to be light hearted about it and support from you colleagues. You know and some of the things, it's not inappropriate what we say but it's just our way of dealing with it, you know after. It's our way of lightening the load. Erm, so yeh it's humour as well and just trying to lighten everything up.

Int Erm yeh, to make it easier – help you cope.

Mel Yeh it is it yeh- it does make it easier.

Int Yeh absolutely. Erm ok. Can you tell me about an experience where you've felt you could've handled a dementia related behaviour differently?

Mel Erm (pause), erm let me think, erm. Yeh I've got one. I've got a lady, very young. Erm, only in her 50s and she's got cognitive impairment, she's got dementia. Early onset dementia and she was adamant that she wasn't having a bath. Erm, her daughters had spoken to myself and said "Well before she was ill she had at least two baths a day. A very well kept lady and this is what we want. My mum would want this, if she was poorly and you know she couldn't do it for herself". So we set about trying to bath her or shower her and we decided we was going to shower her and it was trying to get the right approach and the right time to get her into the shower room to try and get – because she had her clothes on for like 3 or 4 days and therefore she's not attended to her personal hygiene. We didn't think. And taking in mind what the daughter had said that she always had two baths and it all went wrong because she wouldn't go in the shower room, but we felt that we needed to get her in. And the staff came and took out the shower chair and put her in it in the middle of the room and it all just went – So I quickly ran in and just said "no you can't do that, let's put her into the shower room" and that went wrong because 1. Her dignity, 2. It was like can we justify you know giving her that shower if she's refusing. The whole point – and the shower chair has a belt on it. So there's all that kind of – that issue of – was we acting in the best interests, or –so that was quite a lot of the staff – we had a disagreement about it because we was all coming from – you know we all had different ideas about it. Erm some were saying "are we doing it or are we not?" Erm but then you've got this poor woman in the chair then – erm or are we not. So then you've got to think about well are we acting in the best interest? Can we do it under deprivation of liberty? That kind of thing. Er, so that wasn't

one of my proudest moments really because it wasn't dealt with properly. Although this lady was very young, she – but she was very cognitively impaired – it was, it could have been handled differently. But things happen unfortunately and its – and the only way that I could try to resolve it was to make sure she was in the shower room as quick as possible. Erm, so that her dignity wasn't you know.

Int How did you – what sense did you make of her not wanting to shower? So considering what her daughters had said about her.

Mel Erm – just be – what – I know that – a lot of the most common things for patients with dementia is that they self – neglect. Become self-neglectful and they just don't attend to their hygiene because they just don't see it as a priority. Erm, and ..

Int What do you think that's about? What do you think that is?

Mel Erm, I just – I don't know really. I just think it's erm, it's, it just doesn't become a focus in their lives and other things become a focus. Whether it's the amount of confusion that they're experiencing – like whether they're searching for a place or they're searching for a person. The – it's as if their personal hygiene just goes out the window and other things become more of a priority. I don't know I think that might – you know there's patients that are constantly searching for the – for things and "have you seen Arthur? Have you seen such and such? Have you seen my daughter?" I think those things become more of a priority then what actually – the washing and dressing and brushing your teeth become. I think that becomes more paramount and you know more important to them at that time then actual hygiene. I think that just gets lost and erm – you know – or whether they forget that they've done it. I don't know whether they've forgot that they've attended to their hygiene or they think they have. I really don't know, but I know it's important for us to make sure that they do you know keep personal hygiene well because of things like the skin, infections, especially with ladies, with like urinary infections and thrush and things like that. It's just going to add to the problems they've already got which can then cause more confusion if they're got a UTI on top of the confusion that they've got with the dementia. So there's things like that but you kind of always questioning whether you're acting on their best interest or not. You know at what point do you act you know and with that lady she'd not bathed for 3 or 4 days, not changed her clothes. Its justifying to yourself "was I right to do that after 4 days?" You know, erm yeh but that was probably the one that sticks in my mind that I don't particularly like talking about it because I feel like I've failed in a sense. Erm but, things do happen.

Int Yeh. Yeh of course.

Mel And it is all about communication and if things are not communicated properly or you get a disagreement with staffs opinion. We've all got our own opinions and you know I think that also – that played a part in it as well. And the approach, staff were like "right come on let's get her in, let's get her washed. We're just going to have to get on with it. She's not going to want to do it anyway. She's gonna be resistive. Let's just get it over and done as quickly". But then there was probably a different way to deal with that. Erm, that – you know, we could have spoken to her or we could have tried another member of – a few members of staff. Sometimes some females strangely erm react better to older people or younger people or even men. We find that ladies, although it's strange, respond better to men. Erm, so it – I think that should have been the avenue right that we'd taken first with this particular lady.

Int So having a think about what to do ..

Mel It's all in hindsight yeh

Int yeh

Mel It's all in hindsight and it's a learning curve. And we're always learning you know and reflecting on it you know, if there was a different way we could have done it.

Int Yeh yeh. Why do you think you responded the way you did at the time? What sense do you make of your response at the time?

Mel Erm. I think it's been – At the time DoLs – Deprivation of liberty was fairly new. Erm, it had only come out where we was to have patients on a DoL from the 31st of March I believe it was. So it was all – March last year – so it was all fairly new and people are still not to sure about the guidelines and you know and what they expected from us so I think, I think it was not knowing enough and not know the boundaries and where – you know at what point and what the definition of deprivation of liberty is and what is depriving a person of their liberty, of their freedom erm.

Int Yeh. It's so broad isn't it?

Mel It is and I think it was the, it was that. I mean after that we got proper training. We had training on deprivation of liberty erm and it was, and not because they've had to make so that patients are either on a section or on a DoL, erm we have DoL assessors come in who also educate us and they explain why they think this patient should be on a DoL or not. So I think it's all about education and it – made me feel uneasy because I wasn't knowing whether I was doing the right thing or not, so I wasn't sure. You know, do I deprive this patient of their liberty? Am I able to? Am I acting right by going just getting it – your know her washed and dressed? Or not? Or should I – it's

very very difficult when you're not quite sure and you – you know you're a bit unsure about the legislation and – and that – you're not educated enough.

Int Yeh. Yeh absolutely.

Mel But now we are (laughs). We're experts now because we've had that many DoLs assessors here and you know and it's – we've been doing it for a while now. I mean most of our patients are on DoLs so we know. You know and now if I had that incident – because the HCAs also that was involved in that particular issue, they're more educated now, so we would all kind of – be singing from the same book and know what we should be doing. So I think it was the now knowing for both the health care assistants and the staff – the nurses.

Int Yeh. So your – that response was impacted on by legislative procedures erm not knowing at the time…

Mel Yeh what's right and wrong, boundaries,

Int Dignity, privacy. Were there any other factors that – that might have influenced things at the time for you?

Mel Erm, probably erm health care assistants' attitudes or you know responses – personality's maybe.

Int Tell me a bit more about that.

Mel I think – two health care assistants that attended to the incident erm were very brashy and very "come on let's get them in". Where maybe if I'd had two other care assistants that would have been like "ok what are we doing, are we sure" then it would've probably been different outcome. So I think that makes a big difference as well. The staff that you're actually on with. Although these two are very very good HCSs, at this particular issue, wasn't – not so good and kind of jumped the gun a little bit instead of communicating a bit more with the staff nurses and myself that what – what was we definitely doing (laughs). Or what we wanted to do, what we all thought together. Erm and I think that was one of the main issues as well.

Int How did this woman react to that response? What did she do? I guess she – you mentioned she was sat there while you were kind of deciding on "do we take her in now do we not". But how did she react to the response?

Mel Erm, she was confused, she was confused. Erm she – and in the end I decided to let her go. I felt there was just something that didn't sit right. I know they always say go with your gut feeling and I – there was something that didn't sit right with me and I just wanted her out of that chair and out of that belt as soon as possible. And then the health care assistants were like "oh we've already got her in". I was like "I don't care. Get her out". Because all it's going

to do is lead to more distress and at that particular time, because I wasn't easy with it and unsure of where I stood, I couldn't go through with it.

Int Is that what didn't sit right with you?

Mel It was yeh. It just didn't sit right with me and I just had to get her out and get her calm again.

Int And how was she when you got her out?

Mel She was ok. She was ok. I thought she wouldn't be actually I thought she wouldn't be. She wasn't overly agitated or anything while she was in there. She was just kind of sat there as if like "what's happening". So luckily for me, I didn't feel like I'd distressed her too much. Although it was probably me that was more distressed and it was more upset than what she was, because I was just kind of like "woaw this is getting out of hand, what's going on here? Hold on a minute. Let's just take a step back. I'm not very comfortable with this", you know and it was that – so probably out of everyone it was probably me more than the patient that felt uneasy and felt a bit you know. So she was fine, she just walked out and walked off up the ward and obviously with a cognitive impairment she probably would have forgot the incident anyway unlike me that still kind of thinks about it sometimes and definitely if the same thing happened – well it wouldn't happen. If it was the same kind of issue, I definitely wouldn't be doing that again.

Int And there's something about it staying with you you mentioned

Mel Yeh but obviously with her, she wouldn't recall it, she wouldn't remember it, but I do. So I'm the one left – I'm the one left with the memory.

Int Yeh. Yeh. It's hard.

Mel Yeh

Int ok. Thank you for sharing that with me. Erm are there any other experiences that you would like to share with me about challenging behaviours that you've experienced, that might come to mind after we've been talking?

Mel Erm. We've had one patient that was particularly – he'd been with us for years erm and he targeted patients. Especially like vulnerable patients. Erm and there was a question of whether he had capacity or not. Erm, and he – he was – he did target certain patients and on particular time we'd got a lady that needed changing – she's been grossly incontinent of faeces and we was taking her up the ward and she was struggling and she was trying to hit out. So staff had to put her in a passive hold to actually take her to the toilet and that's when we were taking her to the toilet, the patient stood out and just punched her straight in the face while she was in restraint.

Int Oh

Mel Things like that, we didn't know. We couldn't have avoided it. We didn't know he was just gonna come out of his side room and punch her. He was an opportunist. But the sad thing is later on, he was seen to have capacity. The consultant at the time said he hadn't got capacity, then the next consultant that we had said – because he was with us for years – said "this man's got capacity. He's premeditated he know exactly what he's doing". After so many attacks on staff and patients, they said "yes he's got capacity" and pressed charges. Because it's assault. For when he - when he did eventually – once we got that he had capacity and then we went and assaulted a male patient and that could have been – that was all about diagnosis and assessment and whether he was assessed for capacity. And up until that point we couldn't we couldn't even do anything because he was just an opportunist. He was just very unpredictable. We couldn't always foresee those kinds of things. Erm, but he was challenging in that sense that he was so unpredictable, but he was calculating. And we was all saying how he's definitely got capacity but then the consultant was saying "no he hasn't", so there was nothing we could do about it. Erm and unfortunately that poor lady she did suffer from that because every time that staff had to intervene with her, when she was incontinent, it made her worse because she thought she was going to be punched in the face or whatever you know. Erm, so yeh things like that – it's you know, assessing capacity you know – it could have been a different outcome if he'd been assessed to having capacity in the first place.

Int What would have been different?

Mel He would have been charged. He would have – he would have been made to – you know to pay for his actions. Erm, but because they said he hadn't got capacity, he didn't know what he was doing, so therefore he wouldn't be charged because it was his illness that was causing him not to be able to have insight and to have capacity to know what he was doing, where eventually the consultant said "he has got capacity he knows exactly what he's doing. He's an opportunist. He's pre-meditated. You know he's seeking out the vulnerable, He's able to recall the incident". Erm so in that sense we knew what he was doing was wrong. It wasn't that it was his illness and he couldn't recall it or he didn't know what he was doing or anything. It was because it was wrong and what he was doing was wrong and abuse to the other patients.

Int Hmm. Did you initially think that it was dementia related?

Mel We did. Yeh we thought he got vascular dementia. Erm which is obviously it's not the same deterioration as Alzheimer's. It's more when they get a stroke or something happens that they deteriorate more erm. So he'd had a year or so where he'd not deteriorated because he'd – he'd stayed stable and he was questioning and he was quite behavioural. So he was – he would sometimes –

you'd ask him a mini mental and he'd go I'm not sure about that, but then in conversation he'd be fine. You know he'd be able to respond very well, erm. So sometimes use to play us a little bit on assessments, but we could only go by the assessment that we did with him. So he used to play it a little bit which made it difficult. And he knew that because he had insight and that's what we was all saying "we know he's got insight. He knows what he's doing. You know, he's jeopardising these assessments". But unfortunately the consultant that we worked under was not of the same opinion and their opinion was final and it wasn't until we got another consultant that turned around and said "he has got capacity".

Int So initially you thought it was a dementia related behaviour?

Mel yeh

Int And it was out of his control as such but then as you …

Mel (interrupts) the sort of incidents we had and we watched him and monitored him and it was the vulnerable patients. It was always a vulnerable – when a patient was on their own and walking down the corridor, something happened. Never happened in the day room when staff was present. I mean the patient when we was restraining her she was in a position where she couldn't help herself and he just stood out and punched her one straight away. Nothing we could have done. We've got her in restraint, our arms were taken up by the patient. She was leaning forward, couldn't do anything and all those little things added up, erm which after a while you know that it's – it's calculated behaviour.

Int How – how did you respond – what was the difference in your response to when you thought it was dementia related as opposed to when you thought it wasn't and actually he had capacity and he knew what he was doing?

Mel Erm approach – that's the hardest thing about it because then you've then conflicting feelings. Because you're feeling do come into it when you know that they are doing it on purpose. And it's hard to manage - you just have to like put the wall up even more so because you can't let your judgemental feelings or you now you can't be judgemental – you can't let your feelings – although you know you might think it's so wrong what he's doing and it does get you angry and you know frustrated, especially if they've punched them and they've got bust lips or whatever. Erm but it's – it was - a lot of the time it was that we just had to you know play it by the book. You know strict instructions to him. Obviously, nurse him the same but you still had to you know just keep your feelings, and, it was difficult to separate them feelings when you knew what he was doing. It was abuse.

Int Hmmm. And did you find that those feeling then interfered with how you then responded?

Mel Yeh, I think – I think – the way to – my way of dealing with it was just to think right "this is your job, you know do what you need to do", he was diabetic as well, so you still had to intervene with him, do his BMs. Just treat him – but try and keep it at the back of your head what he was doing. Not focus on those incidents, so that it allowed you to nurse him.

Int Yeh, ok. Thank you. Are there any other factors that you fell influence the way you respond to behaviours? Just as a – I mean you've mentioned a fair few already in terms of legislative procedures, risk of other patients, staff, yourself. Is there anything else that comes into it for you?

Mel Yeh. There's – we're only human at the end of the day so it's your own personal things. If you've got something going on at home or you know things like that. I like to think that – because they always say that in your nurse training that you've got to be aware of your abilities and limitations erm I like to think I am and if – sometimes if I was having you know there's a lot on at home or things was affecting me – I'd like to think that I gave that – I gave more of a responsibility to my colleague so that it wouldn't affect what was being done at work, and knowing that - ah ok you know I'm a bit stressed and not feeling you know too great or whatever you know – illness – if you're not feeling too well. If you're not feeling up to it – got a head cold, migraine, I would be like "look I'm really not feeling well, do you mind if you take over, you become in charge today", because I think at the end of the day it's the benefit of – for the patient that's paramount. It's them that's – that you came in for and I'd like to think that – that they was getting the best care that they possibly could whether I was having an off day or feeling ill or whatever. Erm, so yeh, that probably, you know we're all human at the end of the day. We're all you know unwell some days. We still come to work, feel off, erm or have got things on his mind.

Int Yeh absolutely. Anything else?

Mel Erm, no. I think a lot of its erm, difference of opinion. Like with the health care assistants and staff nurses. That sometimes has a – that's quite an effect.

Int yeh it seems like it from what you said.

Mel But yeh that's about it really I think. That's about it.

Int Ok.

Reflections:

Parts of Mel's account were filled with a great deal of emotion, which required careful managing during the interview. I ensured my body language was empathic at these times, as she spoke for long periods of time where I did not interrupt. The feelings that she was displaying felt very tangible in the room. I was struck by the emotion her account was eliciting in me. I felt sympathetic towards her and was aware that her account was one of the few interviews that had really helped to shift the preconceived views. I felt in admiration of her resilience, of what she went through day in day out as part of being a nurse in this setting.

Appendix X. Example of part of Mel's coded transcript

Descriptive, Conceptual, Linguistic

Line	Transcript		Coding
763. 764. 765. 766.	Vidya	You spoke about it having an effect on staff as well. What kinds of an effect does it have on staff?	
767. 768. 769. 770. 771. 772. 773. 774. 775. 776. 777. 778. 779. 780. 781. 782.	Mel	Erm, it just – it's just mental strain and erm just – there's feeling of guilt there but you've got to do it because you sometimes forget that if you didn't do it nobody else would because he can't do it for himself. But you tend to forget that sometimes and you do focus on you know "poor such and such" you know and it is upsetting, it's very very upsetting. But like I say when you go back to the – when you become complacent, I think when	**Impact of response on staff – mental strain** **Impact of response on staff – feeling of guilt** **Making sense of response – personal care needs to be done as no one else will do it – highlighting reliance of patient on staff to have needs met** **Impact on response – sometimes forget the reliance PWD has on staff for personal care** **Impact on response – compassion towards patient distress vs duty/job role** **(conflict again)** **Conflict: Personal emotions vs job role – very very upsetting** ***(very x2 to emphasise the high level of upset it can cause staff)***

783.	you've been doing it a long	
784.	time, sometimes erm, I find	Impact on response – amount of time working in the setting
785.	with a lot of student nurses	Impact on response – complacency
786.	they get really upset, tearful.	
787.	We have to kind of build a	Coping – building a wall or you can't do your job
788.	wall up to that erm, because	Building a wall – comes with length or time wwd / experience
789.	if you don't you can't do	Could the emotional withdrawal be related to pressures of the job role – needing to get the job done?
790.	your job. Erm, so you have	Building a wall - perceived need to disconnect emotionally in order
791.	to just – you learnt to just	to be able to act (convergence with example above about addressing
792.	focus on the matter in hand	man's needs and later when she says 'emotions get … (in the way)'
793.	which is getting them clean	(There is a real struggle here to act in a way which incorporates
794.	and dressed and that is how	emotional connection to the patients pain alongside 'professional
795.	you deal with it. And if you	caring behaviour')
796.	do let your emotions get – I	Building a wall– focusing on the matter in hand without emotions
797.	mean we all do – these	getting in the way
798.	particular patients that are	View of PWD – absolutely brilliant
799.	absolutely brilliant, right	View of PWD – right little characters
800.	little characters you know	(this could be why it may be difficult to not let you emotions get in
801.	and sometimes it really does	the way?)
802.	touch you. But you have to	Wwd – touching
803.	try and just focus on what	(natural emotions e.g. empathy and upset are seen as a vulnerability
804.	you're doing and the task if	factor for staff)
805.	you like erm because if you	Impact on response – the level of emotional involvement of staff
806.	bring your emotions in too	(building a wall is protective for staff and to a certain extent patients
807.	much if can affect – it can	it seems)
808.	affect what you're doing.	

809. 810. 811. 812. 813. 814. 815. 816. 817. 818. 819. 820. 821. 822. 823. 824. 825. 826. 827. 828. 829. 830. 831. 832. 833.	Vidya Mel	(*Nodding)* You mentioned building a wall up. Can you tell me a bit more about what that means for you? Erm, building a wall. I feel that if you – it's like not letting your emotions get to you. Erm because I think when you let your emotions get to you, you overthink things and we can all overthink things and then look into it and you know and you make more of it, but if you keep it simple and try to dis-attach yourself, it enables you to do your job and if it enables you to do your job then you're benefitting the patient. If all your emotions come into it, you're not – you don't do your job as effective. Erm, they – it's like they need us to do that task and to do that you have to just try and keep your emotions separate.	**Building a wall – not letting emotions get to me** **Building a wall – If I don't build a wall I will overthink things (which is seen as unhelpful)** **Building a wall – detaching self will keep things simple** **Building a wall – detaching self will enable me to do my job** **Building a wall – benefits the patient** **Building a wall – allows me to do my job effectively** ***'They need us'.*** **This could indicate that Mel feels that PwD are powerless/dependent. It also highlights the increased sense of responsibility that she may feel.** **Building a wall – allows me to do the tasks patients need me to do (need vs want?)** **Building a wall – protective and beneficial for me as a nurse wwd?**

Appendix XI. Table of initial themes for Mel (Object-descriptors)

Superordinate theme	Subtheme	Line Number	Kew words/comments
Wwd	Challenging	6:17	Very challenging Mentally draining
	Can become complacent	6:17	
	Liking to PwD	702:834	Brilliant, right little characters
	sometimes feel like you live here	837:947	Feels like home because of constant exposure? Transference/countertransference
	Referred to as 'a business'		
View/understanding of dementia	Have a different language	47:85	They don't understand our language
	Confusion is protective against fear?		
	Slave to their confusion		
	'a beast'		
DRB	Various behaviours	22:42, 47:85, 90:92 957:1029	Aggression, agitation, frustration, confusion, muddled speech, expressive dysphasia, erm, a lot of frustration, becoming upset, falls, not wanting to bathe
	Different behaviours		
Impact of behaviour	It's confusing		
	Becomes normal – desensitised?		
	Emotional impact		
	Less focus on more vulnerable PsWD		
Making sense of behaviour	Automatically know how they'll be	6:17	Complacency – regular exposure – becomes an automatic SM process
	Emotional distress misinterpreted as negative behaviour	22:42	Fear misinterpreted as aggression Frustration is from confusion and disorientation – don't know who we are where they are
	Negotiation of dementia related (loss of control) vs having control		
	Behaviours are all linked to each other	22:42	I think a lot of the behaviours erm are linked up together they actually cause either the – agitation or aggression from it or fear.

	PwD gaining insight	47:85	Realise 'this is my life'
	Pwd perceiving high level of threat from staff	469:681	Aggression when attending to personal hygiene - He felt violated, disorientated, he couldn't understand why, didn't recognise, will run away from us anyone, like we were going to rape, attack kill him,
	Changes in sense making		
	PwD misperception	90:169	Their perceptions all wrong, walk into walls, no spatial awareness
	Grounding	90:169	Feels safer on the floor – sense of gravity
	Influence of ward dynamics	291:338	Pwd trigger each other behaviours Personality clashes – noise vs wanting silence Behaviour dependent on ward dynamics – moment specific PwD that are confused wandersome don't interact get on ok
	Neurological/ cognitive impairment	339:389	The more impaired the more they scream – don't know why – not able to communicate verbally – no shared language (convergence)
	Sometimes we just don't know	339:389	Because of communication barrier – don't have a magic wand
	Influence of self-beliefs/ values		
	Trial and error	339:389 436:478	Through outcome of response (medication) Using medication
	Differential diagnosis within dementia	404:436	Pain vs hallucinations → use of pain scales – monitoring patterns throughout the day HCAs picking up on signs
	Recognising patterns in behaviour	404:436	It takes a long time
	Perspective taking	469:681	Comes with experience, putting self in his shoes
	Empathising	469:681	His emotions are real to him, getting in sync with patients
	Not related to dementia		
Responding to behaviour	Trial and error	339:389	Through outcome of response (medication)
	Recognising patterns in behaviour	436:478	Through the trial and error process

	Responding to meds despite emotional distress	469:681	Needs to be done
	Do the job quickly	469:681	The longer we took the longer he endured the fear
	Restrain	702:834	During attending to personal hygiene
	Attempt to attend to personal hygiene	857:1029	It wasn't right we didn't think – shower as opposed to bathe which is what the lady had
Difficulty responding	Communication barrier	47:85	Hard to give reassurance – hard of hearing , Don't understand our language (us and them – PwD have a different language? What use to also be their language has become our language – distancing?)
Making sense of response	Unpredictability	90:169	Don't know when they're going to fall Can't make sense of PwD perception – unpredictable
	Complacency	6:17	Exposed on a regular basis
	Response based on sense making		
	Level of risk/harm to PwD and others	195:276 291:338	High risk – isolation to take away risk Minimising risk of aggression to others or injury to self Maximising safety and choice of PwD – if behaviours is repetitive (he want to be on the floor) and it's safe – let him stay there Negotiating management of emotional distress which is perceived to be linked to aggression
	Able to fit into predetermined roles?	469:681	Can't fit into containing carer role therefore will distance self emotionally
	Reducing amount of time of emotional distress experienced	469:681 702:834	Make it as quick as possible The longer we took the longer he endured the fear Focus on the end Restrain and focus on the end
	(Restrain) to be able to attend to needs	702:834	Due to level of anxiety – needed to attend to physical well being
	Protecting PwDs physical wellbeing	469:681	Needs to be done – responsibility

	Staff disagreement	857:1029	Difference in staff views – Staff dynamics
	Building a wall (emotional disconnection)	702:834	Benefits PwD as their needs are met, try to detach self to do the job If you bring emotions in it can affect what you're doing
	Preventing use of meds		
	Negotiation/justification through service policy	957:1029	Can we do it through DoLS?
	Influence of own personal experience		
	Influence of others	957:1029	Wishes of families Families perception of what pws would want
	Identification/continuation of prior routine	957:1029	She had a bath twice a day
	Protecting pwds personal hygiene	957:1029	She hadn't washed for ¾ days
	Risk to PwD and others		
Difficulty in sense making	No time to get to know the patient		
Outcome of response	Fear of scrutiny	90:169	Looks like we're neglecting the PwD by leaving them on the floor
	Emotional distress	702:834	For staff and PwD Staff feel mentally drained and guilty
	Staff disagreement	957:1029	Difference in staff views – Staff dynamics
	PwD dignity compromised	957:1029	She was left in a chair – 1. Dignity 2. Cant what we're doing be justified
Making sense of outcome	staff response can make it worse	47:85	Communication barrier – can make them more confused if they don't understand the reassurance
	PwD emotionally distressed	469: 681	He's too frightened and confused – no amount of reassurance is going to help in that moment – hopeless for that moment
Conflict	Patient distress vs self-distress	90:169	Leaving pwd on the floor where they feel safe vs feared perception and criticism of others
	Self- emotional distress vs job responsibilities	702:834	Feel guilty but have to do it
	Pwd emotional distress vs job responsibilities	469:681	Physical wellbeing vs emotional wellbeing – no matter what we'd do he was going

		702:834 957:1029	through this Restrain – to help get the job done quicker PwD dignity/wishes vs staff responsibility and service policy Issues of restrain, it all went wrong, can we justify what we're doing best interest?
Dealing with internal conflict	Self- justification and reassurance	469:681 702:834 837:947, 957:1029	Give him a hug – justifying although there's all the negatives – there's a positive They need us to do the task so have to separate emotions
	Self-questioning	957:1029	Is it in the best interests
	Distancing/ depersonalisation/ breaking emotional connection	469:681 702:834	Do the job, get what we've got to get done – quickly, focus on the end, focus on the action Restrain to get the job done quicker and reduce time of emotional distress for PwD and self
Sense of responsibility	Alleviating sense of responsibility	404:436	Leave the consultant to make the clincal decision on what to do
	Need to care for physical needs	469:681	
	No one else will do it	702:834	If you didn't do it nobody else would
Sense making process and impact :	It's difficult	339:389 404:478	Don't have a magic wand (sigh) Communication barrier Not knowing – it's tragic
	Can take a long time	404:478	Can take a long time to recognise a pattern and sense make – all staff to report the same thing etc.
	Trial and error	339:389	Through outcome of response (medication)
	The need to sense make	469:681 837:947	It's all about understanding why he's acting like he is – getting your head around that The need to self-reflect constantly to process what is going on – to prevent burnout
	Empathising		

	Seeking expert view	339:389, 404:436	Asking the consultant → hence the response was medical – use of medication Give them information and leave them to their clinical decision
	Reliance on HCAs	404:436	HCAs are more hands on – need to pick up on ;little things
	Perspective taking		
	In the moment reflection	957:1029	Paralleling emotion of experience in interview – chaotic experience – recollection and account is chaotic
	Self-questioning/ reflecting	90:169	Do we let them stay on the floor? Is it in their benefit
Sense of a reward	Conflicting view	469:681	I wouldn't say it's a reward, but you feel better with yourself that their fear is gone (emotional connection)
	Tangible reward		
	not many opportunities for reward/success/satisfaction with pwd/job		
	Desperation to feel good		
Having undesirable feelings	Hopelessness/helplessness		
	Frustration	339:389 436:478	Just don't know what to do for PwD PwD unable to communicate with us – not able to tell us
	Feeling criticised	90:169	Others criticise the care without having insight
	Breaking emotional connection	702:834	It can touch you but you have to focus on the task – so have to separate emotions to do the job (egodystonic)
	Guilt	469:68 702:834	Guilty feeling, no matter what we done he was going through this
	Really upsetting	469:681	
	Coping with the feelings	469:681 837:947	1. Distancing/depersonalisation/ breaking emotional connection -Do the job, get what we've got to get done – quickly, focus on the end, focus on the action 2. Self-justification/reassurance Give him a

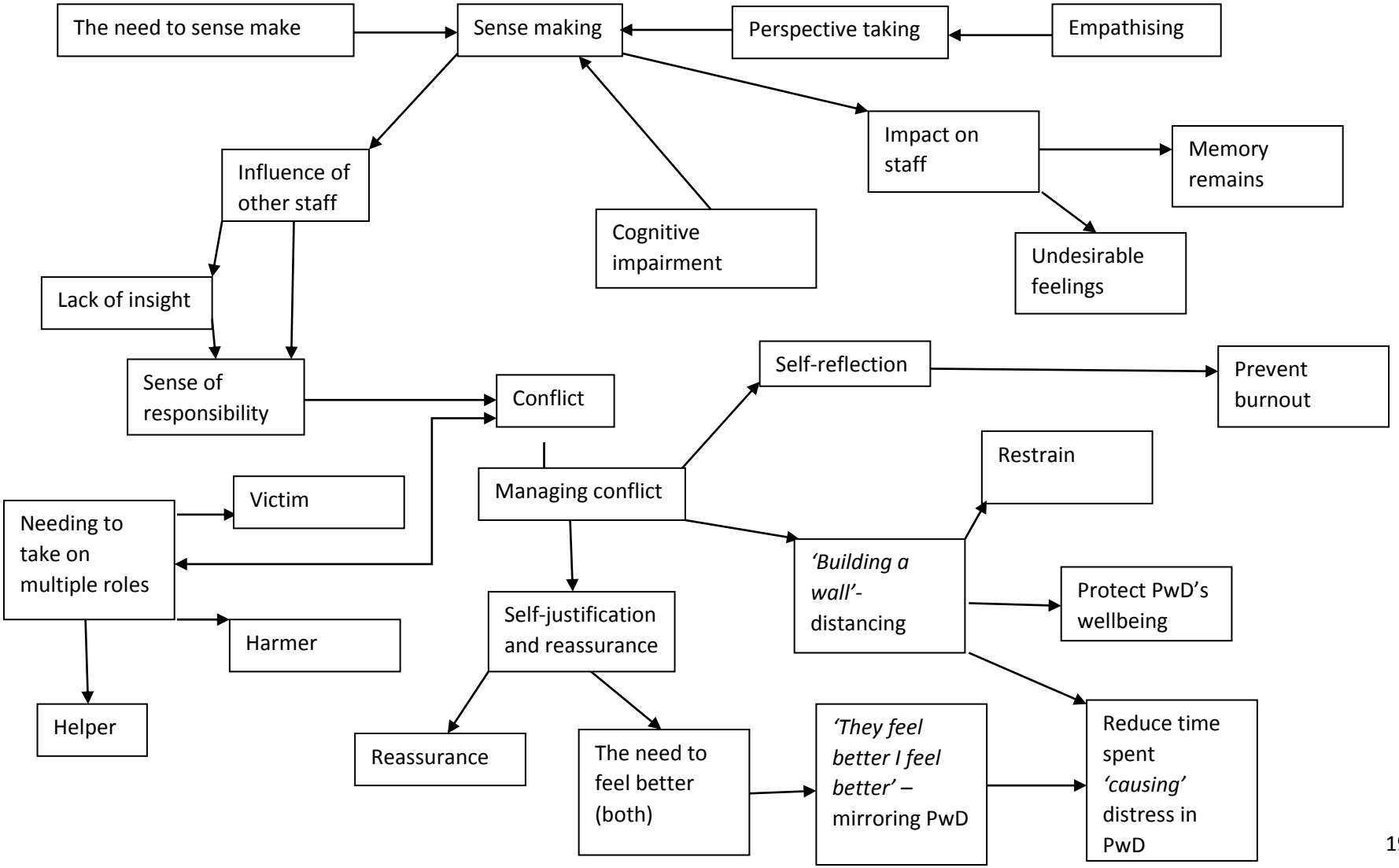
		957:1029	hug – justifying although there's all the negatives – there's a positive Stepped process – do the job – you feel better if they feel better Balancing out the guilt through looking/convincing myself of my value. Humour, staff support Trying to keep thing under control – focus on achievable in a place where ultimate control doesn't exist (stopping dementia) Justification of action through service policy – possibly alleviates guilt knowing they have to do it
	Memory remains	469:681	They'll forget the incident with the short term memory loss but we'll have to live with the emotion
Emotional distancing	In this business		
	No visible pain		
Emotional connection	Easy to get involved		
Preventing burn out	Self-reflection	837:947	Processing the conflicts that arise and why they arise – being able to process what has happened to manage the distress Also referred to having lots of wine
	Taking a step back		
Style/roles of nursing / multiple selves	carer/nurture		
	Victim	469:681	Really upsetting Memory remains with us – trauma moves from him to them and although he forgets the memory it remains with the staff
	Protector/rescuer	569:681 837:947	
	Expert	90:169	Others don't have insight into dementia (I do)
	Abuser/ perp – inflicting harm/	469:681	He thinks we're going to rape, attack, kill him, the longer we took the longer he

			endured the fear

Appendix XII. Theme table for Mel

Superordinate Themes	**Subthemes**
Processes	Empathy Perspective taking Knowledge of dementia
Nurse factors	Influence of others Undesirable feelings – memories remain High sense of responsibility
Managing conflict	Building a wall Self-reflection Need for a reward
Taking on multiple roles	Victim, Helper, Harmer

Appendix XIII. Mind Map for Mel



Appendix XIV. Table of tracked processes for every participant

Handled well

Participant	Experience/process
Jan	Aggression → no SM → uses reassurance, PRN, restraint → Accidental SM – Pwd unable to communicate pain → administers meds → behaviour decreases → view of PwD changes 'absolute darling' → retrospective SM – staff requests exacerbating pain → PwD happy → Jan proud and happy, felt a part of 'bringing him back'
Ali	Aggression → 1st SM - paranoia, hallucinations → Response – restrain and IM, seek more male help → SM response PwD bigger than him – fear reaction 'fight' → Reflection later SM – aggression as a result of wanting to leave the environment
Ayo	Physical aggression → context, taken by single escort to general hospital, unfamiliar environment, confusion, used to be a soldier, frustration → response – distraction and de-escalation → SM response – restraint not possible as he was solely trained in MVA
Deka	Shouting → No initial SM → Trial and error response – isolation → SM through trial and error– he likes space and his radio → felt good – shift manageable – I don't feel like I've failed if shift is manageable
Jill	Running continuously and stripping → SM - feels lost, anxious, agitated; unable to communicate his distress → Response – reassurance, PRN, restraint using a chair (progressive response dependent on outcome) → SM response – grounds PwD, helps his physical health, privacy and dignity, restraint made it easier to give him the care he needed → negotiation of restrictive responses vs patients wellbeing → physically the patient was better but emotionally was still lost → for Jill it was more manageable
Mel	Aggression when attending to personal hygiene → SM fear and anxious of being attacked, fighting for his life, unable to understand that staff wanted to help, communication barrier → Response restrain → emotional distancing – making it as quick as possible, build a wall → compassion/empathy vs responsibility → feeling of guilt → reconnection – pwd feels better and Mel feels reassured
Paul	Verbal aggression → SM – bereavement process – in denial of her husband's death (context – Paul's mother recently passed away – emotional empathic connection) → Response – sat down and spoke with her – established recall → taking the opportunity to do good – they don't arise often → wanting to take away the emotional pain → easy to engage with → satisfying to deal with behaviour without resorting to meds – (importance of formulation)
Romy	Agitation – pacing, wanting to leave the ward → SM knew it was a trigger to aggression, he wanted his family and was looking for them (importance of family, congruent with her own personal values) → Response – stopped other duties and spent time with him showing his album → he was calm after this → glad restraint wasn't used

- SM present or established
- Response successful in reducing behaviour
- SM linked to an emotional connection
  - empathic
  - pleasant
  - fear

- Response makes the shift manageable
(- reconnection)
(- guilt)

Handled Differently

Participant	Experience/process
Jan	Aggression → 1st SM - PwD did not recognise the need to shower (dementia), embarrassed, private man → Response - got him to shower, used a towel to cover him, reassurance → more aggression → 2nd SM → towel kept falling off → restraint used → Jan felt horrible , frustrated → aggression continued → used a novel method – sarong → PwD relaxed and calm → Jan felt better
Ali	Absconding → SM – because of dementia and behavioural problems → response – staff tactically located him, restrain in a wheelchair → reflection – discussed the risk in ward round and gained psychology input
Ayo	Pulling the alarm continuously → SM - intentional for attention of staff, entertaining what she wants → Response - PRN and isolation → SM response – she was becoming unsettled, other responsibilities, one person can't have all my attention → response upset PwD → guilt → self-justification → reflection on alternative response
Deka	Pacing, invading peoples space → SM - can't tell us what's wrong → Response – isolation → behaviour continued → spoke to patient and found out premorbid routine → SM – routine not being following – forced him to bed when he didn't want to go
Jill	Screaming → Multiple SM – wanted staff attention, too reliant on staff, tormented, had depression for a long time before (feeling of failure in the system previously), feeling she might have been sexually abused in the past (SM more empathic as she talks) → Response – using food to calm her which led to mobility issues → empathy vs helplessness – feeling of dehumanising the pwd → no real reward → emotional detachment/distancing → guilt and feeling of failure → self-justification → fear of facing mortality → self-protection
Mel	Refusing to bath → SM – hygiene is less of a priority, loss of family and finding them becomes the priority, confusion and cognitive deterioration → Response – let the pwd go, challenged staff decision to put her in the shower – privacy and dignity – personal emotions – discomfort → guilt – self justification → had to get her out and get her calm again → sense of failure when pwd is upset
Paul	Repetitive behaviour – intentional, seeking staff attention, degree of control → Response – ignoring → SM response – it detracts attention from the other patients, non-sensical behaviour → no pleasant emotional connection – anger and annoyance → self-justification → reflection of alternative response
Romy	Repetitive speech and questioning → SM she was anxious, she had a level of understanding but wanted reassurance → Response – ignore her – distant → SM Response – after several nights – fed up –childlike negative behaviour → pwd became more anxious → guilt → reconnected

- SM achieved
- SM ambiguous/unknown
- Changed SM
- Staff experienced unpleasant emotions; guilt, horrible, failure
- New response used
- Alternative response suggested

- Unhelpful/unsuccessful response
- Self-justification of actions
- Pleasant emotional connection
- Unpleasant emotional connection
- Emotional distancing
- Reconnection

Behaviour that challenged

Participant	Experience/process
Jan	Aggression → SM – cognitive decline, misperceptions → reassurance and distraction → aggression continues → Jan feels helpless → no choice but meds → Personal values – want to treat patients how I treat my disabled child and family →feel awful I can't → guilt → self-justification
Ali	---
Ayo	---
Deka	Aggression → SM ex-soldier - guarding his territory – everyone's an enemy → contextual fear – challenging behaviour unit → Response – speak to him from a distance, distract, restraints.
Jill	---
Mel	Physical aggression → SM – intentional, opportunist, in control, has capacity → restraint – follow protocol for aggression →anger, no pleasant feeling → emotional detachment – duty vs personal emotions – conflicting feeling → hierarchy in the system
Paul	---
Romy	Physical aggression → SM – fear during washing and dressing, not attacking you – trying to get away, might be related to past history → Response - using holds to wash and dress him → SM response – duty of care → responsibilities vs empathy → don't know whether to go against the care plan → physically see him relax when he walks away → (impact of personal values – trying to respond with a calm approach

Similarities –
- Emotions elicited in participants
- Negotiations

Differences
SM

Appendix XV. Final themes table and participants within each theme

		Participants							
Superordinate Theme	Theme	Jan	Jill	Ayo	Ali	Mel	Romy	Paul	Deka
CONSCIOUS EFFORT TO SENSE MAKE	Trial and error								
	Drawing on existing knowledge								
	"Putting myself in his shoes"								
PRESSURES OF THE ORGANISATION									
BALANCING PERSONAL AND PROFESSIONAL SELVES: AN UNDERLYING EMOTIONAL CONNECTION									
"LOOKING BACK ON IT…"									

Appendix XVI. IPA Group support email trail

Me to the group

Hi All,

I'm a first timer using IPA.

As I am going through the transcripts for the initial noting stage, I find myself putting more emphasis on the interpretative level of analysis and struggling to analyse phenomenologically. I was wondering if any of you felt this when you first began using IPA (or still do come across this) and how you managed to bring in phenomenology during analysis? Any tips or advice would be hugely appreciated.

Many thanks,

V

Response:

Hello V at the University of Nottingham,

You may be a *first timer* with regard to IPA, but you ask a most apposite question about how we *managed to bring in phenomenology during analysis*. I have found it helpful in asking questions of transcripts and systematically organizing the results to use categories directly borrowed from phenomenology. In constructing and checking knowledge of this philosophy, I noted recently that there are several guides existing in their entirety online.

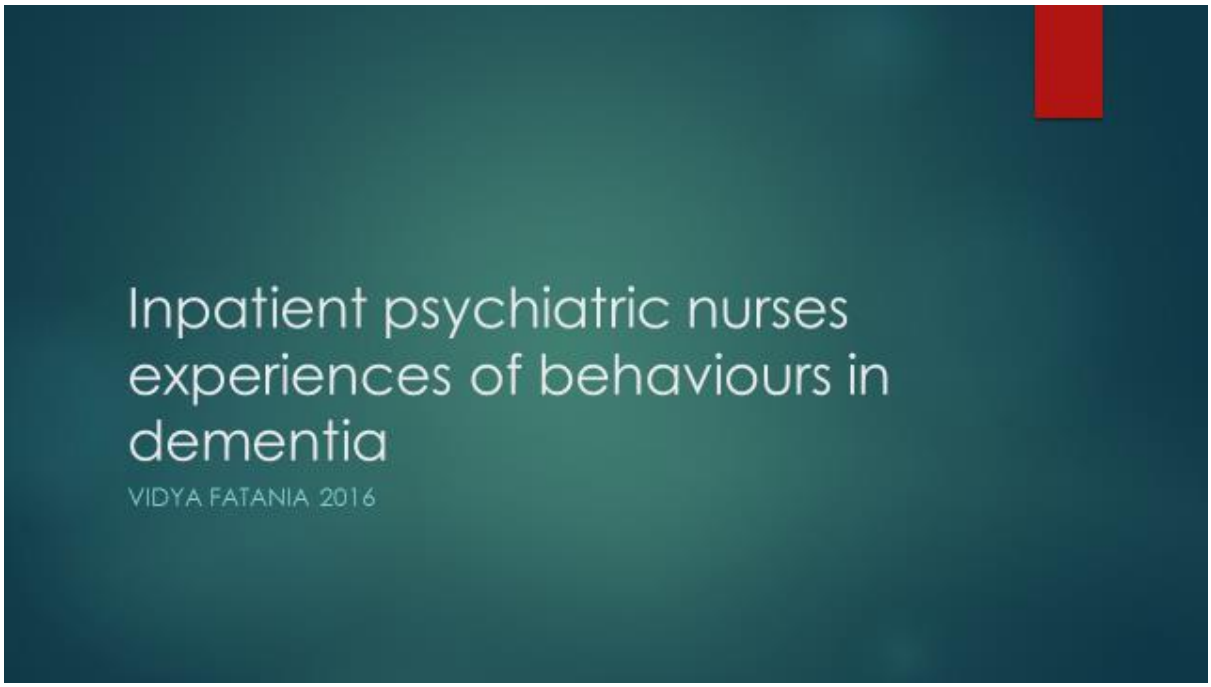
As you may know, one of the more illustrious commentators on phenomenology is Herbert Dreyfus. (I think his lectures are available on YouTube). His book on Heidegger is at:
<http://ir.nmu.org.ua/bitstream/handle/123456789/133914/8997df0543cfecab79ab214697022c44.pdf?sequence=1>
A Commentary on Heidegger*s Being and Time Division I (MIT Press): this version is helpfully organized: you may like to look for *The Three-Fold Structure of Interpretation*.

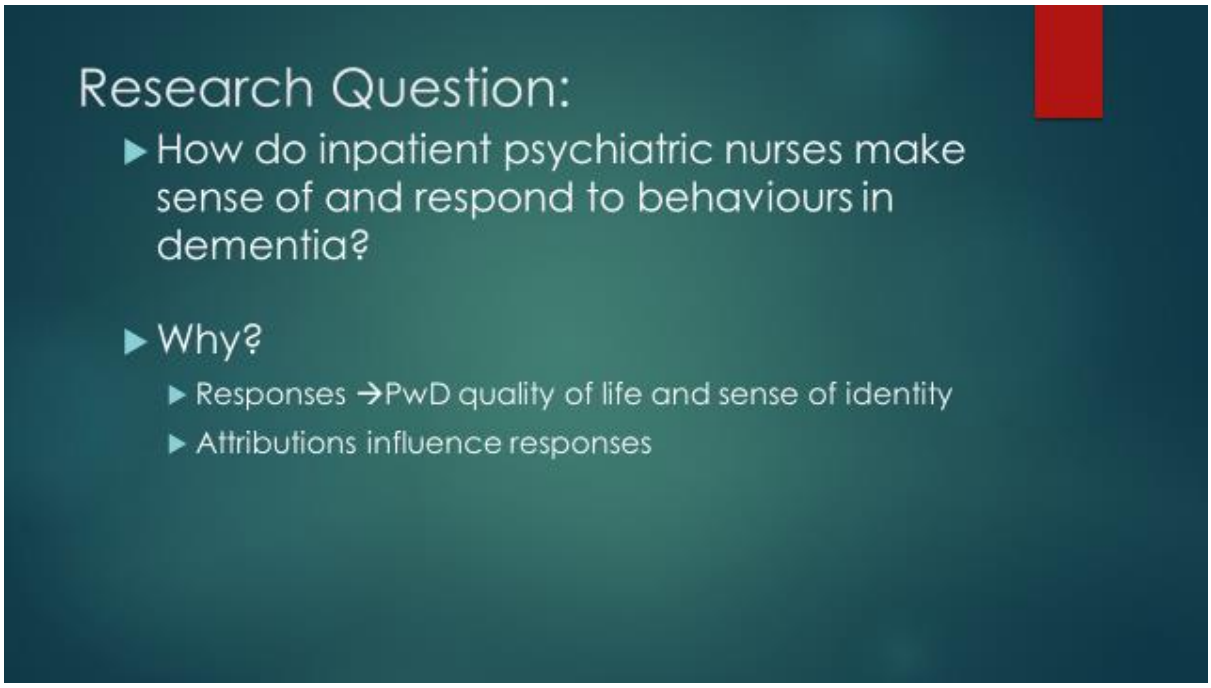
Another guide available online is:
Dermot Moran Introduction to Phenomenology, Routledge
You could read Chapter 7 and pp. 276-278
Heidegger *saw that humans are primarily caught up in living their lives, wrapped up in moods and emotional commitments, in cares and worries, falling into temptation,
projecting themselves into possibilities, seeking to make themselves whole.* (228)

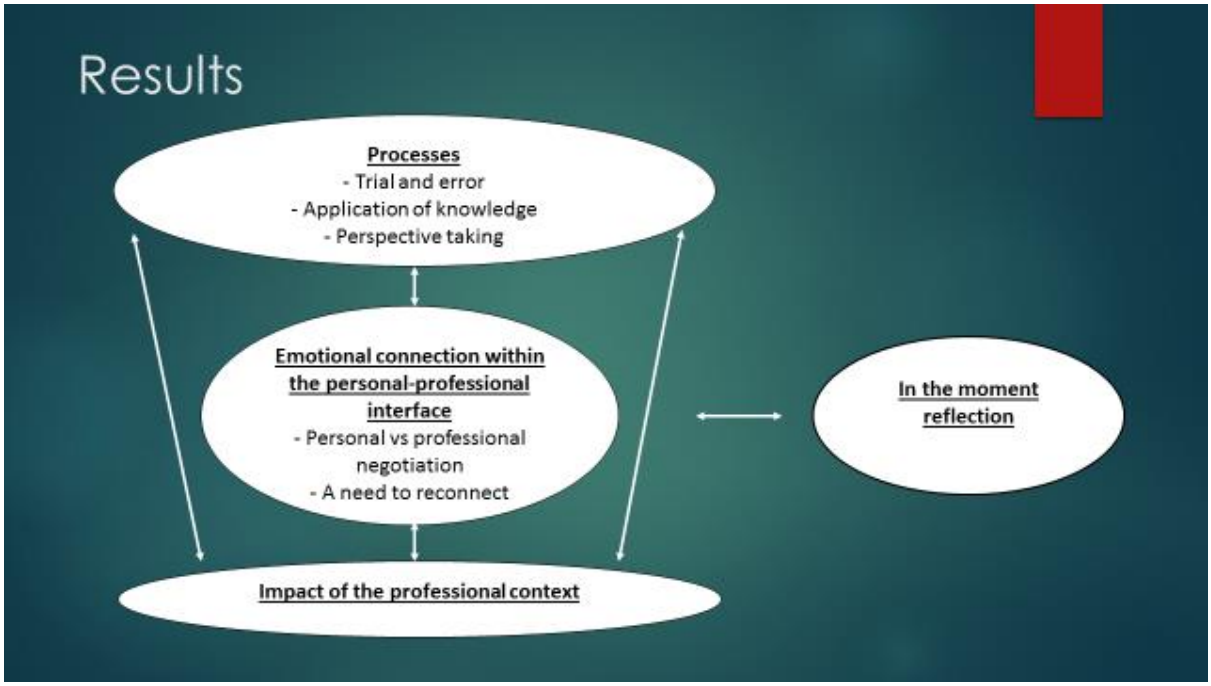
A third guide which I think remains available online is:
Stephen Mulhall, Heidegger and Being and Time. Routledge, Chapter
I suggest Chapter 2 The Human World: Society, Selfhood and Self-interpretation

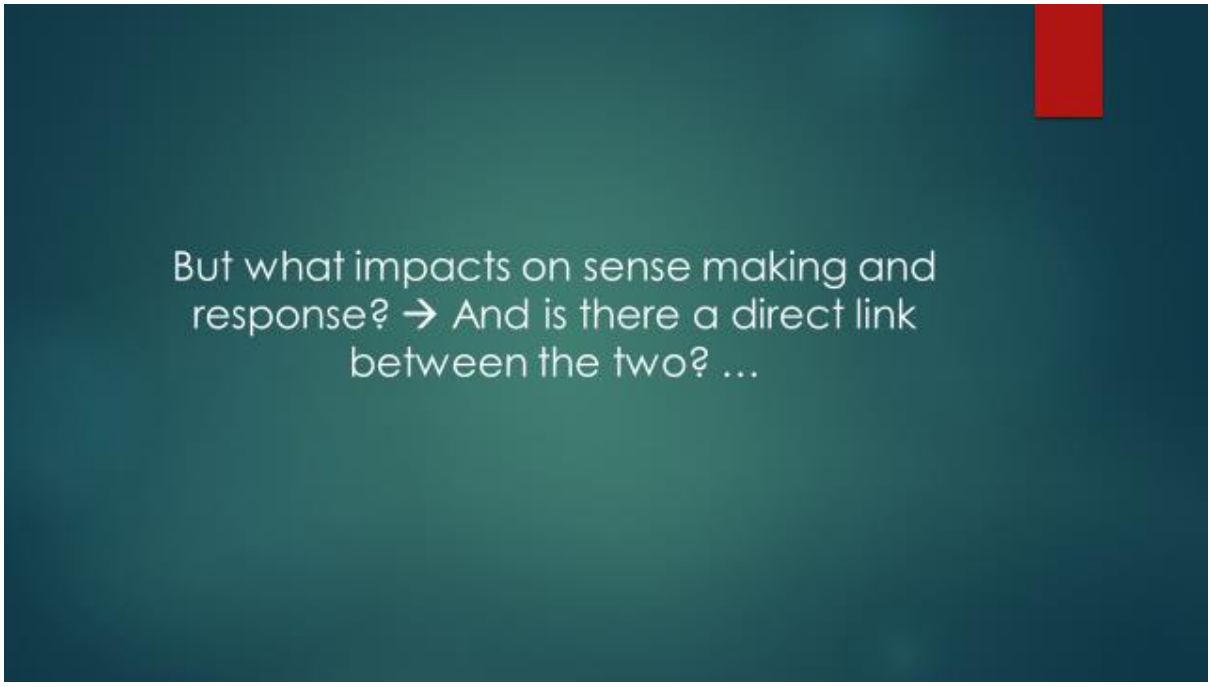
Regards,

Appendix XVII. Presentation disseminated at the service clinical effectiveness meeting






Results
Processes
- Trial and error
- Application of knowledge
- Perspective taking
Emotional connection within the personal-professional interface
- Personal vs professional negotiation
- A need to reconnect
In the moment reflection
Impact of the professional context


But what impacts on sense making and response? → And is there a direct link between the two? …

In short ….. No

- Sense making does not always guide intervention
- Sense making might be constructive but the response is not always constructive

But why is?

The data suggests…

- There's an impact of the professional environment
- Emotional connection within the personal – professional interface
  - *Harmonised or conflictual → determines response*
  - *E.g. Conflict*

Mel: 'he's totally disorientated to person so he's not able to know who we are… it was as if you were going to attack and kill him, rape him or something like that… it's putting like yourself in his shoes. That if we was in a room with random people that we didn't know… it's taking on board and understanding the emotions that he's experiencing are real emotions – and you know they're real to him … You know just get what we've got to get done. No amount of reassurance is going to do anything because he's in the moment, he's so frightened and confused… It can touch you but you have to focus on the task… so have to separate emotions to do the job … you build up a wall to manage your emotions and to be able to get on with a task and then that leads to guilt of having to do that and dealing with their confusion and anxiety'

Reconnection …

- Wanting to reconnect emotionally with the patient

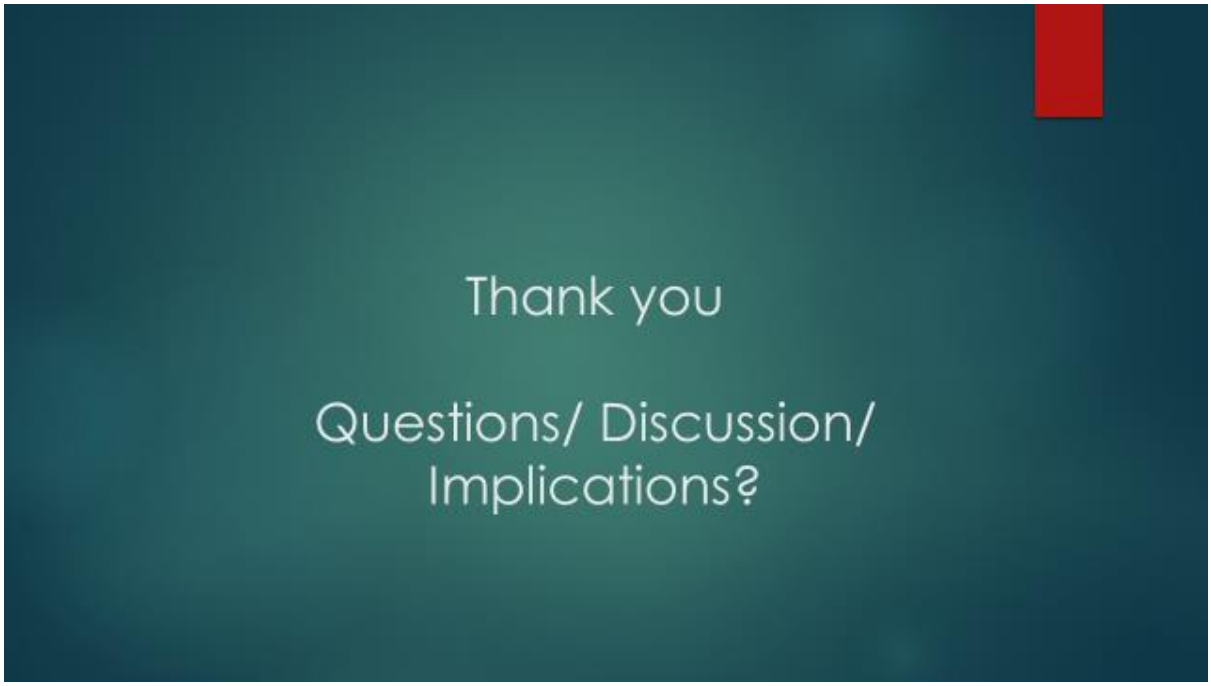
Mel: 'we wasn't able to sort out the agitation at the time of having to attend to his personal hygiene and that was really upsetting for all of us. But what we could do and what I did was after, he used to pace off like run off as if he was running away, but then give it – I used to give him a few minutes and then he'd come and I'd give him a cuddle . And he'd just hold on tight and I'd say "It's fine, it's ok, it's ok, don't worry, everything's alright now, you're alright"… although we weren't able to get through to him because of his – you know his anxiety and his fear was so high, but at least after I was able to – I was able to be there and to give him a cuddle and that reassurance.'

- Reassurance for Mel as well as the patient
- But '…

'… obviously with a cognitive impairment he probably would have forgot the incident anyway unlike me that still kind of thinks about it sometimes – I'm the one left with the memory.'

Cycling through a spectrum of emotional connection





Reflection:

Dissemination to the service required careful consideration of what in particular would be beneficial for the audience I was presenting to. The audience consisted of the Community Head of Services, Team Leaders, OT Lead and Psychologists. I used this opportunity to think about what I would want to know in my clinical work should there be a presentation of research. This led me to think about the themes that were most relevant for clinical implications and the most efficient way to deliver this in a short period of time. I was able to gain some good experience of dissemination in a clinical environment rather than academic and enjoyed the difference of this experience. It felt less pressured and more relaxed with a real interest from those observing in realtion to their clinical practice. I came away from it with a sense of confidence and pleasure that the findings elicited further desire for discussion.

CONFERENCE READY PAPER

Dementia: 'What do I do?!'

Vidya Fatania[1#], Anna Tickle[1], Danielle de Boos[1], David Connelly[2]

[#]Email: lwxvf@nottingham.ac.uk

Background:

There is a national drive to improve dementia care[1]. Existing literature suggests perceived understanding of behaviours in dementia can influence responses of nurses[2 3 4]. Responses have been found to impact on patient quality of life of and personhood[5 6]. Absent from literature however, is the psychological processes nurses go through to make sense of and respond behaviours, particularly in inpatient acute settings where there is limited time and a different range of pressures.

Research Question: How do inpatient psychiatric nurses make sense of and respond to overt behaviours in dementia?

Method:

A qualitative methodological design was used of Interpretative Phenomenological Analysis [IPA][7],

Eight nurses working in acute inpatient dementia wards were recruited from two National Health Service (NHS) sites across one Trust. Semi- structured interviews were conducted, transcribed and the methods stages of analyses[7].

Quality was assessed using criteria specifically developed for IPA.[8]

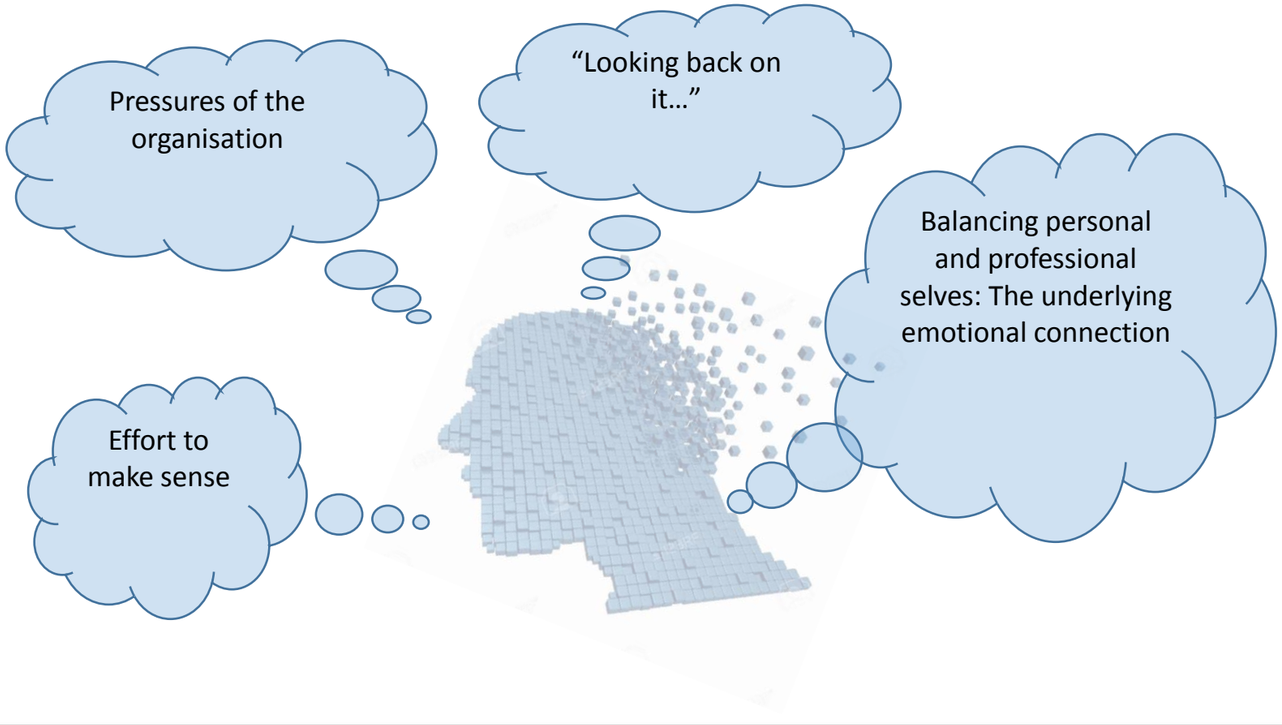
A reflective diary was kept throughout the research process which included examples of reflexivity.

Results:

Four interrelated themes were found which have been depicted in the image.

Psychological understanding of behaviour through a range of processes can inform more helpful responses and build empathy towards patients. However, this can be influenced by the pressures related to the professional role[2 3 9] as well as the underlying emotional connection formed with the patient.

This emotional connection formed a spectrum which ranged from empathic connection to avoidance or termination of connection. Nurses needed to adopt different positions on this spectrum within one experience to be able to fulfil professional duties



Conclusions and Implications:

Sense making is dynamic and occurs through a range of psychological processes, which may change moment by moment dependent on the influences on and around nurses.

Nurses need to be supported to move flexibly through a range of emotional connections which were found to underlie negotiations made at work and its subsequent influence on sense making and responding. Furthermore, support is needed to emotionally reconnect following disconnection, which is hypothesised to have a positive impact on staff and patient wellbeing

References: [1]Department of Health. (2009). *Living well with dementia: a national dementia strategy.* Leeds, UK: Department of Health.; [2]Todd, S. J., & Watts, S. C. (2005). Staff responses to challenging behaviour shown by people with dementia: An application of an attributional-emotional model of helping behaviour. *Aging & Mental Health*, *9*(1), 71-81; [3]Eriksson, C., & Saveman, B. (2002). Nurses' experiences of abusive/non-abusive caring for demented patients in acute care settings. *Scandinavian Journal of Caring Sciences, 16(1),* 79-85; [4]Dupuis, S. L., Wiersma, E., & Loiselle, L. (2012). Pathologizing behavior: Meanings of behaviors in dementia care. *Journal of Aging Studies, 26*(2), 162-173; [5]Jing, W., Willis, R., & Feng, Z. (2016). Factors influencing quality of life of elderly people with dementia and care implications: A systematic review. *Archives of Gerontology and Geriatrics, 66*, 23-41. ; [6]Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, England: Open University Press; [7]Smith, J. A., Flowers, P., & Larkin, M. (2009). Interpretative Phenomenological Analysis: Theory. *Method and Research London: Sage*; [8] Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis: A reply to the commentaries and further development of criteria. *Health Psychology Review, 5*(1), 55-61; [9] Stacey, G., Johnston, K., Stickley, T., & Diamond, B. (2011). How do nurses cope when values and practice conflict? *Nursing Times, 107*(5), 20-23;