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**STAFF EXPERIENCES OF CARING FOR PEOPLE WITH DEMENTIA WHO ARE
DISTRESSED**

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ABSTRACT

Introduction: Research has indicated that distressed behaviours (such as calling out, refusal of medication and personal care) are prevalent in people living with dementia on acute hospital wards. Whilst the different approaches to managing distressed behaviours within general health hospitals are well-documented, there is a limited amount of research which has investigated staff experiences of providing care within this context, particularly in relation to coping styles and how staff understand the behaviours of the person living with dementia. The current study therefore aimed to explore ward staff experiences of distressed behaviours for people living with dementia in an acute hospital setting.

Method: A qualitative methodology was adopted in which nine ward staff working in an acute hospital setting were interviewed using a semi-structured interview format. Staff were invited to talk about their experiences of providing care to patients with living dementia who were displaying distressed behaviours. Each participants' transcribed interviews were then analysed using Thematic Analysis.

Results: Four key themes emerged from the participants experiences of providing care to people living with dementia in an acute hospital setting. These themes were: 'How I understand the behaviours of the person living with dementia', 'The context in which I undertake this work', 'The emotional load' and 'What I do to manage' when supporting distressed behaviour. A further 15 subthemes were identified under these headings. Multiple factors shaped responses to distressed behaviour. Participants spoke about the importance of familiarity when providing care to people living with dementia and ways in which they try to achieve this whilst working in a fast-paced acute hospital setting with short lengths of stay. Participants spoke about the ward context and the difficulties this created in providing person-centred care that is responsive to the needs of people who are distressed. Importantly, participants highlighted the significant emotional impact of providing care to people living with dementia who are distressed and outlined coping strategies they utilise to overcome the emotional component of this work. Of particular interest was the reluctance of staff to disclose the extent of this

emotional load with colleagues or managers. Instead, staff referred to hiding the emotional impact (for example, crying in the toilets or at home).

Discussion: The study highlighted that the emotional load of providing care to people living with dementia who are distressed is unlikely to be fully recognised or supported by colleagues and management because this is rarely shared or spoken about by ward staff. Further, the study demonstrated the emotional and practical ways ward staff cope with, and support people who are distressed, as well as the ways in which ward staff interpret and respond to distressed behaviours. Distressed behaviours appeared to be interpreted in part due to modifiable beliefs shaped by perceptions of dementia and were not always helpful. This has implications for future training and support provided by the organisation.

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LIST OF ABBREVIATIONS

- ABC – The ‘Antecedent Behaviour Consequence’ model
- A&E – Accident and Emergency
- BPSD – The Behavioural and Psychological Symptoms of Dementia
- CMAI – The Cohen-Mansfield Agitation Inventory
- DoLS – Deprivation of Liberty Safeguards
- GDPR – General Data Protection Regulation
- HCA – Healthcare Assistant
- IPA – Interpretative Phenomenological Analysis
- MCA – Mental Capacity Act
- NICE - The National Institute for Health and Care Excellence
- NHS – National Health Service
- PICT – Psychologist in Clinical Training
- PLST – The Progressively Lowered Stress Threshold model
- RGN – Registered General Nurses
- TA – Thematic Analysis
- NVQ – National Vocational Qualification
- WHO – World Health Organisation

INTRODUCTION

Dementia is a syndrome characterised by a deterioration in intellectual, mental, and later physical function, which leads to disability and mortality, and is beyond what might be expected from normal ageing (World Health Organisation; WHO, 2016). It is estimated that 47.5 million people worldwide have dementia and a further 7.7 million cases are being diagnosed every year (WHO, 2016). Within the UK, 1 in every 14 people over 65 are believed to have dementia (Prince et al., 2014). Dementia can affect memory, thinking skills, orientation, visuospatial abilities, language and executive function (Rozsa, Ford, & Flicker, 2016). The condition also includes behavioural and psychological symptoms (Finkel, Silva, Cohen, Miller, & Sartorius, 1997).

It is estimated that cognitive symptoms (e.g. difficulties with attention, concentration, orientation and language), emotional symptoms (e.g. frustration, apathy and irritability) and behavioural symptoms (e.g. aggression and agitation) affect up to 90% of people living with dementia (Alzheimer's Society, 2014). Within the realm of the behavioural symptoms exhibited by people living with dementia, displays of behaviour that are considered societally to be negative are often described as 'challenging behaviours' (Krishnamoorthy & Anderson, 2011). More recently, the term 'distressed behaviours' has been used to describe a range of symptoms which are often shown for people living with dementia during a hospital admission. The Cohen-Mansfield Agitation Inventory (CMAI; 1997) classifies distressed behaviours into three types:

- (1) **physically aggressive behaviours** (e.g. hitting, kicking, spitting, throwing things, biting);
- (2) **verbal agitation** (e.g. screaming, crying, cursing/ verbal aggression); and
- (3) **physical non-aggressive behaviours** (e.g. repetitive mannerisms, restlessness, pacing, aimless wandering, disrobing and trying to get to a different place).

Distressed behaviours often manifest during a hospital admission as people living with dementia may have difficulties orientating their surroundings and communicating their needs.

Determining a distressed behaviour is complex. Some researchers (Crowther, Brennan, & Bennett, 2018) say it is synonymous to any negative emotional state. However, this overlooks the fact that not all negative emotional states are observable through exhibitions of behaviour. It is also important to add that there is nuance to all exhibited behaviour in that not all behaviours that may be seen as negative are signalling distress (for example, not all wandering is distressed, it is just going for a walk). It is important we are able to interpret behaviours exhibited by people living with dementia accurately in terms of whether a behaviour is a signal of distress or otherwise, if we are to respond sensitively to their needs.

Within the current study, the term 'distressed behaviours' will be used to describe any negative emotional behaviour state displayed by people living with dementia. This may include, for example, an individual refusing their medication or personal care, wandering or frequently pressing the call bell, and relates to how ward staff understand and respond to distressed behaviour.

Whilst distressed behaviours in people living with dementia have been well researched within residential and care home settings (Rapaport et al., 2018), there is, by comparison, very little written about staff experiences of responding to and understanding distressed behaviours in people living with dementia within an acute hospital setting. As nursing staff are the main providers of dementia care in acute hospitals (Baillie, Cox, & Merritt 2012), it is imperative that a level of understanding about their roles in managing distressing behaviours is reached so that adequate support for those roles, and the emotional impact they have on staff, can be put into place. Additionally, experiences of strain have been shown to lead to burnout in ward staff which can impact their ability to perform good quality nursing care (Edberg et al., 2008). It is therefore important to understand how staff

understand and respond to distressed behaviour in people living with dementia as this will ensure that good quality care for people living with dementia is provided.

The current literature describes a range of approaches (e.g. medical, risk management, person-centred and psychological) used to manage distressed behaviour. As very little is known about how staff understand and respond to distressed behaviours in people living with dementia (Pinkert et al., 2018), this study aims to ascertain more information about how ward staff cope with these distressed behaviours for these individuals within an acute hospital setting. The findings from the study will provide much needed information about how staff understand and respond to distressed behaviours and how they can be better supported in the future.

CHAPTER ONE: LITERATURE REVIEW

In the following chapter I will introduce some key demographics relating to dementia in general hospital settings. I will then go on to define what is meant by distressed behaviours and the prevalence of these behaviours within a general hospital setting. I will then introduce the current approaches including the medical, risk-management and person-centred care approaches, used to manage distressed behaviours in an acute ward setting. Psychological models in understanding distressed behaviours will then be described alongside current management guidelines. Lastly, staff experiences of responding to distressed behaviours for people living with dementia will be discussed.

1.1 Dementia in General Hospitals

Multi-morbidity is associated with age and hospital admission (Barnett et al., 2012), with older people more likely to be admitted to general hospitals for medical treatment. Approximately 25% of hospital beds are used by people living with dementia at any one time, with an increased length of stay nearly two weeks longer than compared to those without dementia (Alzheimer's Society, 2009; Dementia Action Alliance, 2011; Lyketsos, 2000; Reynish et al., 2017). This can result in increased pressures for nursing staff to care for people with a dementia diagnosis (Sampson, Blanchard, Jones, Tookman, & King, 2009).

A hospital admission, combined with unfamiliar surroundings and memory problems, can be a frightening and disorientating time for people living with dementia (Cunningham, 2006). The physical layout of wards within general hospitals are often unsuitable for people living with dementia as there is often too little space between beds and nursing stations are placed too far away (Moyle, Olorenshaw, Wallis, & Borbasi, 2008). Further, people living with dementia may have difficulties filtering out unwanted noise which may exacerbate levels of confusion (Cunningham, 2005). Insufficient stimulation, physical discomfort and psychological factors, such as agitation and distress, may also be apparent (Pieper et al., 2013). A period of hospitalisation for people living with dementia has also been shown to have an adverse effect on their health including increased rates of

falls, a loss of function and increased mortality rates (George, Long, & Vincent, 2013; Watkin, Blanchard, Tookman, & Sampson, 2012). Additionally, increased levels of confusion and agitation can also result from physical ill health such as delirium which is common amongst people living with dementia during a hospital admission.

1.2 Dementia and Distressed Behaviours in General Hospitals

The factors described above can often lead to behaviours which are perceived as 'disruptive' or 'difficult' to manage by staff (Cunningham, 2006). Further, the heterogeneous presentation and behavioural features of dementia can mean that staff find it difficult to meet the needs of people living with dementia in response to their primary symptoms, or do so in a way which is incongruent to their personal preferences, habits or health difficulties (Alzheimer's Society, 2009; Reynish et al., 2017). This can often lead to increased levels of agitation for the person living with dementia (Kales, Gitlin, & Lyketsos, 2015).

1.2.1 Defining distressed behaviour.

The term 'distressed behaviours' is a broad umbrella term often used to describe any negative emotional behaviour state for the person living with dementia (Crowther et al., 2018). Distressed behaviours are often shown for people living with dementia during a hospital admission as they may have difficulties orientating their surroundings and communicating their needs. There appears to be some interplay with how distressed behaviours are interpreted within the literature. The term 'behaviours that challenge' describes the relationship with the person living with dementia and locates the problem as an interpersonal issue. The term 'distressed behaviours' can therefore be interpreted as a concept for ward staff to communicate their understanding and interpretation of a behaviour displayed by the person living with dementia. These symptoms can cause or exacerbate sleep deprivation, fatigue and eating problems (Watson & Green, 2006). Zwijsen et al. (2014) highlighted the ambiguity of challenging behaviour as a concept, in that the term does not clearly define how severe the behaviour must be to be categorised as 'challenging'. Additionally, it is not clear as to whom the behaviour must present a challenge to.

The term 'Behavioural and Psychological Symptoms in Dementia' (BPSD) is still widely used in clinical settings and is conceptually linked to challenging behaviour, or 'behaviours that challenge'. Often, these symptoms can result in behaviours that staff may find difficult to manage and respond to (Kales et al., 2015). The term BPSD has been critiqued for creating the impression that behaviours can be treated effectively with medication (James & Moniz Cook, 2018). Further, it is recognised that the presence of symptoms and behaviours which pose as a challenge for staff to respond to are invariably a way in which the person living with dementia is communicating an unmet need (James & Jackman, 2017).

Within the current study, 'distressed behaviour' will henceforth refer to any negative emotional behaviour state displayed by the person living with dementia and relates to how ward staff understand and respond to the behaviour.

1.2.2 Prevalence of distressed behaviours in general hospitals.

The prevalence of distressed behaviours within acute hospital settings has been explored. Sampson et al. (2014) found that distressed behaviours affect approximately 75% of people living with dementia at some point during their hospital admission. The study also found that aggression, sleep disturbances and anxiety were the most frequent types of distressed behaviours for people living with dementia who were admitted via the emergency department. Gonski and Moon (2012) found that wandering represented the most frequently encountered distressed behaviour for staff to respond to. This was followed by verbal aggression which was often accompanied with physical aggression. The study reported that distressed behaviours commonly occurred when staff were delivering personal care to the person living with dementia; similar findings were also found by Borbasi, Jones, Lockwood, and Emden (2006).

1.2.3 Consequences of distressed behaviours.

The consequences of distressed behaviours can be severe, especially in the long-term. It can result in an over-reliance of anti-psychotic medication and physical interventions, increase physical and psychological ill-health to both the person living with dementia and ward staff, and can lead to high staff turnover resulting in

reductions in permanent members of staff and a greater need for agency staff (George et al., 2013). Further, the authors reported that this can result in increased pressures for organisations to meet their legal duties to protect staff and vulnerable individuals, as well as pressures to deliver important national agendas to improve acute hospital care for people living with dementia.

In care homes, non-pharmacological interventions have been shown to decrease distressed behaviours for people living with dementia and improve the well-being of staff (Deudon, Maubourguet, & Gervais, 2009; Kales et al., 2015; Livingston, Johnston, & Katona, 2005). However, it has been found that pharmacological interventions, specifically antipsychotics, are often used before non-pharmacological alternatives (Cohen-Mansfield, 2013). The consequence of such interventions can increase the risk of mortality and adverse events such as seizures and weight gain (Langballe, Engdahl, & Nordeng, 2014). Further, there appears to be limited data to describe how distressed behaviours are currently managed in acute hospital settings (White et al., 2017).

1.3 Approaches to Distressed Behaviours in General Hospitals

In UK general hospitals, a variety of approaches are currently used in response to distressed behaviours for people living with dementia.

1.3.1 Medical approach.

A medical approach takes a diagnostic stance and offers a clearer understanding towards the aetiology of the dementia syndrome. Although this approach is useful in terms of excluding other possible causes of the behaviour, for example, infection and prescribed medications (Hersch & Falzgraf, 2007; Zaman, 2002), in isolation this may be too biologically-orientated and may treat the syndrome as opposed to the person (McGreevy, 2015). The biomedical approach, however, does facilitate a better understanding of the disease. The approach can help staff understand the associated pathologies of the condition. Consequently, care can be planned with more effective care pathways provided to people living with dementia (Houghton, Murphy, Brooker, & Casey, 2016).

1.3.2 Risk management approach.

A risk management approach is often seen on wards in order to reduce risks for people living with dementia, staff and the organisation; however, the emphasis of safety procedures (for example, excessive monitoring, specialising and restraint) can often neglect the needs of people living with dementia (Clarke & Mantle, 2016). A focus on safety can result in fundamental physical and psychosocial needs becoming less of a priority (Cowdell, 2010). Conversely, Handley, Bunn, and Goodman (2017) found evidence that addressing risk in a way that supported the person living with dementia's abilities, choices and independence reduced adverse incidents. For example, they reported that wards with locked door access meant people living with dementia could be monitored from a distance without restricting their movement around the ward and could help staff perceive 'wandering' behaviours as positive rather than challenging (Zieschang et al., 2010).

Within an acute hospital setting, people living with dementia are at a high risk of falls due to their cognitive difficulties affecting their reaction time, balance and visuo-spatial abilities (Stevens et al., 2002). Mintzer (1993) found that by providing care which supported the person living with dementia's needs (both in terms of level of nursing care and support around the ward), resulted in staff being able to provide appropriate levels of care and prevented adverse events in a timely manner. Gonski and Moon (2012) completed a retrospective review of patients admitted to an inpatient behavioural unit which provided specialised management to patients displaying distressed behaviours due to delirium and/or dementia. They reported a low incidence of falls and lack of subsequent injury when environmental features of the unit facilitated a closer interaction between nursing staff and patients. They also reported that positively there was a reduced use of 'special nurses' compared to general hospital wards. Despite these findings, the results may not be transferable to an acute hospital setting due to the ward set-up within an inpatient behavioural unit. Additionally, whilst the authors described the findings as positive, it highlights concerns regarding restrictive risk-based practice.

The phenomenon of restrictive risk-based practice of care for people living with dementia has been studied within long-term care settings (Kable, Guest, & McLeod, 2012) but appears to be limited within an acute hospital setting (Clissett, Porock, Harwood, & Gladman, 2013; Houghton et al., 2016). This is despite an increasing prevalence of people living with dementia being admitted to general hospitals (Sommerlad et al., 2019). Featherstone, Northcott, and Bridges (2019) explored restrictive risk-based practice within the acute hospital setting and found that resistance to care (for example, care delivered by the person's bedside) by people living with dementia was a routine and expected part of the ward culture. The study also found that patient and staff experiences were largely shaped around the ward timetable (for example, set times for mealtimes, medication rounds and personal care). This appeared to further trigger the person living with dementia's resistance to care. Additionally, the individual's needs were superseded by a focus on the delivery of essential care and that ward staff were confined to delivering routines of care that triggered patterns of resistance.

1.3.3 Dementia-friendly ward environments.

The concept of dementia-friendly environments was developed by the WHO (2007). The term reflects the physical and social environment for the person living with dementia that promotes social inclusion, acceptance and accessibility. At a patient level, the care that individuals receive reflects the ability for people living with dementia to engage with services and manage their health and thus improves outcomes for the patient (Department of Health, 2015). From a ward environment perspective, dementia-friendly environments recognise how dementia can affect perception and vision. Providing adjustable lighting systems, colour-coded bays and personalisation of bed space can help orientate people living with dementia during a hospital admission and can reduce distressed behaviours (Brooke & Semlyen, 2017).

The King's Fund (2014) developed an assessment tool, based on best practice, for staff to use to assess the ward environment for people living with dementia and to help orientate them during an acute hospital admission. The tool aims to help people living with dementia to make sense of their environment, develop

relationships with staff and to pursue meaningful activities. The tool also advises to minimise frequent moves on the ward and for the continuity of staff to be encouraged to help reduce distressed behaviours, such as confusion and agitation, for people living with dementia (Fitzpatrick, 2018).

Whilst guidelines and recommendations for providing dementia-friendly wards have been developed, it is well recognised within the literature that environments for people living with dementia still remain unsuitable (Reynish et al., 2017). Further, an admission to an acute ward is often associated with poor outcomes for people living with dementia. Moyle et al. (2008) suggested that one of the main reasons for this is due to the acute ward itself. Environments within acute hospital settings are often unfamiliar and threatening for people living with dementia. Additionally, acute wards are busy and have a constant change of staff during each shift. People living with dementia are also expected to adjust to the noise and brightness of the ward and receive care from staff who they are unfamiliar with (Featherstone, Northcott, Harden, et al., 2019). It is unsurprising that this can cause a degree of disorientation and confusion for people living with dementia and can be a trigger for distressed behaviours within an acute setting.

1.3.4 Person-centred care.

Person-centred care can be defined as putting the needs of the person living with dementia at the centre of care (Clissett et al., 2013). It is considered the overall aim in dementia care irrespective of the care setting (Fitzpatrick, 2018). Person-centred care is considered a more 'nursing-focused' approach. The goal is to ensure that the person living with dementia's personhood is respected regardless of their cognitive impairment. Further, one of the defining aspects of person-centred care is acknowledging the role of 'personhood' as a fundamental attribute for the person living with dementia (Kitwood & Bredin, 1992; NICE, 2011). Personhood is the central component to person-centred care and is understood to involve the qualities of the person living with dementia (Smebye & Kirkevold, 2013). Kitwood (1997) linked personhood to the provision of care for people living with dementia and highlighted different processes which often occur in dementia care settings which affect the personhood of the individual. For example, a loss in meaningful

activities and relationships, as well as a loss of everyday activities and skills. Kitwood (1997) referred to these processes as 'malignant social psychology' which are seen to have a negative effect on an individual's personhood. This term has also been used to describe a range of behaviours that undermine the personhood and wellbeing of an individual (Kitwood, 1997). Kitwood (1993) describes different types of interactive processes which often occur in dementia care that can have a negative effect on an individual's personhood. These interactions can subsequently lead to personhood being undermined and can lead to unmet social and psychological needs for the individual.

Implementing a person-centred approach with meaningful and engaging activities for people living with dementia not only offers a sense of personhood, but also reduces distressed behaviours (Kim & Park, 2017). Person-centred care takes time to develop and is usually most easily achieved through consistent longer-term relationships with caregivers (Clissett et al., 2013). Acute hospital settings, however, commonly have a strong medical focus built on medical routines and organisational efficiency. This means that the service provision prioritises attending to medical needs and discharging patients as soon as their medical condition is stable, which can prevent ward staff being able to provide person-centred care (Nilsson, Lindkvist, Rasmussen, & Edvardsson, 2013). While the acute hospital setting requires ward staff to have particular knowledge and skills that uphold the personhood of people living with dementia, this can be a particular issue in relation to staff working across the wider spectrum of acute care contexts as they may lack experience of this type of care (Nolan, 2007). A national audit of dementia care in general hospitals in England (Royal College of Psychiatrists, 2013) found that care was largely task-focused and delivered in an impersonal manner. This can lead to additional distress for people living with dementia and results in longer hospital stays (Surr, Smith, Crossland, & Robins, 2016).

Although there are challenges with nursing staff being able to provide person-centred care for people living with dementia in acute settings, Scerri, Innes, and Scerri (2015) provided evidence of person-centred care being delivered within an

older persons acute hospital ward. They found that healthcare professionals participating in the study were able to identify experiences where they felt satisfied with the level of care they were able to provide to people living with dementia. Furthermore, most of the nursing staff were able to provide experiences that focused on being able to respond to individuals who were displaying distressed behaviours. Ward staff were also noted to express the importance of getting to know the patient, particularly in relation to communicating effectively using strategies such as distraction and validation. The authors also provided examples detailing instances of nursing staff providing their own experiences of attempting to understand the meaning behind the person's distressed behaviour. They also found evidence of staff using the person's own language and genuinely listening to what their patients were saying, indicating that nursing staff were aware of communication strategies to maintain personhood. This study provides examples of positive care and can offer an understanding of what quality dementia care might look like within general hospital clinical practice.

1.3.5 Psychological approaches.

Distressed behaviours in people living with dementia can cause great frustration, worry, sadness and fear for staff (Bryden, 2005). Further, the way in which staff try to respond to distress may be interpreted as threatening by the person living with dementia and may, counterproductively, increase their level of distress (Jackman & Beatty, 2015). Central in being able to respond to distressed behaviours is to have a better understanding of the person living with dementia's past experiences. Psychological approaches are widely used within dementia care (James & Moniz Cook, 2018). A psychological formulation to distressed behaviours has been shown to help staff understand the possible causes of distressed behaviours for people living with dementia and are often used within residential care home settings (James & Jackman 2017). This approach encourages an alternative reason for the behaviour as opposed to it being seen as a result of a neurodegenerative process (de Pfeiffer, 2016). A number of psychological models have been proposed which aim at promoting a better understanding of how distressed behaviours for people living with dementia are responded to.

1.3.5.1 The unmet needs model.

The 'Unmet Needs Model' (Cohen-Mansfield, 2001) identifies possible precursors to distressed behaviours and can help staff to understand the functions of a behaviour (see Figure 1).

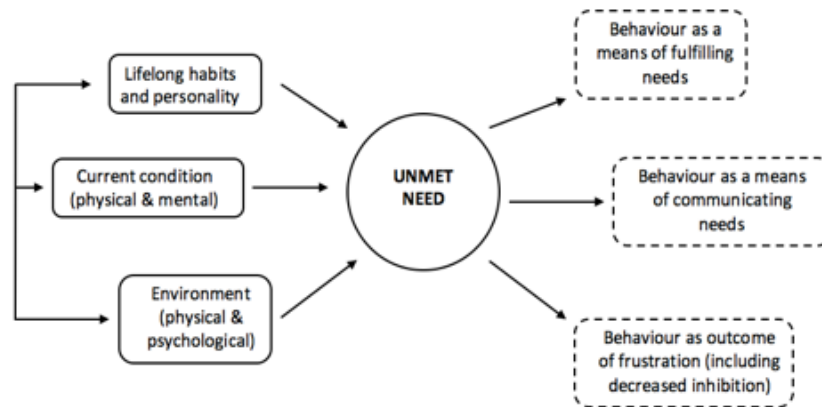


Figure 1. Cohen Mansfield's Unmet Needs Model.

The model suggests that distressed behaviours occur following an interaction involving the person living with dementia's lifelong habits and personality, their current condition (physical and mental) and the environment. The model also recognises that an unmet need may relate to pain, physical or psychological discomfort, inadequate stimulation within the environment or difficulties communicating. In the context of a busy, acute hospital ward, which places high demands on staff, the priority is to monitor and manage the needs of all patients on the ward (Houghton et al., 2016). This often results in staff being unable to meet the needs of the person living with dementia or do so in a way which is incongruent to their personal preferences or pre-morbid personality causing distress for the person living with dementia (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015). Evidently, this model highlights the knowledge about the person living with dementia as essential in responding to distressed behaviour (Antuono & Beyer, 1999; Prior et al., 2016). However, the heterogeneous presentation of the condition acts as a further barrier for staff working within an acute hospital setting who have a limited time to build a therapeutic relationship with the person living with dementia. Further, understanding an individual's needs may take time to develop and is usually most easily achieved through consistent

longer-term relationships as opposed to a short-stay acute ward within a general hospital (Clissett et al., 2013).

1.3.5.2 'Antecedent Behaviour Consequence' (ABC) approach.

The 'ABC' approach is another psychological framework used to understand distressed behaviour. It provides staff with a structured method for recording and assessing the contextual factors which may precipitate the occurrence of distressed behaviours for people living with dementia (Hurt et al., 2008). The approach is based on learning theory and suggests behaviours can be reinforced either intentionally or unintentionally (Cohen-Mansfield, 2003). It allows staff to consider the environmental and social factors which were present before the onset of the distressed behaviour (the Antecedent), the behaviour itself (the Behaviour) and how the behaviour was responded to by staff (the Consequence) to be recorded. With this information, the approach aims to provide any patterns of distressed behaviour which allows for changes to be made within the environment; consequently, this aims to reduce the levels of distress for the person living with dementia. Completing an 'ABC' chart also provides insight into what triggers distressed behaviours and can help to define the problem and prevent further incidents that may arise if the person living with dementia's needs are misunderstood (Cunningham, 2005). Further, research has shown that an 'ABC' approach to distressed behaviours provides staff with a sense of control of the situation (Omelan, 2006). The 'ABC' approach has been critiqued for being too simplistic and only useful in straightforward cases (Spira & Edelstein, 2006); however, the simplicity of this model may be seen as a strength in a busy clinical environment where time is limited and staff are medically focused and who are not psychologically trained. Further, research has found that an 'ABC' approach can lead to changes in attitudes towards the person living with dementia from their caregiver (Kitwood, 1997).

1.3.5.3 Functional analysis.

Other psychological models have been used to improve staff understanding of distressed behaviours in people living with dementia. Functional analysis is considered an extension from an 'ABC' approach (Moniz Cook et al., 2012). It uses

the information to develop a hypothesis about the nature of the behaviour (Joyce, 2006), and is person-centred and idiosyncratic in nature (Bird, 1998). Whilst functional analysis has had positive effects on the frequency of distressed behaviours in both family and care home settings (Moniz Cook et al., 2012), research within an acute hospital setting is sparse.

1.3.5.4 The progressively lowered stress threshold (PLST).

The PLST (Hall & Buckwater, 1987) is a person-centred concept which suggests that when the person living with dementia's cognitive abilities decline, their threshold for experiencing and tolerating stress also decreases. The model is a useful way of understanding why a person living with dementia may become overstimulated within a busy, clinical setting which is noisy and has bright, artificial lights. It also helps staff to understand a person living with dementia's vulnerability for when the environmental demands exceeds their threshold (Richards & Beck, 2004). Importantly, the model recognises the impact that fatigue and impaired sleep may have in terms of triggers for the person living with dementia's lowered stress threshold (Richards & Beck, 2004); however, the model does not consider whether distressed behaviours are a result of the person living with dementia experiencing under-stimulation within the care environment (Mileski et al., 2018).

1.3.5.5 The Newcastle model.

The Newcastle model (James, 2011) has also been used to understand distressed behaviours predominately within residential settings. It acknowledges the importance of having a range of contextual information about the person living with dementia, similar to the 'Unmet Needs Model' (See Figure 2). This information helps staff to understand why an individual may become distressed (Jackman & Beatty, 2015). As with the other approaches described, person-centred principles are embedded within the model; however, the model is a complex model and perhaps too resource intensive (de Pfeiffer, 2016); subsequently, this may limit its application within an acute hospital setting.

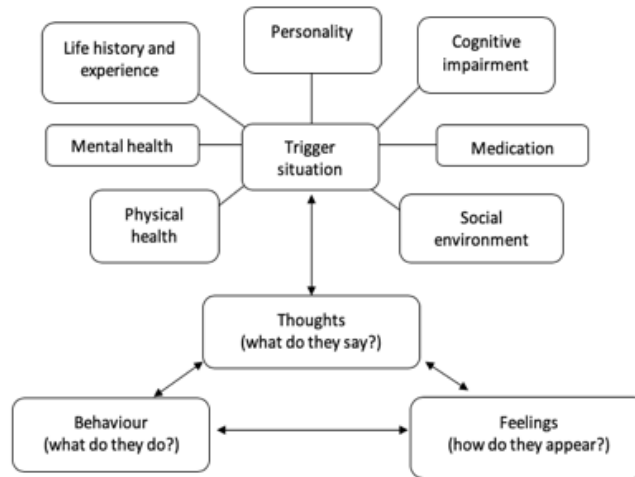


Figure 2. The Newcastle Model.

The psychological approaches described highlight the importance of embedding person-centred care when responding to distressed behaviours within an acute setting. Further, the approaches acknowledge the importance of the ward environment for people living with dementia and supports the work completed by Moyle et al. (2008). The PLST, for example, helps to explain how overstimulation within a busy acute ward setting may see an increase in levels of distress for people living with dementia. These approaches appear to be well studied within residential and home care settings; however, there is limited research within an acute hospital setting. Further, the 'ABC' approach appears to be the most feasible approach for understanding and responding to distressed behaviours within a busy clinical environment. This is due to the simplicity and ease of completing charts without having prior knowledge of the person living with dementia; however, this approach works most effectively when changes in the ward environment can occur. Subsequently, this may be a potential barrier for ward staff working in a busy, acute setting.

1.4 Current Guidelines for Managing Distressed Behaviours

Several guidelines and protocols have been developed to support staff members caring for people living with dementia. The Department of Health (2014) published a document, Positive and Proactive Care which provides guidance on reducing restrictive interventions for individuals presenting with distressed behaviours. The guidance aims to end the use of restrictive interventions in health and adult social care, including dementia care. Recommendations were made following this report

to ensure that the quality of life for people displaying distressed behaviours were better met.

The National Institute for Health and Care Excellence (NICE; 2018) published guidance for the assessment, management, and support for people living with dementia. The guidance advises that before starting treatment for distressed behaviours, an assessment to explore possible reasons for the behaviour should be completed, as well as checking for, and addressing, any clinical or environmental causes. NICE (2018) also recommends that people living with dementia should continue to access psychosocial and environmental interventions for distress and that personalised activities to promote engagement, pleasure and interest should be offered to the person living with dementia.

While some people living with dementia who become distressed receive excellent care, it has been reported that many receive a largely antipsychotic-based response, with prevalence rates of distressed behaviours remaining high despite guidelines being available (Wetzels, Zuidema, de Jonghe, Verhey, & Koopmans, 2011). Furthermore, adherence to guidance in clinical practice is low (Zwijssen et al., 2015). A systematic review of dementia guidelines found that recommendations on the management of dementia often lack depth and consistency. Further, the complexity of guidelines is often a barrier to implementation within clinical practice (Ngo & Holroyd-Leduc, 2015). It has also been reported that the treatment and interventions offered to people living with dementia has grown by chance rather than by active planning or commissioning leaving considerable gaps in older people's care services and clinical care (Banerjee, 2009).

1.5 Staff Experiences of Distressed Behaviours

Providing care to people living with dementia who become distressed during a hospital admission can be demanding for staff due to understaffing, task-orientated care and time pressures (Alzheimer's Society, 2009; Eriksson & Saveman, 2002). Further, there appears to be a lack of dementia specific or friendly pathways and services available (Royal College of Psychiatrists, 2013, 2017). Staff are required to have the knowledge and skills which support the personhood of the

person living with dementia (Nolan, 2007). Ward staff report difficulties with being able to manage distressed behaviours effectively, in particular communication and wandering (Alzheimer's Society, 2009). Staff also report increased levels of stress and feelings of guilt when responding to distressed behaviours such as repeated questioning and calling out (Bourbonnais & Ducharme, 2010). Feelings of uncertainty around responding to people living with dementia have also been identified. Pinkert et al. (2018) looked at experiences of ward staff providing care to people living with dementia in acute hospitals in Germany and Austria. The study found that staff face great uncertainty in providing care to people living with dementia and that individual nurses react in different ways to address their uncertainty, for example, sticking to routines. They concluded that, even for nurses who provided person-centred care, the hospital environment imposed contextual constraints which were related to inadequate training, limited time and staff resources and problems with interdisciplinary collaboration.

Furthermore, the concept of familiarity has also been studied. It has been reported that staff are not always aware that an individual has dementia when admitted into hospital. When there is limited information about the person living with dementia, it can affect the care which is provided (Royal College of Psychiatrists, 2017). A limited understanding of the person living with dementia by staff is also associated with less positive aspects of care when staff respond to distressed behaviours (Moyle, Borbasi, Wallis, Olorenshaw, & Gracia, 2011); however, the development of individualised care plans and person-centred strategies has demonstrated more positive outcomes for people living with dementia, with reduced levels of distress reported (Goldberg, Whittamore, Pollock, Harwood, & Gladman, 2014).

1.5.1 Consequences of distressed behaviours for staff.

The difficulties described can have a detrimental impact on staff responding to distressed behaviours with an acute hospital setting. There is a growing body of research which has looked at the impact distressed behaviours in people living with dementia can have on the wellbeing within care teams (Elliot, Williams, & Meyer, 2014; Moyle et al., 2011; Schmidt, Dichter, & Palm, 2012). It is well recognised in the literature that caregivers of people living with dementia are exposed to stress,

burden and loss of psychological well-being. The term 'burnout' has been used within the literature as it provides an understanding of the negative attitudes, both to the person living with dementia as well as a negative appreciation of one's own work, which result when responding to distressed behaviours (Grafstrom, Fratiglioni, Sandam, & Winblad, 1992). A study by Cocco, Gatti, de Mendonça Lima, and Camus (2003) found levels of stress and burnout among staff working in acute hospital settings are significantly higher than those in nursing homes. Distressed behaviours, such as violent behaviours, appear harder to manage and are more likely to result in emotional burnout for staff (Isaksson, 2013). A lack of reciprocity between staff and the person living with dementia can also cause emotional exhaustion, feelings of depersonalisation and burnout in healthcare professionals (Clissett, Porock, Harwood, & Gladman, 2014; Leeson, 2010). Further, Featherstone, Northcott, and Bridges (2019) highlighted that care routines which triggered patterns of resistance can also result in emotional and physical burnout for staff. Evidently, responding to distressed behaviours in people living with dementia can add to the emotional impacts for staff and highlights the need for staff to feel supported when working in an acute hospital setting.

Despite the more difficult aspects of providing care to people living with dementia who become distressed, there are examples of positive care documented. Handley et al. (2017) completed a review to identify approaches which make healthcare delivery in general hospitals more person-centred and dementia-friendly. The authors provided a context-relevant understanding of how these interventions can lead to positive outcomes for people living with dementia. The review considered a range of factors within the hospital environment which could influence staff perceptions in adopting positive dementia care practice. The review found that when staff understood distressed behaviours as a communication of an unmet need, they were more likely to investigate the underlying cause rather than attempting to restrict the behaviour (Banks et al., 2013; Dowding et al., 2016). Consequently, staff reduced the person living with dementia's level of distress as their unmet need was addressed (Scerri et al., 2015). This way of responding to distressed behaviour supports the application of Mansfield's 'Unmet Needs Model'

previously described (Section 1.3.5.1) within a general hospital setting. Goldberg et al. (2014) found that when staff were given the opportunity to organise their work around the needs of the person living with dementia, rather than be restricted to the ward routine, this led to a better provision of person-centred care for people living with dementia. Additionally, when staff had time to recognise and respond directly to distressed behaviours, the well-being of the person living with dementia improved (Bray 2015). While the results from this study are positive and provide evidence to support the benefits of person-centred care, Handley et al. (2017) found that these approaches are used variably as opposed to being engrained within the provision of dementia care. For example, factors such as increased work demands, long shifts and staff fatigue can lead to staff disengaging from the person living with dementia and is often a barrier to responding to distressed behaviour within a busy, acute hospital setting (Goldberg et al., 2014).

1.5.2 How staff understand and respond to distressed behaviour.

An acute hospital stay can be confusing and frightening for people living with dementia and can cause the individual to become distressed. This can place increased demands on staff teams in supporting and responding to distressed behaviours (Brooke & Semlyen, 2017). Further, a factor which influences the emotional demands for staff is the way in which they understand the condition and how they respond to the distressed behaviour. Staff often face tensions and dilemmas in deciding how best to respond to the behaviour, particularly when their first attempt to respond to the distressed behaviours was unsuccessful (Rapaport et al., 2018). The authors concluded that by having a better understanding of how staff manage distressed behaviours, and what can make things harder or easier, can inform the development of psychosocial interventions.

The ward environment has also been associated with how staff respond to distressed behaviours. A fast-paced environment can place increased emotional demands on staff and can often be a barrier in understanding and responding to distressed behaviours (Cunningham, 2005). This is further supported by Borbasi et al. (2006) who described factors such as a lack of resources and time pressures can influence the management of care for people living with dementia and can

determine what makes a behaviour easier or more difficult to manage. Additionally, Borbasi et al. (2006) highlighted the importance of a positive therapeutic relationship between the person living with dementia and ward staff in terms of being able to respond to distressed behaviours effectively.

When staff are exposed to behaviours which are harder to manage, or in situations when staff are unable to acknowledge, recognise or describe the distressed behaviour, this can result in negative attitudes from staff and may contribute to how distressed behaviours are responded to (George et al., 2013). The emotional responses from staff to people living with dementia have been suggested as influential in determining whether an intervention is effectively implemented or not (Todd & Watts, 2005). Further, inappropriate beliefs about the causes of distressed behaviours are likely to result in an inappropriate intervention being offered to the individual (Hastings & Remington, 1994). This further highlights the importance of staffs' understanding of distressed behaviours in people living with dementia. In a recent study by Featherstone et al. (2018), it was found that responses from staff can inadvertently lead to behavioural responses from the person living with dementia. In this study, staff were observed to repeat instructions, raise their voices and contain the person living with dementia to their bed, leading to refusal of care from the staff and expressions of distress from the person living with dementia. This resulted in escalating cycles of resistance and distress for the person living with dementia, their family and staff.

1.5.2.1 Diagnostic overshadowing.

Diagnostic overshadowing is when an individual's presenting symptoms are put down to their health condition, rather than considering other potential causes to the distressed behaviour (Jones, Howard, & Thornicroft, 2008). This can result in delayed or inadequate treatment on account of the misattribution of their physical symptoms to the distress (Shefer, Henderson, Howard, Murray, & Thornicroft, 2014). Borbasi et al. (2006) found that although staff have a good understanding of dementia, there is evidence of staff attributing distressed behaviours to the person living with dementia's condition as opposed to an unmet need.

Dupuis, Wiersma, and Loiselle (2012) found evidence of diagnostic overshadowing in a long-term dementia care setting. They found that although staff understood the distressed behaviour to be a result of the person living with dementia communicating, staff perceived the distressed behaviour as a communication strategy related to the dementia as opposed to an unmet need. This meant that staff rarely responded by working to understand what was being communicated and instead used re-direction, distraction, ignoring, and in extreme cases, restraint when their responses in an attempt to cope were unsuccessful in reducing the distressed behaviour. Evidence of diagnostic overshadowing was also found in the recent study by Featherstone, Northcott, Harden, et al. (2019). The study found that ward staff typically interpreted resistance as a feature of a dementia diagnosis, which overshadowed the person living with dementia. Perry et al. (2018) found evidence of potential diagnostic-overshadowing, where symptoms of psychiatric co-morbidity were attributed to distressed behaviours. These findings highlight the importance for healthcare professionals to consider a more holistic approach in managing distressed behaviours which allows a better understanding of the precipitating and predisposing factors within an acute hospital setting.

1.5.2.2 Attribution theory.

Attributions are inferences that people make about behaviour to explain why it occurred. This allows people to predict future behaviour and can reduce uncertainty (Polk, 2005). Weiner's Attribution Theory (1980) suggests that an individual's attribution about the cause of a behaviour, combined with the emotion generated and their expectancy of being able to influence the event in the future, will determine the way in which the individual responds. The theory predicts that 'helping behaviour' is more likely to occur if the individual makes the attribution that the cause of the behaviour is external and stable, that is, it is both outside the control of the person in need and likely to be causal in the future. If an individual perceives the behaviour as undesirable and they believe the person has control over their behaviour, the individual may feel anger and reject the person. The assumptions that staff hold about the causes of distressed behaviour is therefore critical in determining how they respond to distressed behaviours within an acute hospital setting (Todd & Watts, 2005).

Bledin, Kuipers, MacCarthy, and Woods (1990) found that carers did not criticize behaviours often considered more difficult to manage (for example, incontinence) but did feel more frustrated with behaviours like repetition and aggression. The authors concluded that carers felt more frustrated as they perceived these behaviours as controllable. Tarrrier (2002) found that caregivers' beliefs about patients' controllability were associated with increased caregiver criticism and hostility, whereas beliefs of uncontrollability were associated with more positive caregiving. Whilst there is limited research into staff attributions in dementia care (Polk, 2005), caregiver attributions for people with intellectual disabilities demonstrated that attributions may result in more negative caregiver reactions for mild disabilities and less negative reactions for severe disabilities (Tynan & Allen, 2002). Additionally, Hastings, Reed, and Watts (1997) found that experienced care staff differed in their views on the likely causes of distressed behaviours when compared to less experienced members of staff. Tynan and Allen (2002) found that staff can sometimes feel that only someone with specialist knowledge would be able to understand and offer appropriate support for individuals displaying distressed behaviours. Subsequently, caregivers may not be receptive to behaviours and may disregard them. This may result in caregivers missing out on important communication cues and information. There may also be some difficulties with the accuracy of the caregivers' attributions in terms of what behaviours are attributed as part of normal aging, which behaviours are a result of a degenerative process and what behaviours are due to the person living with dementia's pre-morbid personality (Polk, 2005).

1.5.3 Support for staff working with distressed behaviours.

Attempts have been made to address the impact that time constraints and understaffing can have for staff being able to provide good dementia care. Some NHS Trusts employ staff with specific roles prioritising psychological, emotional and social needs for the person living with dementia. Employing staff in this way improves the experience for the person living with dementia and has been shown to reduce distressed behaviours (Bray 2015). Furthermore, research has found that when activities were scheduled during times of high-need and distress for people living with dementia (for example, when sun-downing may occur or when staffing

levels were stretched during medication rounds and meal times) this led to a reduction in distressed behaviours (Zieschang et al., 2010).

Research has found that staff working within a general hospital setting do not always feel adequately prepared to work with the potentially complex needs of a person living with dementia (Chater & Hughes, 2013). Research also suggests that staff may lack the skills, experience and knowledge about what good quality care looks like (Innes, Kelly, Scerri, & Abela, 2016). Research has also found that specific dementia training to support staff in understanding the condition, as well as distressed behaviours, is a prerequisite for providing good quality care; however, it is unclear how training may influence staff knowledge and confidence in responding to distressed behaviours (Galvin et al., 2010). Similar findings have also been found in a recent study by Surr et al. (2020) which reported that dementia training can lead to improved care practice. Further, improved staff knowledge in understanding distressed behaviours in people living with dementia may provide staff with a sense of control and awareness of where they can access support, and are all protective factors in reducing staff burnout (Clissett et al., 2014).

Sampson, Vickerstaff, Lietz, and Orrell (2017) found a significant improvement in nursing staffs' sense of competence in dementia care and quality of interactions for people living with dementia when a train-the-trainer model was implemented across eight acute NHS hospital trusts. Developing staff confidence and knowledge of dementia by having access to 'experts' in dementia care has been shown to influence working practice (Scerri et al., 2015). Although these studies demonstrate positive outcomes for staff as well as the person living with dementia, other studies have shown that when ward staff have access to dementia specialists, unrelated physical or medical healthcare issues are often deferred to the experts. Consequently, this has potential for the responsibility to fall back to experts alone as opposed to a culture whereby all ward staff are responsible (Handley et al., 2017). In some cases, the use of reflection of good care practice gave staff members a framework to work with for providing good care. It has, however, been argued that whilst these practices are often referred to by staff as 'going the extra

mile', that these skills should be an expectation of their role rather than being an addition to their workload (Scerri et al., 2015).

1.6 Introduction to Research Project

Whilst distressed behaviours in people living with dementia has been well-researched within residential and care home settings (Rapaport et al., 2018) relatively little is known about how ward staff understand and respond to distress on acute wards within general hospitals. Further, the transferability of findings from a residential setting to an acute ward setting is limited. This is because the length of stay within an acute setting is far shorter and ward staff have limited time in getting to know the person living with dementia which makes it difficult for staff to understand the triggers to distressed behaviour. This means that there are limited opportunities for ward staff to familiarise themselves with the person living with dementia and to provide person-centred care. Additionally, disorientation and confusion may increase during a hospital admission due to the person living with dementia being in an unfamiliar environment, physical ill health and the increased risk of delirium. These are all factors which can perpetuate distressed behaviour. Consequently, these experiences can result in difficult interactions between nursing staff and the person living with dementia, creating a 'maligned social psychology' (Rapaport et al., 2018).

As ward staff are the main providers of dementia care in acute hospitals (Baillie et al., 2012), it is important that they feel supported. Experiences of strain reported by staff can impact their ability to perform good quality nursing care (Edberg et al., 2008). This further highlights the importance for appropriate support to be offered to staff, particularly in terms of managing and understanding distressed behaviours. Although there are a range of approaches which may be helpful in understanding and responding to distressed behaviours, very little is known about how staff understand and respond to distressed behaviours in people living with dementia in acute settings in general hospitals. Although the psychological ways of thinking about distressed behaviours may seem relevant, it is unclear whether staff find these useful or practical to use within a general hospital setting.

1.7 Research Questions

In order to address these issues, the research questions for the study were as follows:

- (1) What staffs' understanding of distressed behaviours is?
- (2) Where do staff get their understanding?
- (3) How staff respond to distressed behaviours?
- (4) Why staff respond the way they do?

The findings from the study will provide much needed information about what works well when supporting distressed people living with dementia in hospital, and any ways in which care could be improved in the future.

CHAPTER TWO: METHODOLOGY

This chapter begins by outlining the research design for the study followed by the methodological approach that was selected. A rationale to explain specific decisions regarding the methodological approach undertaken is also discussed. The sample selection and recruitment strategy are then described, before outlining the topic guide and interview process. The chapter then goes on to outline the ethical considerations for the study and the data analyses which were used, namely Thematic Analysis (TA). Finally, the quality checks are detailed alongside a reflective statement.

2.1 Design

The aim of the study was to explore staff experiences of providing care for people living with dementia who were displaying distressed behaviours in an acute hospital setting. As the research explored staff experiences, a qualitative approach was used as it allowed for staff experiences to be studied in a natural environment and gave participants the opportunity to make sense of these day to day experiences. Semi-structured interviews were completed on two care of older people's wards within a busy physical health hospital. The interview data was transcribed and analysed using Thematic Analysis (TA), as described by (Braun & Clarke, 2006; see Section 2.12)

2.2 Methodological Approach

Qualitative research methods are exploratory approaches providing rich descriptions of phenomena which allows for participant experiences to be explored (Braun & Clarke, 2013). Qualitative analysis provides a more flexible approach in understanding how ward staff understand and respond to distressed behaviours expressed by people living with dementia. Due to the limited research in this area, it was also felt that a qualitative approach would give a voice to ward staff and their perspective of providing care to people living with dementia.

Several qualitative approaches were considered for this study. An ethnographic approach was considered as it provides a detailed understanding of the problem

being studied. After discussions with research supervisors, it was felt that it would not be feasible to complete detailed ward observations as part of the project. Questionnaires and structured interviews were also considered; however, this may have affected the richness of data collected from participant responses. Semi-structured interviews were then considered as they are often used in qualitative research, particularly when using TA (Braun & Clark, 2006). Using this approach allowed me to engage in a real time dialogue with participants and enabled follow-up questions to be asked, so that ambiguous responses could be clarified. This approach allowed participants to tell their own personal stories in their own words and provided a more flexible approach for questions to be adapted depending on the responses given.

Before selecting TA other approaches including Grounded Theory (Glaser & Strauss, 1967) and Discourse Analysis (Hodges, Kuper, & Reeves, 2008) were carefully considered. Although these methods would have provided a unique insight into what it is like for ward staff to provide care for people living with dementia, it was felt that as the present study aimed to explore lived experiences, the most appropriate methodological approach would be Interpretative Phenomenological Analysis (IPA). As the study progressed, however, it became apparent that IPA was not feasible. This is because IPA is wedded to a phenomenological epistemology and is about understanding people's everyday experience of reality, in great detail, in order to gain an understanding of the phenomenon in question (Smith, Larkin, & Flowers, 2009). Due to staff availability and nursing ratios, interviews were relatively short (average 43 minutes) for a typical IPA study and did not provide enough opportunity to probe in sufficient detail each staff member's individual backgrounds, contexts and experiences. It was also not possible to complete follow-up interviews. After discussions with thesis supervisors, TA was selected on the basis that it offers "an accessible and theoretically-flexible approach to analysing qualitative data" (Braun & Clark, 2006, pg. 2) which allows rich and detailed data to be gathered within a flexible framework. TA provides a flexible and useful research tool which can provide a rich and detailed, yet complex account of data when the sample size is small. TA

identifies patterns within the data which can be useful when carrying out research in a new area. It also acknowledges my role of a researcher in terms of my theoretical positioning and the active role I have taken when analysing data. How I used TA is discussed further in Section 2.12, Data Analysis.

2.3 Sample

In qualitative research, determining an appropriate sample size involves judgment, as well as experience in evaluating the quality of the information collected against the uses to which it will be put, the particular research method and purposeful sampling strategy employed, and the research product intended (Sandelowski (1995). Braun and Clarke (2013) provide guidelines for the number of participants needed in TA. For small projects, this would be between six to ten participants. After discussions with research supervisors, nine participants were recruited into the study as it was felt this would provide rich, detailed accounts of what it is like for staff providing care to people living with dementia who exhibit distressed behaviours.

Previous literature has highlighted the importance of including staff from different backgrounds and differing levels of experiences of providing care to people living with dementia, as well as level and knowledge of dementia training (Surr et al., 2016). In order to explore how these varying characteristics may influence the way in which ward staff make sense of distressed behaviours for people living with dementia, the sample was varied in terms of experience (e.g. length of time working on the ward, duration of time spent working in care of older people) and job role. Purposeful sampling was used to ensure a variety of staff experiences were included in the study, allowing for a range of experiences to be interviewed and analysed. This included staff with a variety of professional backgrounds (for example, healthcare assistants (HCA's), registered general nurses (RGN) and non-clinical ward staff) and with differing degrees of dementia training and experience. It was felt that it would be important to recruit both clinical and non-clinical members of staff into the study as both would have valuable experiences of providing care and responding to distressed behaviours in people living with dementia.

2.3.1 Inclusion and exclusion criteria.

Inclusion and exclusion criteria were discussed with my research supervisors and the following criteria was agreed:

2.3.1.1 Inclusion criteria.

To be eligible to take part in the research project, staff were required to have current experience of providing professional care, treatment or support to people living with dementia on acute older people's wards.

2.3.1.2 Exclusion criteria.

Staff members were not eligible to take part in the research study if they were working on the ward as a student or working on the wards on a temporary basis, for example, as agency staff, or on a voluntary basis.

2.4 Recruitment

The study took place on two acute older people's wards in a large general hospital in the North of England. It was hoped that this hospital setting would provide an in-depth insight into the challenges ward staff face in providing care for people living with dementia. It is, however, recognised that people living with dementia will be cared for in most hospital wards and staff in less specialist wards may have different experiences of trying to support them. Ward-based nursing and support staff rather than other professionals such as medics, occupational therapists or physiotherapists were chosen as they would have the most first-hand experience of providing care for people living with dementia.

Prior to completing the interviews, I visited the wards to explain the purpose of the project to ward managers and staff. Visits were arranged for when there were as many ward staff available. Alongside a verbal explanation of the study, a poster explaining the project was displayed in the staff room (Appendix A). Participants were provided with a Participant Information Sheet (PIS) informing them of the study (Appendix B). Participants were also given the opportunity to give their contact details via a consent to contact form (Appendix C) which allowed me to contact them at a later date to see if they were interested in taking part in the

research study. I also returned back to the ward to see if the ward staff were interested at a later date.

2.5 Description of Hospital Setting

2.5.1 The wards.

Ward A is an “acute frailty care of older people’s ward”. Patients admitted are over the age of 65 with some having a confirmed dementia diagnosis. The average length of stay on the ward is 72 hours. Ward B is a long stay ward providing care to older people. Ward B is split into two smaller wards: ward 1 has 19 beds and ward 2 has 22 beds. Due to the complexity of patients on the ward, patients can be on this ward for several months. The clinical presentation of patients typically admitted onto Ward B includes hospital-related delirium, mixed diagnoses and patients with systemic social care needs.

The hospital participates in John’s Campaign (Jones & Gerrard, 2014). This campaign follows the simple belief that carers should not just be allowed into hospital, but they should be welcomed, and that a collaboration between the patients and ward staff is crucial to their health and their well-being. In view of this campaign, both wards involved in this study meant that carers can visit their relative in hospital at any time of day and that there is no restriction on visiting hours.

2.5.2 The dementia support team.

The dementia support team was set-up five and a half years ago and provides support to the wards, as well as to people living with dementia and their relative during a hospital admission. The team is led by a Band 7 nurse with over 30 years of experience working in dementia, supported by two full-time Band 2 dementia support workers, all of whom have specialist training in supporting people living with dementia. The team accept referrals from all wards at the hospital. They screen 75+ year olds routinely for dementia, complete assessments and investigations and refer on to other services as appropriate.

2.6 Data Collection

Data collection took place from 30th August 2019 to 11th November 2019.

Interviews were completed during various times of the days and on varying days of the week. This was largely influenced by staff availability and when the wards were less busy (predominately evenings and at weekends).

2.7 Topic guide

The interview topic guide (Appendix D) was developed based on the research question and the existing research literature, alongside discussions with research supervisors. Psychological approaches were used to understand distressed behaviours and to inform the interview schedule [e.g. the behavioural 'ABC' model; James (2011) and the 'Unmet Needs Model'; Cohen-Mansfield (2001)]. These psychological models were chosen to enable participant experiences to be explored in more detail, providing information about how participants responded to, and made sense of, distressed behaviours for people living with dementia. The topic guide was tested with another Psychologist in Clinical Training (PICT) with useful feedback provided.

Key topics were explored with probing and follow-up questions used to explore individual situations and events. The interviews aimed to be conversational in style and it was important to ensure that participants felt relaxed and listened to throughout the interview; therefore, a great deal of consideration as to how best to ease participants into the interview. Active listening alongside asking open-ended questions meant that rapport was built quickly and resulted in a trusting interview relationship with the participant. As part of the topic guide design, 'warm-up' questions were asked to reduce the interviewees' tensions and get them ready to discuss more sensitive issues in more detail (Pietkiewicz & Smith, 2012).

Informed by the psychological approaches described in Section 1.3.5, participants were asked to talk about a recent example of providing care for a patient living with dementia who was displaying distressed behaviours. Participants were then invited to talk about another experience of providing care to a different patient

living with dementia. Participants were asked how these experiences felt for them, which provided a more analytical level of data.

2.8 Interview procedure

In-depth, tape-recorded interviews were conducted in a quiet room in the hospital. Interviews lasted between 29 to 56 minutes (average 43 minutes). Interview data sheets were completed for each participant interview. These data sheets recorded the ID number of the participant, as well as the time, date and location of the interview. Hand written notes were also made during each interview which acted as a prompt for follow-up questions. Out of the nine interviews completed, I transcribed two interviews. The remainder were transcribed by a professional transcriber. I checked these transcripts against the original tape for accuracy.

2.9 Participants

Nine participants were recruited into the study (8 female and 1 male). The participants represented a diverse sample of ward staff with participants working in various clinical and non-clinical capacities (1 Matron, 2 Sisters, 1 RGN, 3 HCA's, 1 support worker and 1 ward clerk). Pen portraits are provided in the following chapter (Section 3.1).

2.10 Ethics

2.10.1 Ethical approval.

Ethical approval was obtained from the School of Medicine Research Ethics Committee (SoMREC 18-052) and the Health Research Authority (IRAS Project ID 261651). Mid Yorkshire Hospitals NHS Trust provided confirmation of capacity and capability for the study (See Appendix E and F).

2.10.2 Informed consent.

Participants were identified and approached in two ways: (1) via a clinical gatekeeper (a senior member of the nursing team) and (2) via visits to the wards in which I explained the study and asked interested people whether they would be happy to be contacted at a later date (via a consent to contact form). Participants were provided with a PIS and a verbal explanation of the study. The PIS described the study and the interview process. All participants were given the opportunity to

discuss the study with me and were given the option of declining to take part if they wished. Full written consent was sought from all participants who decided to take part in the study (Appendix G). Each of these documents ensured that participants were fully informed of what the study involved and gave participant's the opportunity to decide whether they would like to take part in the study or not. I was aware of being in a potential position of authority and did not coerce participants to take part, or remain in, the study.

2.10.3 Anonymity.

The anonymity of participants was maintained for the study, with pseudonyms used for the write-up. All quotations used in this study have been anonymised. Thesis supervisors were only permitted access to anonymised transcripts and did not have access to any personal information. Participant interviews were allocated a code and all participant identifiable information were removed from the interviews at the point of transcription.

2.10.4 Confidentiality.

The research study adhered to the principles of the General Data Protection Regulation (GDPR), the Caldicott Principles and the University's policies on data protection to ensure the data was protected. All participants were fully informed of the procedures relating to confidentiality in the PIS and the consent form. Participants were informed that if any concerns relating to patient care were disclosed during the interviews, then it may be necessary to breach confidentiality. When participants were asked to talk about their experiences on the wards, they were reminded during the interview not to provide the real names of any patients they discussed. This ensured that all patients on the ward were protected and that no identifiable information was disclosed during the interview. The transcriber was required to sign a Confidentiality Statement (Appendix H) in accordance with the British Psychological Society's Code of Ethics and Conduct (2018).

2.10.5 Data protection and storage.

All of the interviews were recorded using an encrypted Dictaphone from the University of Leeds. All audio recordings were transferred to a folder on the

University's m:drive (a secure drive accessible only to the researcher) on the day of the recording, and then deleted from the Dictaphone, with no more than two or three recordings temporarily stored on the Dictaphone at any one time. Any written notes which were taken during the interview were typed up and saved on to the University's 'M' drive once the interview was completed. All paper notes were subsequently shredded once they were typed. Typed notes were saved onto the University's 'M' drive.

The interview recordings were provided to a professional transcriber on an encrypted USB. Participant details were removed, and pseudonyms were used during transcription and data analysis. The USB was returned to the researcher upon completion of transcription, along with the files containing the transcription.

Participant names and contact details were stored on a password protected file stored securely on the University drive. Participants were allocated an ID to link their name with the interview data and only the researcher had access to this data. All paper-based data (e.g. consent forms) were stored in a locked filing cabinet in the office of the Leeds Doctorate in Clinical Psychology programme research coordinator. All data will be destroyed three years after submission of this thesis.

2.11 Consideration of Possible Problems

2.11.1 Availability of ward staff.

I considered participants' availability, particularly if the wards were under-staffed and the demands of patient care were high. I avoided conducting interviews during busy times on the wards when ward staff were less accessible. I negotiated interview timings with ward managers which were flexible to fit the availability and convenience of ward staff, with several interviews completed during the afternoon and at weekends.

2.11.2 Relationship between researcher and participant.

It was important to ensure that participants felt comfortable engaging in the interview process and felt able to talk about their own experiences without feeling judged. I checked-in with participants during the interview and reflected answers

back to ensure they had been understood. This gave participants the opportunity to clarify any points. Assurance was also provided to participants that their responses were confidential, and that all identifiable information would be removed for the write-up of the study.

2.11.3 Protection of participants.

I recapped the main study objectives at the beginning of each interview. If participants were anxious about anything they discussed during the interview, we agreed what to do with the information (for example: assurances that all data will be reported anonymously, withdrawal of interview data, agreement not to use it in the extract of the thesis write-up and report, or to withdraw from the interview).

2.12 Data Analysis

Prior to analysing the data, the interviews were transcribed with the participants' identifiable information removed and each participant being assigned a pseudonym. I printed out the interview transcripts in their entirety so that each transcript could be annotated. As discussed previously, TA was selected as the analysis of choice for this research project

TA was used as the qualitative method for the research study as it allows for themes to be identified, analysed and reported, and can assist with interpreting the study questions described in Section 1.7 (Boyatzis, 1998). Braun and Clarke (2006) describe TA as the foundation for qualitative analysis and is a method of analysis which provides fundamental skills which can be used with other methods of qualitative analysis. Despite the wide use of TA within qualitative research, it has been critiqued for having no clear agreement about what the analysis is, and how to go about doing it (Boyatzis, 1998). Furthermore, as TA is not attached to any pre-existing theoretical frameworks it is important to identify the process and practice to the reader of the methods used for the study.

The TA was informed by the general principles and specific practice as described by Braun and Clarke (2006) and are outlined in the table below.

| <i>Process</i> | <i>Stage</i> | <i>Criteria</i> |
|-----------------------|--------------|---|
| <i>Transcription</i> | 1 | I, or an external transcriber, transcribed the interviews verbatim. The transcripts were checked against the recordings to ensure they accurately reflected what was discussed during each interview. Amendments were made as appropriate. |
| <i>Coding</i> | 2 | Firstly, I read the transcript several times to get a sense of the data, making notes of my initial thoughts. I then re-read the transcript whilst listening to the audio recording at the same time. This was to immerse myself back into the interview situation and providing more context to the interview. Each transcript was given equal attention during the coding process. The coding process was thorough and comprehensive. Transcripts were annotated notes capturing my initial thoughts. |
| | 3 | Secondly, I completed a thorough and comprehensive coding process. All relevant quotes were collated to support each theme which was identified. |
| | 4 | This process was repeated for each interview. All transcripts were given equal attention during this process. Initially, between 7-10 themes per interview were produced. |
| | 5 | The initial set of themes were sent to my research supervisors in which some themes were identified as overlapping. |
| | 6 | I then began to compare across the interviews and made notes of overlapping and/or similar themes which arose during each interview which produced four emerging themes. |
| <i>Analysis</i> | 7 | The data was analysed and interpreted with further discussions had with my research supervisors, adding credibility to the analysis. This also addressed some of my own biases as my research supervisors have different clinical backgrounds to that of clinical psychology. |
| | 8 | Upon discussion with my research supervisors, the themes were re-organised in a way which produced a convincing and well-organised story about the data and the interview topic. |
| | 9 | An even balance of quotes from all participants as well as my analytic interpretation has been provided. |
| <i>Overall</i> | 10 | Sufficient time was allocated during the research process to ensure that all phases of data analysis were adequately completed. |
| <i>Written report</i> | 11 | Appropriate quality checks have been completed and are described in Section 2.13. |
| | 12 | The method described as part of this research study is consistent with the reported analysis. This bespoke table provides specific details to the reader as to how the data was analysed. |
| | 13 | I have positioned myself as an active researcher within the research process and have demonstrated clearly how each theme has emerged from data. |

Table 1. TA checklist to demonstrate the processes involved during analysis.

2.13 Quality Checks

As previously discussed, although TA is widely used in qualitative research, it has been critiqued for having no clear framework for carrying out analysis (Boyatzis, 1998). Braun and Clark's (1996) paper which provides a framework of how to conduct TA sufficiently now means that quality research can be carried out in a more rigorous way. Further guidance for qualitative data analysis has also been provided by Elliott, Fischer, and Rennie (1999). Seven principles behind ensuring quality in qualitative research have been identified and are described below in relation to the current study.

2.13.1 Owning one's perspective.

In qualitative research, it is important that I specify my theoretical orientations to the research project, both describing in advance, and what becomes apparent during the research. This includes recognising my own values, assumptions and interests to the project and how these may impact on my understanding and interpretation of the data. A reflexivity section has been included at the end of this chapter to describe this (Section 2.14)

2.13.2 Situating the sample.

The guidelines advise describing the research participants to provide the reader with a description and context surrounding the participant's life which may be relevant to the project. This information has been provided through the use of pen portraits for each participant involved in the study (described in Section 3.1).

2.13.3 Grounding in examples.

This study has included examples of the data to demonstrate the analytic procedures used and the understanding developed as a result of this. This will provide the reader the opportunity to reach alternative meanings and understandings to the data.

2.13.4 Providing credibility checks.

After receiving the transcribed interviews, I verified these against the transcriptions. This process entailed listening to the interview recordings alongside reading the transcriptions. This ensured that the transcribed interviews provided

an accurate representation of the raw data. I also used supervision to ensure the validity of the themes. Checks were also completed with thesis supervisors to justify participant responses. The validity and quality of the analysis was enhanced by asking my thesis supervisors, who had extensive experiences working in this area, to look over the analysis and supporting data. Any discrepancies, corrections or elaborations were made to the data.

2.13.5 Coherence.

Coherence refers to the understanding reached from the data. This has been illustrated by presenting an overall story of the data but still retaining the detail. This has been shown by including the overarching categories and themes whilst also including the subthemes grounded in the data.

2.13.6 Accomplishing general vs. specific research tasks.

An understanding of how ward staff experience distressed behaviours for people living with dementia has been provided. This phenomenon has been based upon a range of accounts from participants with varied clinical backgrounds and experiences. Limitations of generalising the findings to other contexts are discussed. Conversely, the process to which the results have been attained have been thoroughly reported. This will allow the reader to understand how the conclusions to the research were reached.

2.13.7 Resonating with readers.

Research supervisors provided feedback relating to the way in which the material has been presented. This will allow the reader to assess whether the material accurately represents the subject matter.

2.14 Reflexive Statement

The concept of reflexivity is considered an important component when carrying out qualitative research in psychology (Shaw, 2010). The purpose of reflexivity is to provide the reader with insight into the relationship between myself, the participants and the data collected (Mills, Durepos, & Wiebe, 2010). A summary is provided below to give the reader some context on my background and any influences which may have shape this research project.

Prior to starting clinical psychology training, I had several years' experience working as a healthcare assistant and assistant psychologist providing care to people experiencing cognitive or behavioural difficulties as a result of a degenerative condition, such as dementia, or an acquired or traumatic brain injury. Working in these clinical roles highlighted the challenges ward staff face when delivering care to individuals with cognitive difficulties who display distressed behaviours. In brain injury, staff would often request support from psychology when they felt unable to manage behavioural difficulties on the ward. Behavioural guidelines would be written for ward staff by psychology and would include a formulation around how staff could respond and manage particular behaviours more effectively; however, these guidelines were not always pursued by staff which I found puzzling. This demonstrated that something was missing from the support which was provided by psychology. Further, this is what instigated my research interest for the current study.

I have been mindful how my previous experiences may have shaped the way in which I conducted my research. I kept a reflexive journal which was started after meeting with my thesis supervisors for the first time. The aim of the journal was to make me aware of my own biases and how these may influence my data collection and analysis. The journal included my thoughts and perspectives on the research process including the design stages, recruitment, interviews, analysis and write-up. I tried to ensure that my past experiences did not influence the course of the interview although, at times, this was difficult. During initial interviews, follow-up questions focused on things I was interested in because of my psychological background rather than what the participant was talking about. An extract from an interview is included below to provide an example of when I asked a follow-up question which focused on a psychological model of distressed behaviours. This appeared to hinder rather than help the participant during the interview:

I: What other things other than the sensory aspect do you think might ... cause them to be a bit more distressed?

P: No, reword me that question please?

I: Can you think of anything else that might, have happened or be going on with that person?

My research supervisors brought this into my awareness during supervision to ensure I remained curious to any assumptions which arose, and I was able to lessen this as time went on. Additionally, during the course of this research project, I spent six months on an older adult community mental health placement in which my clinical supervisor challenged my assumptions and encouraged curiosity whilst working with this clinical population.

My background working in brain injury initially made me very focused on the 'ABC' approach to understanding distressed behaviours. Further, the questions which were included within my initial draft topic guide were very much influenced by this psychological approach. As evidenced during the transcript included above, it is likely that had I have used these interview questions within the current study, staff would not have responded well. I subsequently needed to refocus my way of thinking about the topic to align more with ward staff perspectives. This was achieved during meetings with thesis supervisors and discussions which were had with senior management within the Trust.

As a novice researcher I was aware of feeling anxious when completing my first interview. I was conscious that I had agreed with senior management that interviews would last for 30-45 minutes. The pre-occupation I had during my first interview resulted in not asking follow-up questions; however, as I became more comfortable with interviewing this happened much less. Rapport was quickly established, with participants often commenting that they had not realised how long the interview had taken and told me that they felt comfortable during the interview. My interview technique also improved as I completed more interviews, and I became less reliant on the topic guide for probes.

Prior to recruiting staff into my study, I visited the ward which helped build rapport with staff and helped me to understand the ward environment and the context in which staff were working. Additionally, I shared my prior experience of working on the wards as a healthcare assistant with staff who were recruited into the study. This appeared to build a sense of familiarity and rapport with participants and allowed them to feel comfortable and relaxed during the interview. I also explained to participants that I was a psychology student. Making participants aware of this was helpful as they explained things clearly during the interview and revealed more about their way of seeing the world which they may not have done had I not disclosed this to them.

CHAPTER THREE: RESULTS

In this chapter, the results of the TA will be presented along with direct quotes from the participants to demonstrate the themes described. Pen portraits have also been included to provide the reader with a clearer description and understanding of each participant.

3.1 Pen Portraits

3.1.1 Participant 1 – Sarah.

Sarah was the first participant recruited into the study. She has 14 years of experience working in dementia care and currently works in a liaison role at the hospital. Sarah has a Level 2 National Vocational Qualification (NVQ) in Social Care and has attended both internal and external training courses on dementia. Sarah's main clinical duties involve screening patients over the age of 75 for dementia and visiting the wards to see whether staff, people living with dementia and their relatives require any additional support.

3.1.2 Participant 2 – Jill.

Jill is an experienced senior member of staff and has been qualified for eight years. She is responsible for co-ordinating the ward and ensuring care is documented and provided to all patients. Jill played a crucial role in recruiting staff into the research project and helped to identify suitable participants (for example, providing staff off-duty and staffing ratios on each shift).

3.1.3 Participant 3 – Sophie.

Sophie works as a healthcare assistant on an older people's ward and has 15 years' experience working in dementia care. At the time of the interview, Sophie appeared concerned about leaving the ward to take part as she was specialising patients in an enhanced bay. Alongside specialising, Sophie is required to complete patient observations and to attend to patient activities of daily living (e.g. washing, dressing, eating, etc.).

3.1.4 Participant 4 – Jack.

Jack also works on an older people's ward as a healthcare assistant and shared similar clinical duties to Sophie. Jack is the only male participant to take part in the research study. Jack has several years of experience working in dementia care.

3.1.5 Participant 5 – Chloe.

Chloe has 25 years of experience working as a nurse and has spent the last four years working on an older people's ward. Chloe has attended mandatory dementia training from the Trust. She describes one of her strengths as being able to recognise and react to situations developing on the ward with people living with dementia. Chloe was keen to take part in the research study and spoke openly about wanting to support student research.

3.1.6 Participant 6 – Ann.

Ann is a senior member of staff with over 30 years' experience providing care for people living with dementia. She is the lead nurse for a liaison team which provides input onto the wards and has been in this role for over five years. As the main dementia trainer, Ann is responsible for ensuring that all staff working across the hospital sites have completed their dementia training.

3.1.7 Participant 7 – Isla.

Isla works in a non-clinical capacity on the ward. She has worked at the hospital for over 20 years with the majority of her time spent working on dementia wards. Although Isla's role is non-clinical, she would often talk about the support she would provide to people living with dementia and members of the nursing team during busier times on the ward.

3.1.8 Participant 8 – Lucy.

Lucy is a healthcare assistant with six years of experience providing care for people with dementia. She has spent some time working in the liaison team and has spent four years working on the current ward. During her interview, Lucy spoke about the importance of ensuring patients were well presented and that all aspects of personal care were maintained during their hospital admission.

3.1.9 Participant 9 – Emma.

Emma has worked in a senior nursing role for over 16 years. She has spent two years caring for older people and ten years working on assessment units (including care of older people). Emma spoke about her desire to seek out additional training to support her current role and has recently completed an online dementia training course. Alongside the mandatory training provided by the Trust, Emma also has a Diploma in Psychology. Emma spoke openly about wanting to be the ‘voice’ for people living with dementia and often spoke about her passion and drive to “fight for the underdog”. Emma has a lived experience of caring for individuals who are seen as vulnerable in society which drives her professional passion for acting as an advocate for people living with dementia.

3.2 Qualitative Analysis

Four themes were identified which all relate to the way in which distressed behaviours are managed in an acute hospital setting: (1) How I understand the behaviours of people living with dementia, (2) The context in which I undertake this work, (3) The emotional load, (4) What I do to manage (See Figure 3). The core themes were then broken down into subthemes which were further categorised for ease of understanding the outcomes of the analysis. An initial summary of each theme will be provided with subthemes further described. Participant quotes will be used to further illustrate the ideas contained within each theme.

The thematic map shown in Figure 3 provides a visual representation and explanation of the processes involved in managing distressed behaviours. The arrows demonstrate the direction of interactions between all four themes. The zigzag line refers to the intellectual process of how we as researchers understand distressed behaviour. Theme 2 (The context on which I undertake this work) and Theme 3 (The emotional load) are concepts which affect the intellectual process of Theme 1 (How I understand the behaviours of people living with dementia). Theme 2 and 3 provide the output for Theme 4 (What I do to manage).

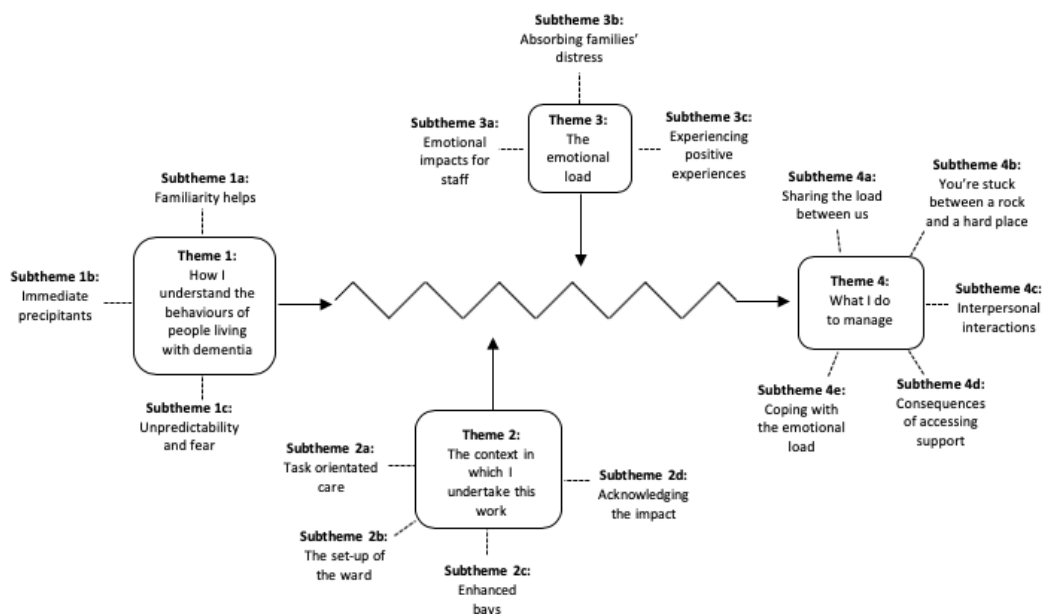


Figure 3. Thematic map to show the analysis of the semi-structured interviews completed with ward staff.

3.3 How I Understand the Behaviours of People Living with Dementia

This theme refers to the way in which staff understood people living with dementia (see Figure 3, Theme 1). This understanding was essential to ensuring that staff felt able to respond to the distressed behaviour effectively. When staff had knowledge of the person living with dementia's likes and dislikes (including any sensory or communication needs), staff described feeling more confident in being able to deliver person-centred, humanistic care. Staff also spoke about the positive outcomes this had for the person living with dementia's care. Familiarity was also recognised as an important factor for responding to distressed behaviours. Staff spoke about the importance of getting to know the individual on a more personal level and that they thought this was helpful for both staff and people living with dementia in managing distressed behaviours. Limited information about an individual's pre-morbid personality often resulted in more difficult experiences and negative emotions for staff, with staff feeling powerless with being unable to meet the individual's needs. Unfamiliarity and uncertainty saw reduced confidence in staffs' abilities to respond to distressed behaviours. Staff expectations of the person living with dementia's personal characteristics also appeared to influence the way in which distressed behaviours were understood and responded to.

3.3.1 Familiarity helps.

Familiarity was a key factor in helping staff to understand and anticipate distress in people living with dementia (see Figure 3, Subtheme 1a). Limited understanding of an individual meant that staff were less aware of potential triggers and were seen to predict negative outcomes.

“You don’t know what’s happened in the past but for us we might strike something.” (Sophie)

Although familiarity was important in terms of staff feeling able to respond to distressed behaviours, the unpredictability of the condition coupled with staff not knowing a patient’s past history was seen to increase feelings of uncertainty and unease for staff.

“They can be so, so lovely one minute and then flip a coin and something’s just triggered a memory.” (Sarah)

The changeability of the condition saw a combination of adrenaline and excitement alongside feelings of failure with staff having to admit defeat when unable to reduce the distress for the individual.

“Bad! Feel like, I feel bad then like, oh I feel like I haven’t looked after them properly!” (Lucy)

Staff spoke about the importance of building a therapeutic relationship with people living with dementia. A ‘Forget Me Not’ is a document completed by family members when their relative living with dementia is admitted to the acute ward. Staff reported feeling more confident in responding to distressed behaviours when they had access to a completed Forget Me Not document as it allowed them to engage people living with dementia in more meaningful conversations. Staff also felt that the Forget Me Not document provided more opportunities to deliver more humanistic, person-centred care in response to patient distress. Whilst staff

experiences of using this document appear positive, these are self-reported experiences. It is, therefore, unclear how staff provide this care in practice and whether these self-reports reflect a more idealised way of responding to distressed behaviours.

In the quote below, Jill spoke about the importance of building trust with a patient. Reciprocity between Jill and the patient increased Jill's confidence in responding to their distress. Whilst at the same time, ensured the person living with dementia felt safe both physically and emotionally.

"I try and just pick something that we may have in common to try and calm the situation as such. So, they might be less agitated. More so maybe so they trust."

(Jill)

There were times, however, when staff did not have access to a Forget Me Not as the person living with dementia did not have family or friends visit. Staff described a sense of having to 'walk on eggshells' when there was limited information about an individual. A trial and error approach in responding to distress was described with repeated, varied attempts of how to respond to distress. A sense of staff wanting to get it right was accompanied by feelings of confusion, frustration and sadness.

"I don't know what they like to do. I don't know what sort of things they like."

(Lucy)

Further, having an understanding of a person's likes and dislikes implemented a sense of caring boundaries for staff to follow which met the person's needs, making them feel calm and relaxed and thus reduced feelings of agitation and distress.

"Some of them might love a cuddle every time they see somebody. Others might not want you to touch them." (Emma)

Building a relationship with family members also appeared to reduce anticipatory anxiety for staff in terms of responding to distress in a patient they were less familiar with. Working in partnership with family members meant that staff felt able to develop an even deeper understanding of the person's pre-morbid personality and led staff to respond to distress in a more helpful way.

"I would use all my normal tactics, and then I would speak to family." (Chloe)

Evidently, within a fast-paced acute hospital setting, having information about people living with dementia which was readily available was valued by staff. The implementation of the Forget Me Not as a prerequisite of admission to the ward highlighted that staff, senior management and the organisation recognised familiarity as an important component to dementia care. However, this approach is limited in that it failed to support people who do not have family members and highlights that support for people living with dementia needs to be addressed in other ways.

3.3.2 Immediate precipitants

Across interviews, understanding people living with dementia was recognised as important by staff; however, despite staff having access to a patient's history (albeit in some cases this was limited or inaccurate) there were examples that staff still struggled to respond to distress effectively. In these circumstances, there was an expectation from the dementia support team that staff should be routinely completing behavioural recording charts to understand potential antecedents for the distressed behaviour (see Figure 3, Subtheme 1b).

"So, my expectation of staff would be to write, this is the behaviour, what, what was he doing before the behaviour? What actually was the behaviour? What do you think triggered it? What did you do and how is he now? (Ann)

Whilst staff were invited to use ABC recording charts by the dementia support team, these were not spoken about during interviews. Staff, however, indirectly spoke about possible antecedents for distress (for example, the ward environment

or an underlying infection), the behaviour that occurred as a result of the distress and the impact this had for a person living with dementia. Staff also acknowledged that the ward environment is not always supportive for people living with dementia. Often, staff spoke about implementing a more 'common-sense' approach to understanding and responding to patient distress. Further, the interviews showed that staff used an ABC framework loosely which was largely dependent on what was going on at the time.

"He was not good on his feet... so I was trying to keep him inside the room [enhanced bay] ... maybe that was the case too..." (Jack)

Limited time and staffing issues may be a possible explanation as to why recording charts were not completed; however, the reasons for this were not explored fully during interviews. The rationale behind a behavioural recording chart is to identify the cause of a behaviour and to change it by adapting the environment. Within a busy, acute hospital it is quite possible that staff are unable to change the ward context due to staffing levels and time and consequently may not see the full benefit of completing them. Although behaviour recording charts are idealistic, limited time and staff mean that it is not always practical.

The consideration of recording charts became less apparent when staff provided examples involving people living with dementia who displayed low levels of distress on the ward and were more accepting of the ward environment.

*"Little ladies who just lay there... and then you'll get one who is screaming at you."
(Sophie)*

The use of the word "one" in the quote above appears to depersonalise the individual and appears to move away from the importance of person-centred care and maintaining ones' personhood. Further, the use of "little old ladies" appears to dehumanise people living with dementia and sees a loss of identity and limited preservation of an individual's personhood. There is also a sense of compliance

with some patients conforming to the role of a 'good patient'. This quote also suggests that whilst low levels of distress are less problematic for staff, it may also indicate that people living with dementia's needs are not being met fully (for example, a quiet patient on the ward may feel quite isolated).

3.3.3 Unpredictability and fear

How staff perceived the person living with dementia appeared to influence the way in which they responded to distress (see Figure 3, Subtheme 1c). Feelings of uncertainty and unpredictability appeared to differ depending on the patient's and the expectation of their behaviour, as opposed to how they actually behaved. It was noticeable that one element of these interactions was influenced by the gender of the person living with dementia. In some examples, the individual's physical size and perceived strength also affected the way in which staff responded and perceived patients as a potential threat.

"So obviously like cos he's big and it's quite scary cos he was tall, and like most of us are like small and stuff." (Lucy)

The emotional impact that this had for staff is demonstrated in the quote below. The use of the word "frightened" on several occasions evokes a real sense of fear for Ann when responding to distressed behaviours. Feelings of anticipatory anxiety appeared to perpetuate the assumption that the patient would become aggressive. This example demonstrates concerns regarding ward staff's safety and well-being. Further, this may have implications for how distress is responded to, for example, avoiding the behaviour due to fear of self-safety means that the person living with dementia remains distressed.

"If you've got a very big person, a big gentleman, for example, that's hovering over you in quite a threatening way, yeah! Of course, it's frightening but it doesn't stop you perhaps being frightened inside. Some of the nurses can be frightened... So em yeah, they [the nurses] can be very frightened." (Ann)

Further, some of the female staff expressed finding it easier to understand and respond to emotional distress as opposed to physical displays of distress.

“And I let her look at me and I, I took my bobble out actually and so she knows I were a girl, they are so sweet, and you make that extra special effort, just so there’s somebody there, you know?” (Chloe)

Negative emotions were also used to describe an interaction between a male member of staff and a male patient who was distressed. A sense of feeling scared and frightened was described alongside quite physical descriptions of distressed behaviours.

“The guy was really aggressive you know, like punching and fighting” (Jack)

In contrast, in the example below, Jack provided an example in which female staff were unable to reduce the distress in a female patient. As a male member of staff, Jack was the only person able to calm the female patient down. The use of the words such as “quite aggressive” and “she was fine” contrast with the words used to describe the distressed male patient, such as “really aggressive” and “punching”. Further, there was a sense that Jack felt more comfortable and at ease responding to female distress over male expressions of distress.

“I just held her hand... she was fine.” (Jack)

Central to responding to distressed behaviour is how staff understand people living with dementia. Although not explicitly discussed as a formulated response, during more difficult times on the wards, staff were seen to make sense of distressed behaviours by formulating the patients’ needs based on (1) what they felt was going on for the person living with dementia at the time, (2) how it must have felt for them during an acute hospital admission (3) how the person living with dementia responded to the intervention provided by staff. Further, unfamiliarity perpetuated feelings of anticipatory anxiety causing staff to predict more negative

outcomes of the distressed behaviour, with the role of gender and physical size of the person living with dementia seen to trigger further anxiety for staff.

3.4 The Context in Which I Undertake this Work

This theme refers to the range of factors within a ward environment which can cause distress in people living with dementia (see Figure 3, Theme 2). Staff acknowledged that the ward environment is not ideal and can restrict opportunities to deliver person-centred care. Staff spoke about the dilemmas they faced when choosing between offering person-centred, humanistic care or care which was focused around minimising risk. A build-up of contextual factors on the ward also appeared to increase the emotional strain for staff; for example, limited time meant that medical care was prioritised over delivering a person-centred approach. Consequently, the ward context was associated with fewer positive outcomes for people living with dementia.

3.4.1 Task orientated care.

The difficulties staff face when delivering care to people living with dementia on a busy, acute ward was described (see Figure 3, Subtheme 2a). As discussed in Section 1.3.1 [The medical approach], staff spoke about needing to prioritise medical care during a shift to ensure all patient needs were met. This task-orientated way of working appeared to supersede a person-centred approach on the ward. In some examples, staff spoke about delivering care in the individual's best interest. In some examples, the focus on task-orientated care not only left staff feeling guilty, but it was also seen to be a trigger for distressed behaviours. Balancing aspects of care often resulted in staff feeling that they had reduced time to respond to distressed behaviours in a way that maintained an individual's personhood. Further, the lack of time also meant that staff did not always have time to spend with the person living with dementia once they were distressed.

“If you say like “oh we’ll watch this.” But then I’m like... I actually haven’t got time to sit and watch something with them.” (Lucy)

Conversely, in the example below, during times in which staff prioritised delivering person-centred care, this led the member of staff to feel judged by colleagues. Although medical and nursing needs are often seen as a priority, engaging a group of people living with dementia in a game of dominoes had positive outcomes for both patients and for staff. Further, by occupying people living with dementia with meaningful activities reduced the likelihood of distressed behaviours, thus reducing the pressures for other staff responding to patient distress on an individual basis. Whilst this cost-benefit approach had positive outcomes for people living with dementia, there was a real need for the staff member to justify why a person-centred approach was chosen over a nursing approach. These experiences further question what constitutes 'work' in this setting. Additionally, the expectations from senior management also appear to constrain staff.

"I was sat playing dominoes with 4 fellas once. We got glared at by ward sisters from [other] wards that day. They were really busy. But all 4 of them were walking floors before we sat playing dominoes. That was best use of my time at that moment!" (Emma)

3.4.2 The set-up of the ward.

The set-up of the ward (which refers to the ward layout, the presence of different healthcare professionals and staffing levels) were all factors which posed as a barrier for staff to respond effectively to distressed behaviours (see Figure 3, Subtheme 2b). Staff alluded to the negative impact the set-up of the ward can have for people living with dementia who have underlying health conditions, such as a delirium. Underlying health conditions, alongside disorientation and confusion, for people living with dementia also exacerbated levels of distress during a hospital admission. Staff spoke about their concerns regarding staffing levels and that this limits their ability to respond to distressed behaviours.

"If there was a greater understanding... then you're not causing another problem by putting them in a different environment." (Emma)

Across interviews, it was noticeable that staff expressed feeling frustrated with the ward context. The use of exclamation marks within the quote below reinforces Isla's anguish in feeling unable to provide good quality care to patients when working in a restrictive environment. Further, a sense of wanting to protect patients admitted onto the ward due to their "vulnerability" was apparent. There was a real sense of helplessness during Isla's interview in which she felt conflicted with wanting to get to know the person living with dementia versus needing to get the job done. The quote not only highlights issues relating to time pressures but also highlights issues about the wider culture staff work in. There is a sense of staff feeling trapped by the system which causes them to feel unable to respond appropriately to distressed behaviours.

"I don't think we've got enough staff anywhere on, on, especially on elderly! To deal with, because they're so vulnerable... There's not enough time, nobody's got enough time for them. Cos nobody gets to know the patients anymore!" (Isla)

It was also noticeable across interviews that staff expressed feeling frustrated when working against the organisation, with the ward context inflicting further feelings of exasperation on staff. This appeared to be related to the organisation having limited knowledge and understanding of how the ward environment can be an antecedent for distressed behaviour. This suggests that the organisation can sometimes fail to recognise the emotional impacts for staff and people living with dementia with staff describing a real sense of tension between providing care to people living with dementia and working within the constraints of the organisation.

"They move them to create a bed into another area. That patient will get delirium! Someone, living with dementia and then has a superimposed delirium." (Ann)

3.4.3 Enhanced bays.

Within the acute ward environment, people living with dementia who express distressed behaviours are provided more individual support from ward staff within enhanced nursing bays (see Figure 3, Subtheme 2c). The need for the continuous presence of a member of the nursing team is referred to as 'specialing'. The role of

specialling is used within these bays to reduce concerns relating to risk. Staff described that being in a bay with other people who are distressed, is stressful and, at times, chaotic. There was also evidence to suggest that enhanced bays do not always help alleviate distressed behaviours in people living with dementia. This is also another example of how the organisation may do things (for example, putting people living with dementia together in enhanced bays) which may not be fully supportive of staff. A sense of chaos was portrayed in some examples, as were feelings of failure of being unable to meet the person's needs. Further, the examples below demonstrate the moral and ethical dilemmas staff face in being conflicted over risk when delivering basic nursing care. These experiences further highlight the emotional strain which staff face within the ward context.

“There were 2 or 3 other people there and they kept buzzing as well... and you were making sure as well that nobody fell from the bed, and he was going out as well and like constantly going on at you.” (Jack)

Ethical and moral dilemmas faced by staff providing care within enhanced bays were further reinforced by the expectation of senior members who deliver training within the team. It is likely that this leaves staff members feeling conflicted and confused over how distressed behaviours and patient needs should be prioritised and responded to.

“While you nip behind that curtain thinking of her dignity [patient needed a bedpan] the other ladies who are demonstrating this behaviour that challenges may fall and harm themselves.” (Ann)

The examples provided here demonstrate enhanced bay nursing is a stressful place to work. Although staff rotate every few hours to reduce the emotional impacts, there appears to be some disparity of how staff should prioritise patient needs over risk and the emotional impact this then causes. There needs to be a balance with what works well for both staff and the person living with dementia in which the organisation needs to both recognise and support. Additionally, staff described

that being in a bay with other people who are distressed, does not always help alleviate distress for each individual. The interviews also highlighted issues regarding continuity of care for people living with dementia who become distressed especially within enhanced bay nursing. It is often harder to develop familiarity with people living with dementia and for staff to spot possible antecedents to distressed behaviours when staff are rotating every few hours.

3.4.4 Acknowledging the impact.

Staff spoke about the impact of the ward context on people living with dementia and that this can be a likely cause for distressed behaviour (see Figure 3, Subtheme 2d). Staff acknowledged that an unfamiliar environment can make people living with dementia feel frightened, confused and disorientated and can often lead to an increase in distressed behaviours.

“Look out of a window, they recognise that they’re in somewhere else and they’re not [home]!” (Chloe)

Staff also described a sense of sadness and frustration in relation to the lack of choice and loss of identity for people living with dementia during a hospital admission.

Although enhanced bay specialising meant that people living with dementia were not alone and the risk of falls or injury was reduced, it is important to recognise the use of bays and safety as the key goal, and the impacts this has on staff and patients. Staff often felt trapped by the system and provided examples of spending time with people living with dementia whilst also feeling judged by colleagues for doing this.

3.5 The Emotional Load

This theme reflects the emotional difficulties that ward staff faced when responding to distressed behaviours (see Figure 3, Theme 3). Although distressed behaviours placed considerable emotional strain on staff, feeling attuned to an individual’s needs appeared to lessen the emotional aspect of the job with positive

examples of care described across all interviews. Staff described the challenges working with individuals whose condition was often unpredictable and variable, the extent of which it was felt was sometimes hidden by staff from each other. Feelings of helplessness were described when staff were unable to provide humanistic and person-centred care to people living with dementia.

“I often went home and cried!” (Sarah)

It was recognised by staff that the emotional part of the job can, at times, be harder than providing physical care to people living with dementia, particularly if they were working alone in an enhanced bay.

“Most of the staff that you’d speak to... if you said to them would you rather be in a bay specialising people living with dementia or would you rather be out on the floor, answering buzzers, getting bed pans, they’d rather be out on the floor, running about like a headless chicken because it’s, it’s physically demanding is that but it’s not as mentally challenging.” (Sarah)

The word “failure” is used four times within the quote below highlighting the pressures that staff place upon themselves to respond to distressed behaviours. There appears to be some conflict with how staff feel distressed behaviours should be responded to against the stark reality of a busy, acute ward whereby there is limited time to provide person-centred care. Feelings of self-judgement appeared to fuel the emotions associated with feeling unable to meet the needs of people living with dementia. Eventually, a sense of emotional exhaustion is described in the quote below in which Emma is also eager to provide a degree of reassurance to herself that she has done the best she could within a difficult situation.

“And you sit with them to make them feel better, but it didn’t matter what you did it didn’t make her feel better. So, you were a failure, weren’t you? You’re not! You know you’re not really a failure. It’s not you! Lots of other people have tried... So,

you know it's not really you and you're not a failure. But that is how you feel. Like a failure!" (Emma)

3.5.1 Emotional impacts for staff.

Staff described their experiences of the emotional aspect of the job with all staff acknowledging how difficult it can be responding to distressed behaviours (see Figure 3, Subtheme 3a). This was particularly difficult when people living with dementia had underlying health conditions such as a delirium.

"He had a hyperactive delirium... He was very paranoid. He thought we were trying to hurt him hence when anyone came to try to assist him with his eating and drinking and anything, he would hit out. So, the nursing staff were a little bit frightened." (Ann)

Communication difficulties also meant that people living with dementia were more overtly distressed; consequently, staff found it harder to respond to distressed behaviours.

"It's painful as well sometimes because you are trying to help them and, you know, and you can't convey your message to them as well because they are not connecting as well and it's really distressing for you." (Jack)

Feelings of frustration and increased levels of stress were described by staff which limited their understanding of why the person living with dementia became distressed.

"I think sometimes... look we ain't got the time for this, we've got 40 other patients who need us, and you are doing this when you know that you can just buzz us." (Sophie)

Professional identity appeared to be embedded in the way staff responded to distressed behaviours. Further, staff placed increased pressures and higher expectations on themselves for feeling that they should know how to respond to

distressed behaviours and cope with the emotional aspects of the job too. Increased pressures and expectations of 'self' were more prevalent if staff had received training or were working in a more senior role. There was a strong sense of staff carrying the responsibility and trying to protect other staff from the emotional aspect of the job.

"I am kind of the glue that has to try and keep [everything together]. So, if I break down, I think the ward would break down!" (Jill)

The recognition of emotions in people living with dementia and potential reasons of why they became distressed during a hospital admission also added to the emotional strain of the job. This was particularly noticeable when staff felt unable to alleviate sometimes very negative emotions and feelings of the person living with dementia. The quotes below use words such as "terrifying", "anxious" and "distressed" to describe the patient's behaviour. There was a real sense of staff losing control of a situation and feeling unable to fix this for people living with dementia.

"It must be terrifying. It absolutely must be terrifying... But then that in itself must cause anxiety... It must be absolutely terrifying." (Emma)

"You could see that he was really, really anxious and distressed all the time... He was just distressed. Anxious all the time which must be awful." (Isla)

The consequences of staff feeling unable to reduce the distress for people living with dementia also had emotional impacts for staff too. Staff often described a combination of frustration and guilt when unable to reduce the levels of distress for people living with dementia. The word "grate" used in the quote below demonstrates a real sense of irritability for staff wanting to escape an emotionally difficult situation yet feels confined to the ward environment.

"I think that makes you feel bad as a person... you want to be out of that room because it grates on you... I feel like I don't think I can sit here much longer."

(Sophie)

Feeling unable to meet the needs of people living with dementia was an aspect of the job that staff found difficult to come to terms with, which saw escalating cycles of distress for people living with dementia and for staff. The repetition of the word "distressed" in the quote below further reinforces the emotional and psychological discomfort staff experience alongside a degree of emotional overload. The interesting use of the word "perception" in the quote below suggests that Emma is paying attention to different aspects of the patient's behaviour to interpret the cause of their distress.

"So, you're distressed because you can't stop her being distressed. You're distressed because of perception. You're distressed because you can hear [her], out of your ear... You can't make her feel better. You can't stop it. It's awful." (Emma)

3.5.2 Absorbing families' distress.

Distress not only affected people living with dementia and ward staff, but it also affected relatives too (see Figure 3, Subtheme 3b). This often resulted in staff having to deal with distress from family members, as well as from people living with dementia.

That, that lady's son just made me want to cry. Every day he'd come and sit and say to her "please stop Mum. Don't make that noise! You can stop that now Mum. What are you making that noise for?" It was awful." (Emma)

There were examples in which staff felt judged by relatives, particularly if there had been a decline with their relatives' condition. The lack of understanding by relatives of the trajectory of the disease resulted in staff carrying additional emotional burden and self-blame. Further, a deterioration in the person living with dementia also resulted in displaced feelings of anger and frustration from relatives onto members of staff.

“They are blaming us cos we aren’t feeding them and you know and you feel like sometimes saying to them, well you try to do it then.” (Sophie)

“Especially if they [the relatives] get abusive... And a lot of times I’ve just said so I’m sorry I’m not speaking to you anymore! When you come back, and you can be civil... [then I would re-engage].” (Chloe)

When people living with dementia became distressed on the ward, relatives placed increased demands on staff to provide more individual nursing care to their relative.

“Like sometimes you feel like you can’t get, like, forward?... and then yeah, your families can make it just like, it all gets really bad” (Lucy)

“Got a lot of google doctors! We’ve read this. We want this. Can they have this drug? This, that and other!” (Chloe)

This was also combined with a family expectation that staff should be doing more for their relative. These experiences resulted in staff feeling that they were being judged and that they were not doing their job properly. The repetition of the word “awful” in the quote below provides a sense of disappointment and shame that staff feel when they are unable to respond to distress effectively. These feelings are exacerbated when visiting family place additional strain on staff in reducing the distress of other patients on the ward.

“It’s awful! It’s awful. It’s awful to listen to them... I’ve given her things. I’ve, I’ve given her, we’ve done this and [that]”. You feel like you’re not doing your job properly... You get people’s families “well my Mum shouldn’t have to live with that!” And that just really breaks my heart too cos you just think that could be your Mum!” (Emma)

Staff appeared to understand relatives' distress as a combination of high family expectations to nursing care and limited understanding of the condition. The emotional load reduced when staff had access to external support, such as colleagues working within the dementia support team, which appeared to lessen the load for staff. The additional support was also perceived as helpful by relatives.

"So, then I had to educate the family on what delirium is and um reassure them that you know, now we know what's causing it, it's, it's reversible." (Ann)

The layout of the ward also appeared to be a trigger for families visiting their relative in hospital. This was particularly evident if people living with dementia were calling out or frequently pressing the call bell. The limited privacy within acute wards, for example having six beds within a bay with only a curtain that can be pulled round to give privacy, meant that family members found the ward layout difficult to tolerate. Staff were expected to absorb relative's frustration in relation to this which subsequently added to the emotional strain of the job.

"Sometimes what's more irritating is that when they came, their Mum might have been [displaying distressed behaviour]! But their Mum's stopped now. And... when it was their Mum [displaying the behaviour], it was everything in the world, but because their Mum's stopped, they shouldn't have to listen to [another person on the ward]!" (Emma)

3.5.3 Experiencing positive emotions.

Despite strong, emotional responses described by ward staff to unresolved or recurrent distress in people living with dementia, the data suggest that staff experiences of providing care were not always negative. Positive experiences for both people living with dementia and for staff were demonstrated across all of the interviews (see Figure 3, Subtheme 3c).

"It was quite good you know; it was, you feel from the inside that you are doing something good." (Jack)

The positive aspects of the job appeared to help staff overcome the considerable challenges they face whilst working within an acute hospital setting. These experiences were identified when staff felt more connected and attuned with the individual's personhood. Often, these experiences provided a sense of achievement and reward for staff, which built on their self-efficacy. When task-orientated demands for staff were less, this reduced the emotional strain of the job and provided staff with more opportunities and time to respond to the needs of people living with dementia.

The quote below demonstrates the impact of attunement between a member of staff and the person living with dementia. A sense of connectedness and understanding of the person's needs resulted in staff offering a meaningful and engaging activity which maintained the identify and personhood for the individual.

"[the activity of folding laundry] kept her occupied and it made you feel better knowing that she thought she was helping you." (Sophie)

Staff also valued feedback from family members of distressed people they have managed to support well.

"It's really, really humbling to know that they've really appreciated the fact that you've spent that last time with their relative." (Sarah)

In the quote below, Jill described a sense of achievement and gratitude when receiving positive feedback from relatives. The idea of validation and appreciation from family members also appeared to evoke a sense of embarrassment (laughter) for Jill. Despite some awkwardness talking about this, staff appear to internalise positive feedback which may build their emotional resilience for the job.

"I like to [laughs] save them [cards from relatives] because it's, um, it's nice to look back on." (Jill)

Much of the data presented within this theme suggests that staff are not only dealing with distress in people living with dementia as well as their own, but they are also absorbing distress from visiting family members. The negative emotions described by staff, such as “it’s soul destroying” and being made to feeling “like a bad person” highlights the huge impact distressed behaviours has for staff and provides a sense of failure for staff working in this environment. Further, the extent of the emotional strain and burden can cause staff to feel that there are unable to do their job much longer.

3.6 What I do to Manage

This theme captured both the adaptive and maladaptive ways in which staff cope with distressed behaviours for people living with dementia (see Figure 3, Theme 4). Staff spoke about valuing support from external sources (such as the dementia support team), particularly when they were unable to reduce the levels of distress for people living with dementia. Although spoken about to a lesser extent, sharing the load between colleagues (including those working within non-clinical roles) was also discussed. Staff who had more years of experience working in dementia care appeared more confident in responding to distressed behaviours and sharing their knowledge with younger, less experienced members of the team. Although the presence of relatives on the ward was seen to add to the emotional strain of the job, during busier shifts the presence of relatives was valued by staff as relatives were able to ‘sit and just be’ with the person living with dementia.

3.6.1 Sharing the load between us.

Familiarity and trust within the team appeared to be factors which influenced whether staff approached colleagues for support and advice in managing distressed behaviours. It was, however, less clear as to whether staff actively pursued this support suggesting that the difficulties of sharing the load are perhaps partially but not fully acknowledged by staff (see Figure 3, Subtheme 4a).

“I’ve always had colleagues that, maybe not every single person I’ve worked with, but certainly a minority of people that I’ve worked with have been there. And I’ve known I can go to them.” (Sarah)

Although staff knew who they could approach for more physical aspects of support, staff did not always share the emotional aspect with colleagues. Staff were seen to hide the emotional impact away from colleagues or took the emotional load home with them. The emotional impact of the job was, however, recognised by the dementia support team in which their support and knowledge was well received from staff working directly with distressed behaviours. This implicit recognition from external colleagues demonstrates a need to provide support to frontline staff providing care to people with dementia who become distressed.

“I’ll go on now and I’ll say to them “Come take a break” ... Just to offer some support and offer them a little bit of um guidance, if you like?... even now they still value my opinion” (Sarah)

Years of experience appeared to be an influencing factor which determined whether a member of staff accessed support or advice for managing distressed behaviours.

“I think for the younger ones it’s hard, it’s very rare it gets to me” (Chloe)

It was also recognised by more experienced members of staff that younger, less experienced colleagues may find it difficult asking for help or support. Further, more experienced and older members of the team described higher levels of emotional resilience when responding to, and understanding, distressed behaviours.

“I think some of the younger health cares might find that difficult to understand. Because I’m older if you like! [Laughs] and I’ve a bit more experience... it doesn’t bother me in the slightest now.” (Sarah)

Staff were more likely to ask for support from colleagues when interventions such as validation and distraction were unsuccessful or when the individual displayed

physical and violent behaviours. Support in this context usually involved staff calling security. Whilst this appeared to help staff manage distressed behaviours in the short-term, it had less than positive outcomes for the person living with dementia which saw an exacerbation in their levels of distress.

“Their (security) presence does help because I don’t, they’re in a uniform, aren’t they?... Like a, a police kind of figure, cos they have stab vests as well.” (Jill)

Further, female patients were perceived by staff to feel more intimidated by security staff, whereas male patients appeared to be more compliant and responsive.

“But little old ladies, they’re not, they’re going to be even more scared!” (Lucy)

The context of the ward also played a part in how support was accessed by staff. The busy nature of the ward often saw non-clinical members of staff responding to distressed behaviours too, particularly during busier times on the ward.

“I chat to them while I’m working... I don’t really look after them. But sometimes intervene when they’re getting violent with other members of staff.” (Isla)

Additional concerns were raised with the level of support available to night staff. In the example provided below, security were called to help manage the distressed behaviour of a person living with dementia with co-morbid alcoholism. The patient had asked to go out for a cigarette but there was no staff available to take him out which was the trigger for his distress. This example highlighted the implications of needing to share the load when there is limited support available. This not only exacerbated the distress for the individual but also resulted in a member of staff being injured.

“The nurse tried to support him. He thumped the nurse and he knocked a tooth out. So, they called the security team.” (Ann)

Although staff absorb relatives' emotional distress, they were seen to value the presence of family members visiting and sharing their knowledge of the person living with dementia. Sharing this 'expert knowledge' meant that staff could respond more effectively to distressed behaviours. Further, sharing the load in practical terms meant that staff had more time to provide care to other patients on the ward and it provided some respite from the difficult work of trying to support distressed people.

"If you know some of the family names, yeh you can like tell them that that person is coming, so that can be a bit of a calming factor." (Jack)

"Cos some of them are really good and can pick up a trigger at anything!" (Chloe)

3.6.2 You're stuck between a rock and a hard place.

Reverting to policy frameworks and guidelines, for example, the 'Deprivation of Liberty Safeguards (DoLS; 2005)' and the 'Mental Capacity Act (MCA; 2005)', were seen to be another way in which staff responded to patient distress (see Figure 3, Subtheme 4b). The frameworks guide staff on how to manage distressed behaviours and provides further justification to the care being delivered to people living with dementia who become distressed. Whilst this provides a degree of reassurance to staff in responding to distressed behaviour, the guidelines often led to more restrictive, un-humanistic care being provided. Although staff understood the care to be in the person's best interest it had fewer positive outcomes for both staff (feelings of guilt) and for the person living with dementia (resistance to care led to an increase in distress). Frameworks were relied upon more when staff were unable to respond or reduce distress in the person living with dementia.

"You're stuck between a rock and a hard place... I'd hate to think that I've made him feel that we're keeping him locked up and um not letting him go home" (Jill)

3.6.3 Interpersonal Interactions.

Ward staff were able to adopt a range of skills in being able to minimise the likelihood of distress in people living with dementia. Interpersonal skills, prior

knowledge and experience were all seen as helpful ways as treating the person as a human being (see Figure 3, Subtheme 4c).

“If you just getting to their level, their eye level basically? And chatting to them like a normal person.” (Jill)

Further, person-centred care was central to whether the person living with dementia became distressed or not. The example below demonstrated that providing person-centred care in a respectful way, which empowered and maintained all aspects of personhood, alleviated the distress for the person living with dementia and saw a real sense of relief for the member of staff completing the personal care.

“And I, I just whispered in her ear “do your bits” and she went “oh!” What did she call it? Tuppence! And I give her towel. I let her do it. And then I pulled her pants up to her knees and she stood up. It was like automatic pilot.” (Chloe)

The ward culture was described as an area which limited staffs’ ability to deliver person-centred care.

“Quite often I hear bed numbers and not names and that bothers me.” (Isla)

The quote above demonstrated the emotional impact that depersonalisation of patients has for some staff. This caused Isla to feel resentful and angry towards colleagues who referred to people living with dementia as a number. Isla’s role as a non-clinical staff member may mean that she is not in as close proximity to patients as ward staff. From her perspective, referring to patients as numbers might seem depersonalising; however, this might not be an opinion shared with ward staff. Additionally, what is acceptable between staff will differ. Stances on depersonalisation will be mediated somewhat, for example, on a member of staff’s fatigue (i.e. memory for names diminishes with increasing tiredness and therefore

numbers may be easier to recall) and may not necessarily reflect their standpoint on (de)personalisation.

3.6.4 Consequences of accessing support.

Approaching colleagues for support resulted in mixed feelings for staff (see Figure 3, Subtheme 4d). Initially asking for help meant that staff perceived themselves as 'giving in' or having to accept defeat as they were unable to meet the needs of people living with dementia.

The example below relates to a member of staff, Sarah, trying to respond to a distressed behaviour in a person living with dementia. Sarah was struggling to calm the person down and sought help from colleagues by pressing the call bell. During this part of the interview, Sarah described a real sense of helplessness and feeling like a failure having to ask for support. There was a sense of urgency in that moment that she needed support from her colleagues in order to protect herself, as well as the patient:

"I'm trying to get her legs back through the rails as safely as I could. All the while she's lashing out at me!" (Sarah)

Despite the strong emotions described, asking for help from a colleague saw a huge sense of relief for Sarah. The assistance from a colleague arriving led to feelings of guilt that Sarah was unable to calm the person down herself. Further, Sarah spoke about the skin tear which occurred as a result of the person getting her legs through the bed rails. She described a sense of relief that this had been witnessed by another colleague and was an accident:

"Now just, just as that's happening another carer had just walked in... she'd seen this unfolding!" (Sarah)

Interdisciplinary working and communication within the team was seen to be another factor which influenced whether staff felt able to share the load with

colleagues. A sense of staff feeling judged by other health professionals and not listened to within the team appeared to be a determining factor.

In the example below, Emma vented her frustrations over asking for support from colleagues but not feeling listened to. It was only when the medics met the patient (who had been distressed for several days) that Emma felt listened to. This has implications for clinical practice on the ward as if staff do not feel listened to or able to approach others for support in managing distress, the needs of people living with dementia may not be met.

“But members of the team are not always listened to... I think that’s the problem with the NHS. Everyone’s judgemental. Everyone’s busy. And everybody’s far busier than you are. Always! [Laughs]” (Emma)

3.6.5 Coping with the emotional load.

Despite the challenging aspects of the role described across all interviews, staff spoke about the range of ways in which they manage with the emotional strain (see Figure 3, Subtheme 4e). Training was recognised as an important factor of being able to manage distressed behaviours in people living with dementia, in which strategies such as distraction, reminiscence and validation techniques were learnt. The strategies learnt as part of the dementia training were added to a ‘tool box’ which staff could refer to when responding to distress.

“Once I’d got her distracted, she was much better.” (Isla)

*“We try to evoke memories and get them to interact and stimulate conversation.”
(Ann)*

Further, the quote below demonstrated that having knowledge of these strategies built upon staff confidence in feeling able to respond to distressed behaviours. Further, these interventions were not only positive experiences for staff, as shown by the jest and jolliness in Sarah’s interview, but also helped to reduce the levels of distress for the person living with dementia.

“I used again distraction therapy, holding his hands and singing and dancing with him into the bathroom! [Laughs]” (Sarah)

A limited recognition by senior management of the emotional difficulties ward staff face appeared to cause a degree of frustration and resentment. There was a real sense of feeling let down by the wider organisation over the limited recognition of their work and the difficulties they face day-to-day.

“If senior management ever bothered to ask you how it makes you feel to watch ‘em watch your colleagues struggle... but they never ask, they never ask me!” (Isla)

Staff appeared to cope with this by applying a compassionate approach to self-care. This appeared to influence the way in which they provided care on the wards. Self-care within this context appeared to help ward staff cope with the inherent stressors of providing care to people living with dementia who are distressed. This is an important concept to consider as exhaustion, tension and burnout can affect clinical decision-making and can lead to staffing concerns. Further, in order to provide good care to people living with dementia, it is important that they look after themselves too. Self-care was demonstrated in a variety of ways including positive coping statements and taking regular leave from the ward.

“That’s all you can do and do your best at that time. It’s not always enough but if you’ve done your best, you’ve done your best.” (Chloe)

The repeated use of “best” in the quote above appears to provide Chloe with a sense of reassurance that she achieved all she can in providing care and responding to people who are distressed on the ward.

The limited recognition by the organisation of the emotional impacts working on acute hospital wards was further emphasised when staff spoke about hiding the full extent of the difficulties they faced with their colleagues. Marked levels of

distress were shared at home with family members and in some instances, staff were seen to ruminate on the emotional impacts after their shift had finished.

Within the quotes below, both staff members were seen to display a sense of embarrassment about getting upset at work. This was further supported by both staff members seeming somewhat uncomfortable and awkward talking about this. Further, they appeared to mask the emotional impact by laughing whilst talking about how they cope with the more emotionally challenges aspects of the job.

“I would never cry on the ward. Em, but sometimes driving home I could have a little bit of a [laughs] cry going home!” (Jill)

“I often went home and cried! [laughs] I often felt, was there something else I could have done? Should I have done more? Especially if somebody had, had hurt themselves or I’d, I’d always go over things in my mind and think should I have done this? Could I have done that? Would this have helped?” (Sarah)

Further, the repeated questioning within Sarah’s quote above demonstrates escalating cycles of preoccupation of how she could have done things differently on the ward. It is likely that the maladaptive ways of coping demonstrated across interviews may have negative consequences for well-being and emotional burnout.

During busier times on the ward, staff felt unable to share or take the emotional strain to anyone. A sense of needing to hide away from the ward or from direct contact from people living with dementia and their relatives was described. Examples included staff hiding in the toilet or in the manager’s office. Further evidence of hiding their emotions were seen by staff putting up a façade whilst on shift. This often meant that colleagues were unaware of the emotional strain they were feeling, and that the full extent of the difficulties were hidden from their employer. Only one staff member spoke about approaching the ward manager for support.

“Sometimes it does, that’s when I’ll walk away and sit myself in the office for 10 minutes. Then I’ll come back out.” (Chloe)

“I go to, to the toilet on the ward and you just have a little cry. Dry your eyes and then back to it!” (Jill)

The concept of feeling judged was one of the barriers which stopped staff from sharing the emotional strain with colleagues. Instead, sharing the emotional impacts of the job was seen as easier to do with family members or away from the ward. Across interviews, staff spoke about knowing that further support was available (such as a referral to Occupation Health). However, staff appeared ambivalent about accessing this external support and chose to access support by other means. This suggests that even if there is support available, staff are choosing not to access it. Staff may feel constrained by the organisation and their colleagues when showing emotions and may feel that they are being judged. It is, therefore, important that senior management are made aware of this so that staff feel better supported and feel able to access emotional support.

3.7 Summary

To summarise, understanding people living with dementia is central in terms of how distressed behaviours are understood and responded to by staff. A sense of familiarity, aided by the use of relatives’ knowledge of people living with dementia and the Forget Me Not document, was seen to help staff respond to distress in more person-centred and humanistic ways. Unfamiliarity appeared to perpetuate feelings of anticipatory anxiety which caused staff to predict more negative outcomes of the distressed behaviour, with personal characteristics of the individual often triggering further concerns for staff.

The study highlighted the important role that familiarity has on responding to and understanding distress in people living with dementia; however, the context in which staff work in appears to limit this to some extent, for example, a focus on task-orientated care. Further, issues regarding continuity of care were identified, particularly within enhanced bays in which staff rotate the role of specialising every

few hours making it more difficult for staff to spot potential triggers of distressed behaviours.

The emotional load required to undertake the work also shaped staffs' understanding of distressed behaviours. The data demonstrates that staff are not only dealing with high levels of distress from people living with dementia and family members but are simultaneously dealing with high levels of distress themselves as a result of this challenging work. The study has also highlighted issues within the organisation which cause staff to feel trapped by the system when responding to distressed behaviours. Despite this, positive aspects of care were identified which appeared to help staff overcome the considerable challenges of the job.

Finally, the study has demonstrated a variety of ways in which staff manage distressed behaviours in people living with dementia including accessing support from colleagues and reverting to policy frameworks. The study has also found that even though there is support for staff to access, they may feel constrained by the organisation and by colleagues in doing so. Further, the study has revealed that staff choose to hide the emotional aspect of their job from their colleagues which suggests that the full extent of difficulties staff face may be hidden from their employer.

CHAPTER FOUR: DISCUSSION

The results presented in Chapter 3 will now be discussed in relation to the existing literature and study aims. Implications of the findings for clinical practice will then be considered, as well as the strengths and limitations of the study. Areas for future research will then be discussed, followed by overall conclusions.

4.1 Summary of Findings

The aim of the study was to explore how ward staff understand and respond to distressed behaviours in people living with dementia in an acute hospital setting. The themes which emerged from the study clearly link with the study aims originally described in Section 1.7. During the process of writing up my research, however, it became apparent that there was a different emphasis on what the study aims focused on and what participants spoke about. This was an additional element which had not been anticipated and related to the emotional impact of providing care to people living with dementia and how staff cope with this demanding work. Results from the qualitative analysis produced four overall themes in response to the research aim: (1) How I understand the behaviours of people living with dementia, (2) The context in which I undertake this work, (3) The emotional load, (4) What I do to manage. These themes will now be discussed in relation to existing literature.

4.2 “How I Understand the Behaviours of People Living with Dementia”

This theme captured the importance of familiarity in relation to understanding distressed behaviours in people living with dementia. The study found that when staff have knowledge and an understanding of the person living with dementia, this provides staff with a sense of familiarity and confidence to respond to distress.

The ‘Forget Me Not’ document was valued by staff and was seen as a foundation for developing familiarity. The study found that the document helped reduce the anticipatory anxiety staff experienced when providing care to a person they did not know and was seen to be particularly useful when the person exhibited distressed behaviours. Although staff spoke about the many strengths to this document, some

individuals admitted into hospital with a dementia diagnosis may not have relatives visit and it may not always be possible to access this sort of information. Although this information could be gathered by phone, the current study highlighted the demands staff face with ensuring all medical and nursing aspects of care are met for all patients on the ward; therefore, collecting information for a 'Forget Me Not' document, at times, was considered unfeasible.

When information about the person living with dementia was unavailable, staff spoke about other ways in which they responded to distressed behaviours. An expectation from senior management meant that if a person living with dementia became distressed, a behavioural recording chart should be completed to provide a better understanding of the cause of distress; however, the completion of recording charts was not explicitly spoken about by staff within the current study. Research has found that having charts which are too complex or resource-heavy, alongside the nature of working within a busy clinical environment, may limit the applicability of such charts and may explain why staff do not always complete them (de Pfeiffer, 2016). It is also possible that the severity and type of distressed behaviour may influence whether staff prioritise completing a behavioural recording chart to understand the cause of distress.

Another important finding within this theme, which has not been discussed in the wider literature, related to the application of psychological models in understanding distress. The current study found that staff alluded to the 'ABC' model (Cohen-Mansfield, 2003) and 'Unmet Need' model (Cohen-Mansfield, 2001) to understand and respond to distressed behaviours in an individual, despite not being trained to use these models. Within the current study, staff spoke about using the principles of these models, and were perhaps unknowingly using aspects of them in practice, to problem-solve possible antecedents for the persons distress. For example, staff trying to understand distressed behaviour spoke of considering the person's current physical condition (such as pain and infection) and environmental factors (such as noise and multiple staff providing care). Staff were open to considering distress as being a result of an unmet need, such as being in

pain, wanting a drink or needing the toilet. Some staff understood the behaviour to be an outcome of frustration for the person living with dementia, rather than due to the condition itself.

The psychological approaches (discussed in Section 1.3.5) which required staff to collate more in-depth information about the person living with dementia, for example the 'Newcastle model' and the PLST, were spoken about to a lesser extent. For example, although some staff acknowledged that the ward can be an overstimulating environment for people living with dementia, staff placed more emphasis on this being related to an unmet need (for example, feeling lonely) as opposed to a reduced stress threshold for the individual. As discussed in Section 1.3.5.5, the Newcastle model not only requires staff to access past and present information about the individual but requires a functional analysis of behaviours to be completed. A functional analysis takes time to complete as it requires a detailed analysis of a behaviour which aims to identify possible factors that sustain the behaviour. The current study highlighted the difficulties in being able to achieve this, for example, medical aspects of dementia care are seen as more of a priority over person-centred care and limited staff time. Additionally, the complexity of a framework such as this may determine the feasibility and application within an acute ward setting due to time and staffing pressures. Despite this, however, the cognitive-behavioural component to the Newcastle model (thoughts, feelings and behaviour and how these components link with one another; see Figure 2) was discussed within the current study. For example, how the person living with dementia was perceived influenced the way in which their behaviours were understood and responded to by staff. For example, "calling" and "crying out" were attributed to individuals' feeling "terrified" and thinking that they were "trapped". Whether the distressed behaviour was interpreted as threatening to others or not was important as it influenced the way in which staff responded, for example, calling security when individuals were displaying behaviour that was interpreted as more threatening.

4.3 “The Context in Which I Undertake this Work”

This theme captured the range of contextual factors which can exacerbate distressed behaviours in people living with dementia. The theme also reflects the factors which affect the way in which staff respond to distressed behaviours within an acute hospital setting. Of particular relevance is the organisational structure which appears to constrain staff in responding to distressed behaviours. There was also evidence to suggest that the organisation can sometimes fail to recognise the emotional impacts of this for staff and for people living with dementia.

Within the current study, the ward environment posed many challenges for staff and for the person living with dementia. The difficulties staff faced when completing task orientated care often resulted in moral and ethical dilemmas for staff in terms of how they responded to distressed behaviours. Dilemmas appeared to be in the context of staff choosing between providing care in the person’s best interest (a risk management approach) or providing a humanistic, person-centred response. This supports the work on restrictive risk-based practice which found that ward routine, the delivery of essential care and reducing perceived risk, dictated staff priorities resulting in a focus on essential care over an individual’s needs (Gunawardena & Smithard, 2019; Hamers & Huizing, 2005). Additionally, feelings of guilt and helplessness increased the likelihood of emotional and physical burnout for staff and resulted in poor care experiences for people living with dementia (Featherstone, Northcott, & Bridges, 2019).

Staff experiences of working within enhanced nursing bays, and the impact of this, was discussed within the current study. Staff described enhanced nursing bays as an emotionally stressful environment to work in. Although senior management recognised the emotional impact (this was managed with staff rotating an enhanced bay every four hours), the consequence of this resulted in staff rotating their role of specialising multiple times within one shift. This highlights issues regarding continuity of care for people living with dementia who are cared for within an enhanced bay. Although enhanced nursing bays meant that patients were less isolated and concerns relating to risk were reduced, the organisation fails

to recognise the subsequent impacts this has for staff and for individuals who are distressed. For example, the current study highlighted some of the moral and ethical dilemmas staff face in responding to distressed behaviours within enhanced nursing bays. One example related to a person living with dementia asking a healthcare assistant to use the toilet, but the healthcare assistant's role of specialising meant they were unable to leave other patients alone in the bay. This not only demonstrates threats to personal dignity and personhood for the individual (Boddington & Featherstone, 2018) but further highlights the tension staff face in feeling confined in responding to distressed behaviours. This supports the research by Featherstone, Northcott, and Bridges (2019) who found that the acute hospital setting saw staff feeling trapped in delivering routines of care. This appeared to trigger further patterns of resistance from the individual and resulted in staff prioritising risk over the person living with dementia's need in that moment.

4.4 "The Emotional Load"

This theme captured the emotional aspects of responding to distressed behaviours within an acute hospital setting.

The current study highlighted that additional resources, such as increased staffing, were key factors which could lessen the emotional strain of the job. This intuitively suggests that having more staff working on the wards could alleviate some of the task-orientated pressures which have been previously described. However, if staff do not understand and interpret distressed behaviours in person-centred ways it is possible that they will still continue to provide more physical and medically focused principles of care, suggesting that having more staff on the ward may not necessarily help with the emotional load.

Within the current study, the concept of professional identity appeared to contribute to the emotional strain for staff. For example, there was an expectation that staff should be able to respond to distressed behaviours appropriately, particularly if they had received dementia training or were working in more senior roles. The impact of dementia training has been widely studied and has

demonstrated the impact that limited staff training has for staff providing care to people living with dementia (Marx, 2014). The study not only demonstrated that half of healthcare professionals experience distressed behaviours of a physical nature, but three quarters of staff reported feeling frustrated and overwhelmed when delivering care to people living with dementia who were distressed. In the current study, all members of staff had received dementia training yet were still describing difficulties when responding to distress. This perhaps suggests training is not sufficiently preparing staff to deal with the difficulties they face when working with people living with dementia who become distressed.

Another interesting finding within the current study demonstrated that staff were not only responding to patient distress but also to family distress. Family distress appeared to be in the context of high expectations and limited understanding of the trajectory of the disease, causing staff to feel undermined, judged and powerless. Research acknowledges the emotional difficulties families face when their relative living with dementia is admitted to hospital (Jurgens, Clissett, Gladman, & Harwood, 2012). The dementia quality standard guidelines (NICE, 2019) also recognises the importance of families having access to external support whilst their relative is in hospital. The current study demonstrated that when support was offered by the dementia support team, this not only appeared to alleviate the emotional load for family members but also for staff too. Despite the challenges staff face in absorbing family distress, relatives presence on the ward is valued as they can offer 'expert knowledge' (Mendes, 2018). Research has also highlighted the benefits of involving relatives in the care provision within acute care settings as they can help staff recognise possible triggers for distressed behaviours (Yous, Ploeg, Kaasalainen, & Martin, 2019). Additionally, relatives can provide comfort for the person living with dementia and can decrease levels of anxiety for their relative during a hospital admission (Houghton et al., 2016).

Alongside staff dealing simultaneously with high levels of distress from people living with dementia, family members as well as high levels of distress themselves, the study has also highlighted issues within the organisation which cause staff to

feel trapped when responding to distressed behaviours. There were examples in which staff spoke about time and not feeling able to spend time with people living with dementia, as well as other examples in which staff felt judged by colleagues when they did try to do this.

It is important to highlight the many positive aspects of care found within the current study which lessened the emotional strain for staff. Positive experiences were in the context of staff feeling attuned with delivering person-centred care and meeting the persons needs effectively. Feelings of reward and accomplishment by staff within the current study supports the wider literature in which providing person-centred care increased job satisfaction for staff, particularly when staff were able to respond and manage distress effectively (Scerri et al., 2015).

The current study provided examples of what good quality dementia care looks like in terms of responding to distressed behaviours. One example involved a member of staff giving the person living with dementia a meaningful activity to do on the ward. The member of staff described how she felt the task reduced the distress for the patient. A sense of attunement between the member of staff and the individual resulted in an intervention activity which focused on the individual's personal strengths and interests. In this particular example, the member of staff asked the person living with dementia whether she wanted to help fold towels. This not only distracted the patient from becoming distressed but also allowed the member of staff to continue their work on the ward. Additionally, this form of care appeared to support an unmet need for the individual who may have been feeling lonely or isolated on the ward. It also considered the person's life history of working in a laundrette. This supports the notion that when staff understand distressed behaviour as an unmet need, rather than attempting to restrict the behaviour, staff were more likely to investigate the underlying need (Banks et al., 2013; Dowding et al., 2016).

4.5 “What I do to Manage”

This final theme captured the way in which the emotional and practical aspects of the job were managed by ward staff.

Within the current study, staff spoke of managing distressed behaviours through risk management approaches such as referring to guidelines such as DoLS and the MCA (2005). These guidelines appeared to provide staff with reassurance and justification as to how distressed behaviours should be responded to on the wards. One of the main reasons for DoLS applications within acute hospital settings is due to patients refusing care or treatment or attempting to leave the ward issue (Sangars, Taylor, & Sangars, 2014). Interestingly, however, the guidelines and protocols described in Section 1.4, which have been specifically developed to support staff in providing care to people living with dementia (NICE, 2018), were not referred to within the study. This highlights a potential barrier implementing guidelines and frameworks with staff working in busy, acute settings, which are considered complex and too resource heavy (Banerjee, 2009). The current study demonstrated that risk management frameworks such as DoLS can sometimes have less than positive outcomes for people living with dementia and for staff who are faced with moral and ethical dilemmas of care. Overall, there appears to be limited research into the extent of restrictive care, how it manifests, or how it should be managed within the acute hospital setting. (Featherstone, Northcott, & Bridges, 2019; Werner, Tabak, Alpert, Bergman, & Iacono, 2002).

Positively, within the current study, all staff spoke about using non-pharmacological approaches such as distraction, reminiscence and validation techniques. This was seen to improve staffs' confidence with feeling able to respond to distressed behaviour. Conversely, other studies have found fewer positive outcomes relating to non-pharmacological approaches in responding to distressed behaviours. Techniques such as repetition and containing people living with dementia to their bed, resulted in staff inadvertently responding to the person's needs in a restrictive way (Featherstone et al., 2018). This supports the literature around diagnostic overshadowing and misattributions in which staff fail to respond to, or understand, what is being communicated by the individual, and that the behaviour is attributed to dementia without considering other potential causes, such as unmet needs (Dupuis et al., 2012; Featherstone, Northcott, Harden, et al., 2019). Although concerns have been raised in relation to non-

pharmacological interventions to support distressed behaviours, the current study demonstrated that core nursing skills, such as interpersonal and communication skills, were seen to also be helpful. Evidence of treating the person living with dementia as an individual rather than a patient also demonstrated positive aspects of humanistic care.

Within the current study, expectations staff placed on themselves of how they should be able to manage distressed behaviours often resulted in additional emotional strain. This perhaps left staff feeling less resilient if they shared this with their colleagues. Additionally, feeling judged by colleagues also appeared to determine whether staff felt able to share the load with others. Barriers within multi-disciplinary working meant that staff were less likely to ask for help if they felt unsupported or not listened to by other members of the team. Age and years of clinical experience were associated with how likely staff were to ask for support in managing distressed behaviours, with more experienced members of the team referring to more adaptive ways of coping. The literature also highlights the importance of having emotional support within the clinical environment, as well as staff feeling part of a strong and supportive team culture, and that this can help staff manage the emotional aspect of work (Kinman & Leggetter, 2016). This questions what support should be provided in these situations, particularly if less experienced staff do not feel able to do this due to a perceived fear or threat of being judged by others.

Within this theme an important point was raised about staff managing the emotional impact of the work by hiding their distress from colleagues. The study has demonstrated that the emotional impacts of this work is recognised but is also unspoken about. This is important in relation to working with people who are distressed as it raises the question as to whether enough support, or indeed whether staff feel able to access support, is being offered in the workplace to support them with difficult work. Staff have revealed a problem that the difficulties they face at work are being discussed at home rather than at work meaning that colleagues and managers may be partly unaware of the emotional load being

placed on staff by this work. Furthermore, taking the emotional load home was not only shared with junior members of staff but with senior members too who have significant experience of working in dementia care. These findings highlight two potential problems; (1) managers may not appreciate the extent of the difficulties staff are experiencing, and, (2) individual staff are not fully aware that they are not the only one finding this work difficult. This suggests that current approaches to dementia training in acute hospitals are not dealing adequately with how to work with people who are distressed or support for those undertaking this work. Evidently, this has implications for people living with dementia, as well as staff, and suggests that hospitals need to focus more on how to support both groups.

4.6 Strengths and Limitations

4.6.1 Strengths.

4.6.1.1 Analysis and credibility checks.

Particular strengths to this research study include the in-depth analysis which helped understand staff experiences of providing care to people living with dementia in an acute hospital setting. Furthermore, credibility checks also enhanced the quality and validity of analysis. Quality checks were not only completed by myself but also with my research supervisors who are experienced qualitative researchers. My research supervisors offered checks through the discussion of anonymized transcripts and emerging themes and offered alternative perspectives on emerging themes. This, along with the 'Researcher Reflexivity' section (Section 2.13 and 2.14), provides transparency to readers.

4.6.1.2 Adding to the literature.

There are very few studies which have qualitatively explored staff experiences of providing care to people living with dementia who become distressed within an acute hospital setting. The study therefore adds to the literature surrounding how staff understand, respond and manage distressed behaviours. For example, an interesting finding was ward staff choosing to hide the emotional aspect of supporting distressed people from colleagues and either taking this emotional load home to share with family or hiding their emotions from colleagues whilst on shift. The current study also adds to the wider literature relating to an individual's

personal characteristics, such as gender and physical size, and the way in which distressed behaviours are understood and responded to by staff.

The study also helped to explain why psychologist recommended approaches to dealing with distressed behaviour, such as the completion of 'ABC' charts, are not always followed by staff. The complexity of the approaches described in Section 1.3.5 may limit the application and feasibility within an acute hospital setting. Further, the study demonstrated that staff appear to implement a humanistic approach in understanding and responding to distress which saw staff treat the person as an individual, rather than a patient. The study found that these approaches appeared to be underpinned by more simplistic psychological models such as the 'ABC' model and the 'Unmet Needs Model'.

4.6.1.3 Research question.

A further strength of the research is the approach of the research question in itself. This study not only focused on the difficulties staff face in providing care to people living with dementia, but it also gave staff members a voice to talk about positive examples of nursing care. Further, a qualitative approach not only gave a voice to staff but also provided insight and understanding of their own personal experiences of providing care to people living with dementia. The interviews were also completed within a 'real-world setting'. This increases the relevance of the findings to routine clinical practice and to the patients typically seen in an acute care of older people's hospital setting. Additionally, the study has answered the overall aims to the project and implemented a feasible and flexible methodological design.

4.6.2 Limitations.

It is also important to consider the methodological limitations to this study.

4.6.2.1 Recruitment and sampling.

Participants were recruited through a single NHS site. As such, this may have limited the sample of participants who took part in the study. Further, staff experiences may have differed had participants been involved from other NHS

sites. This is particularly important to note as the current study was completed within a dementia-friendly ward environment and therefore staff experiences in other settings are likely to be different. The recruitment process involved a senior member of staff identifying participants who they thought would be suitable to take part in the study. This may have biased who was invited to take part; however, this was largely determined by what shifts staff were working, the availability of staff on the day of the interview, and what days interviews could be completed. It is also possible that the sample in the current study included individuals who were more open to discussing their experiences. It is therefore possible that this may have excluded individuals who may have had a different experience to those in the current sample. Additionally, using the same group of ward staff on two care of older people's wards meant that some of the experiences staff spoke about were similar in nature. For example, two staff members provided the same example of a male patient absconding from the ward and two liaison members of staff provided the same example of using a miner's box to reduce distress by means of distraction for the person living with dementia. In addition, it is not possible to generalize these findings to other ward staff working on non-specific care of older people's wards. The interviews within the current study were limited to around 45 minutes to accommodate busy clinical staff; therefore, longer interviews would have allowed for issues to be explored in greater depth. Lastly, it was recognised that during the first part of recruitment that the sample involved clinical ward staff. As the research study was looking at staff experiences of providing care to people living with dementia, it felt that it would be important to also recruit non-clinical members of staff into the study.

Without question, the ethnic diversity in the sample is limited. The results therefore are more likely to reflect the experiences of specific cultural and ethnic demographics, for example, those of a White British origin. In addition, only one male was recruited into the study and so the findings may be more heavily weighted to reflect female staff experiences of providing care to people living with dementia. Further research gathering a more varied sample may therefore be valuable.

4.6.2.2 Data quality.

Data quality could have been improved through a feedback session with participants to ensure that the themes developed resonated with their experiences, to increase the validity of the current findings. However, this was not possible due to staff availability, as well as the time restrictions with completing a DCLin thesis.

4.6.2.3 Researcher bias.

Although steps were taken to reduce researcher bias, for example, stating my position in regard to TA, completing quality checks as recommended by Elliott et al., (1999) and completing a reflective journal, it is important to note that researcher bias can never be fully eliminated. My professional background as a PICT provided many strengths during the interview process, such as building rapport quickly, as did having previous experience of working in a HCA role prior to starting clinical training; however, these experiences also influenced the way in which I responded to participants and the way in which my questions were phrased. At the beginning of the interview process, my research supervisors brought these tendencies into my awareness during supervision meetings. I subsequently made a conscious effort to maintain my role of a researcher by adapting the language I used during interviews and being mindful to resist the urge to offer interpretation of my participant experiences as I would clinically.

4.7 Clinical Implications

The current findings have important implications for how staff can be supported in the face of increasing demands and the emotional and physical challenges of providing care to people living with dementia who become distressed during an acute hospital admission.

4.7.1 Continuity of care.

The current study has demonstrated the importance of continuity of care when responding to distressed behaviours in people living with dementia. The implications of multiple people being involved in enhanced care bays has been highlighted. This raises the question as to how continuity of care might be

enhanced across changing staff, particularly within enhanced bays. Effective communication is an important feature of continuity of care. Strategies such as daily goal sheets and bedside whiteboards ensures that staff have access to, and can share information, about the same patients. Daily goal sheets have also allowed staff to exchange ideas and information about the patient. This fosters a collaborative working environment among other healthcare professionals and has shown to be effective for professionals working within intensive care settings (Wang, Wan, Lin, Zhou, & Shang, 2018). Within an acute hospital setting, brief handovers or documenting what works when people living with dementia become distressed would provide a consistent response for people living with dementia. Similarly, asking family members what helps when their relative is distressed could also be helpful. Additionally, skills-based training has been shown to develop and improve trust within a team (NHS England, 2019; Weller, Boyd, & Cumin, 2014). This is particularly relevant to the current study when feeling judged by others stopped staff from asking for support in managing distressed behaviours.

4.7.2 Presence on wards.

The current study found that ward staff were more likely to approach the dementia support team compared to other professionals such as psychiatry and clinical psychology, for support with managing distressed behaviours on the ward. This could be due to the presence and visibility the dementia support team have and that their job role is perceived as more similar to nurses than that of psychiatry or psychology. Further, the current study also found several examples in which the dementia support team would actively help staff with daily routine tasks (such as personal care) and would model how to respond to, and manage, distressed behaviours in people living with dementia. This therefore demonstrates the importance of adapting models to fit with the way of working within an acute hospital setting which is helpful for both patients and staff.

4.7.3 Staff well-being, support and training.

The results of the research will be fed back to senior management within the hospital to consider how it might inform the support which is provided to ward staff. The emotional load associated with supporting distressed people suggests

that more support for staff doing this work is required (possibly in the form of a reflective practice group or a drop-in forum for staff). One of the main barriers to offering this type of support relates to staffing levels so this would need to be offered in a flexible way, with support from senior management. This type of set-up may increase staff confidence and competence, which was found in the current study to be an issue in responding to distressed behaviours. Further, a group setting has the potential to promote thought and problem-solving regarding clinical dilemmas which, again, were described throughout the interviews.

Additionally, ensuring the dementia training provided by the organisation continues to raise staff awareness over the challenges of supporting distressed behaviour. There were examples within the current study which showed that sometimes staff attribute distressed behaviours to a person's dementia, which prevents thinking around what in the ward social environment might be contributing to their distress. Drawing on models such as those alluded to within the study, such as the 'Unmet Needs Model', may help staff's recognition and understanding of distress. Further, "distressed behaviours" is a term that already has causal assumptions built into it and is likely to influence how staff respond to people living with dementia who become distressed. It is therefore important that training provided by the organisation makes staff aware of the distinctions associated with distressed behaviours so that staff can respond sensitively to their needs.

Another implication from the current study relates to the support which is available to staff when things do not go so well on a shift. The study has highlighted a need to help staff deal with feelings of grief and failure, particularly as staff were seen to hide the emotional aspect of the job from their colleagues and would take the load home to share with relatives. Education and training to increase knowledge and skills in this area may be helpful, with a particular focus on the development of adaptive coping mechanisms, such as sharing both positive and negative experiences with colleagues at the end of a shift and developing self-care skills.

Further, making managers aware their staff may have hidden support needs when working with people who are distressed would be helpful.

4.7.4 Maintaining positive experiences of care.

The study demonstrated that overcoming the considerable challenges to this work is a positive and rewarding experience for staff. Increased attunement with the person living with dementia leads to improved confidence and feeling connected with an individual. Positive nursing experiences can be maintained so long as staff have the support from management which allows them to build on their knowledge and skills. This has implications for clinical practice as positive examples of nursing care are key to improving experiences for staff and for people living with dementia. Further, it has the potential to reduce staff burnout and may in turn, improve outcomes for people living with dementia

4.8 Future Research

The current study looked at staff experiences of providing care to people living with dementia within an acute hospital setting. Whilst the study provides valuable insight into what it is like for staff, the study findings may not be generalisable to the wider nursing population. For example, staff working on other wards or in other hospitals may have less experience of working with people living with dementia, they may have limited access to external support, such as the dementia support team, and wards may not have enhanced care bays; therefore, future research may wish to use a larger, more diverse sample with a focus on wards which are not specifically dementia-friendly. Lastly, whilst staff experiences are an important area to research in terms of understanding staff well-being and burnout, completing ward observations, as well as interviews with people living with dementia and their relatives would add further depth and insights to future research. Whilst this was outside the scope of the current study, it would make a very valuable contribution to the literature.

4.9 Conclusion

The current study provides some useful ways of understanding and guiding responses to distressed behaviour in people living with dementia in general hospitals.

The study demonstrated that rather than using psychological models to understand patient distress, staff appear to implement a humanistic approach in understanding and responding to distress. The humanistic approach used by staff appears to be underpinned by the psychological models of distressed behaviours, such as the 'Unmet Needs Model' or the 'ABC' of distressed behaviour, albeit these models are used flexibly and not always intentionally. Additionally, the complexity of such frameworks largely determines the feasibility of recording charts being completed within a busy, acute ward setting.

The study demonstrated that the full extent of difficulties staff face in responding to distressed behaviours may be hidden from their employer, and that more and possibly different types of support need to be provided by acute hospitals to support their staff with this challenging work.

Further, the organisational structure appears to constrain staff in responding to distressed behaviours. There was also evidence to suggest that the organisation can sometimes fail to recognise the emotional impacts this has for staff and for people living with dementia.

The study has highlighted how personal characteristics of the person living with dementia can influence the way in which distressed behaviours are understood and responded to. In some examples, staff were noted to anticipate more physical signs of distress in men with dementia and to interpret their expressions of distress as more threatening, with women perceived as easier to care for. How these behaviours were interpreted was important; whether distressed behaviours were interpreted as threatening to others or not influenced the way in which staff responded to distress.

Models of diagnostic overshadowing have been useful to consider within the current study. The study highlighted that in some cases staff fail to respond to, or understand, what is being communicated by people living with dementia when they exhibit distress, with some distressed behaviour automatically attributed to dementia without considering other potential causes, such as unmet needs.

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APPENDIX

APPENDIX A – STUDY INFORMATION POSTER



INFORMATION POSTER

Study Title

Staff experiences of caring for people with dementia who are distressed

I would like to let you know about a research project that will be taking place on your ward.

Why is the research taking place?

The aim of the research is to understand how hospital staff care for people with dementia who become distressed or agitated (for example, by crying out, wandering, refusing care). I would like to understand what works well, and how staff could be supported to help care for people who become distressed.

What will happen?

I would like to talk to nursing staff and healthcare assistants about their experiences of caring for people with dementia who become distressed or agitated. I would do this in an interview at a time and place to suit you.

When will I be visiting the ward?

I will be visiting the ward over the next few weeks to explain the study to staff. I will be very happy to answer any questions you may have.

In the meantime, if you have any questions or concerns, please feel free to get in touch. I can be contacted on umrc@leeds.ac.uk.

Thank you in advance for your help with the project and I look forward to meeting you soon.

Rachel Crane
Researcher and Trainee Clinical Psychologist



Ethical approval has been sought from the School of Medicine Research Ethics Committee (SoMREC project number 18-052 and HRA Approval (IRAS Project ID 26165) on 04.07.2019

APPENDIX B – PATIENT INFORMATION LEAFLET (PIS)



PARTICIPANT INFORMATION SHEET

I am a Trainee Clinical Psychologist at the University of Leeds and I am working on a research project for the Doctorate in Clinical Psychology course. My research project has been approved by the University of Leeds, School of Medicine Research Ethics Committee. I am inviting you to take part in my research project; however, before you decide, it is important for you to understand why the research is being done and what it will involve. Please read and consider the following information, and discuss it with others if you wish, before deciding whether to take part.

Study Title

Staff experiences of caring for people with dementia who are distressed

What is the research about?

The aim of the research is to understand how hospital staff care for people with dementia who become distressed or agitated (for example, by crying out, wandering or refusing care). I am particularly interested to understand what works well and how nurses could be supported to care for people who are distressed.

Why have I been chosen?

You are being asked to take part because you have experience of caring for people with dementia. I am interested in hearing about your experiences of caring for people with dementia who are distressed, what works well and any ways in which you think care could be improved.

What's involved?

If you decide to take part, I would like to meet with you to complete an interview. The interview will involve talking about your experience of caring for people with dementia who are distressed and would last between 30-45 minutes. If at any point during the interview you would like to stop, this is okay. We can discuss whether you would like to continue or arrange another time to complete the remainder of the interview.

Do I have to take part?

No. Taking part is entirely voluntary. You can decide not to take part without giving a reason. If you decide to take part but change your mind after the interview, your information can be withdrawn from the study (within one week) after the interview has been completed. Once data analysis has begun, it will not be possible to withdraw from the interview. You can withdraw from the interview by contacting Rachel Crane, Trainee Clinical Psychologist, Clinical Psychology Training Programme, University of Leeds (umrc@leeds.ac.uk).

What will happen with my information?

Your recorded interview and contact details will be kept safe. Recorded interviews will be stored in a locked filing cabinet or on a password protected computer network. Your

contact details will be kept in case I need to contact you at a later date to clarify anything following your interview, and in order to send out a summary of the findings at the end of the study.

The anonymous research data will be kept for 3 years to help with future research planning. The research findings will be written up into a report and a research thesis. If you agree, some of the things that you tell me could be quoted anonymously in these reports. If you wish, I can send you a copy of the research findings.

Will taking part be kept confidential?

I will be the only researcher that will know who took part in the study. I will share the anonymised research data with my two research supervisors. I could also be asked to show the research data to authorised people from regulatory bodies. They will only look at the data to check that the study is being carried out properly. Should any concerns (e.g. patient safety concerns), be disclosed during the interview, I have a duty of care to inform the necessary person or team. Where there is a legal issue (e.g. reporting of abuse), confidentiality cannot be maintained.

What are the benefits and disadvantages of taking part?

There are not any immediate benefits for taking part in the research study; however, taking part in the study will provide more information about how nursing staff can be better supported in the future. There are unlikely to be any disadvantages to taking part.

Who has given permission for the research?

The details of the research have been checked and approved by University of Leeds, School of Medicine Research Ethics Committee. The Trust you are employed with has agreed that the research can take place on the ward.

What happens to my information?

The University of Leeds is the sponsor for this study based in the UK. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Leeds will keep identifiable information about you for 3 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf>.

The Mid Yorkshire Hospitals NHS Trust will collect information from you for this research study in accordance with our instructions.

R Crane Participant Information Sheet V4.0 04.07.2019

APPENDIX C – CONSENT TO CONTACT FORM



CONSENT TO CONTACT FORM

Study title
Staff experiences of caring for people with dementia who are distressed

I consent to Rachel Crane, Researcher and Trainee Clinical Psychologist, to contact me at a later date to discuss the research study in more detail (please tick)

I WOULD PREFER TO BE: (please tick)

1. Contacted by telephone

I am happy for a voicemail to be left on the telephone number provided

The best telephone number to contact me on is: _____

The best time to contact me is: _____

OR

2. I would prefer to be contacted via the ward telephone number

OR

3. I would prefer to be contacted by email

My email address is: _____

Name of Participant

Date

Signature

Contact Details

Rachel Crane | Researcher and Trainee Clinical Psychologist
umrc@leeds.ac.uk | 07470 110199
Clinical Psychology Training Programme | Leeds Institute of Health Sciences
Level 10 Worsley Building | Clarendon Way | University of Leeds | Leeds | LS2 9NL

APPENDIX D – TOPIC GUIDE

Interview Topic Guide

Notes

- **Intro:** What I am interested in talking to you about is how you respond to people with dementia. I am interested in your personal experiences of how you manage distressed behaviours (e.g. crying, refusal meds/ p.c.). I would like to ask you about a couple of cases.

1. First, I'd like you to talk me through one which was positive

- What happened
- What was it like for you/patient (at time/after)
- What was going on for patient/how did it feel?

2. Any other times this didn't go so well?

- Why was this a problem
- What was happening before, during, after/ outcome
- Did anything work well
- What was going on for patient/ how did you feel

3. Now I'd like to find out if there is any other support available?

- Psychiatry, psychology, training
- What does support look like

4. Ideal world

- What would lessen the challenge
- What would you like to be different, for who?
- Why hasn't this happened?

5. Anything else?

APPENDIX E – ETHICAL APPROVAL

The Secretariat
University of Leeds
Leeds, LS2 9JT
Tel: 0113 3431642
Email: FMHUniEthics@leeds.ac.uk



Rachel Crane
Doctorate in Clinical Psychology Training Programme
Leeds Institute of Health Sciences
University of Leeds
Clarendon Way
LEEDS LS2 9NL

23 May 2019

Dear Rachel

Ref no: MREC 18-052
Study Title: Staff experiences of caring for people with dementia

Thank you for submitting your documentation for the above project. Following review by the School of Medicine Research Ethics Committee (SoMREC) I can confirm a conditional favourable ethical opinion based on the documentation received at date of this letter and subject to the following conditions which must be fulfilled prior to the study commencing:

1. The Research Participant Privacy Notice text and link should be added to the Participant Information Sheet – see the template at http://ris.leeds.ac.uk/downloads/download/212/preparing_your_participant_information_sheet
2. A Data Processing Agreement must be in place and submitted if an external transcription company is to be used to comply with GDPR requirements – see <https://dataprotection.leeds.ac.uk/data-protection-and-personal-data/>
3. Evidence of HRA approval should be submitted once this is available

The study documentation must be amended as required to meet the above conditions and submitted for file and possible future audit. Once you have addressed the conditions and submitted for file/future audit, you may commence the study and further confirmation of approval is not provided.

Please note, failure to comply with the above conditions will be considered a breach of ethics approval and may result in disciplinary action.

| Document Received | Version | Date Received |
|---|---------|---------------|
| IRASRCrane_V2 | 2.0 | 03/05/2019 |
| Consent Form_V2 | 2.0 | 03/05/2019 |
| Consent to Contact_V2 | 2.0 | 03/05/2019 |
| Participant Information Sheet_V2 | 2.0 | 03/05/2019 |
| Risk Assessment_V1 | 1.0 | 15/03/2019 |
| Confidentiality Statement for Transcribers_V1 | 1.0 | 15/03/2019 |
| Study Information Poster_V1 | 1.0 | 15/03/2019 |
| Topic Guide_V1 | 1.0 | 15/03/2019 |

Please notify the committee if you intend to make any amendments to the original research as submitted at date of this approval. This includes recruitment methodology and all changes must be ethically approved prior to implementation. Please contact the Faculty Research Ethics Administrator for further information FMHUniEthics@leeds.ac.uk

Ethical approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The SoMREC takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, and may be subject to an audit inspection. If your project is to be audited, you will be given at least 2 weeks notice.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

The committee wishes you every success with your project.

Yours sincerely

Dr Naomi Quinton
Co-Chair, School of Medicine Research Ethics Committee

APPENDIX F – HRA APPROVAL



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



Miss Rachel Crane
Psychologist in Clinical Training
Leeds Teaching Hospitals NHS Trust
Clinical Psychology Training Programme
Leeds Institute of Health Sciences, University of Leeds,
Level 10 Worsley Building,
Clarendon Way, Leeds
LS2 9NL

Email: hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

04 July 2019

Dear Miss Crane

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

| | |
|-------------------------|---|
| Study title: | Staff experiences of caring for people with dementia who are distressed. |
| IRAS project ID: | 261651 |
| Protocol number: | N/A |
| REC reference: | 19/HRA/3700 |
| Sponsor | University of Leeds |

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, [in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.](#)

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The attached document *"After HRA Approval – guidance for sponsors and investigators"* gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **261651**. Please quote this on all correspondence.

Yours sincerely,
Lucy Roberts

Approvals Specialist

Email: hra.approval@nhs.net

Copy to: NHS Research Ethics Officer

APPENDIX H - CONFIDENTIALITY STATEMENT FOR TRANSCRIBERS



Confidentiality Statement for Transcribers - Leeds Institute of Health Sciences

As a transcriber you are required to adhere to the ethical principles outlined in the research project. You will have access to material obtained from research participants and must ensure you maintain the confidentiality of information obtained from participants at all times. In concordance with ethical guidelines, LHS requires that you sign this Confidentiality Statement for every project in which you act as transcriber.

General

1. I am up-to-date with the appropriate university data protection training and confirm I have reviewed all of the information available here: https://www.leeds.ac.uk/secretariat/data_protection.html and have undertaken the training outlined therein.
2. I am aware of the requirements of the GDPR.
3. I understand that the material I am transcribing is confidential.
4. The material transcribed will be discussed with no-one¹.
5. The identity of research participants will not be divulged.

Transcription procedure

1. Transcription will be conducted in such a way that the confidentiality of the material is maintained at all times.
2. *Either* The researcher will give me the link to a folder containing the audio-recordings on the ~~Network~~, which they have arranged for me to have access to². I will work directly from this folder, either from my University of Leeds computer or via Desktop Anywhere.
Or The researcher will provide me with the audio-recordings on an encrypted USB. I will work directly from the USB, returning the USB to researcher at the earliest opportunity on completion of the transcription.
3. I will ensure that audio-recordings cannot be overheard and that transcripts, or parts of transcripts, are not read by people without official right of access.
4. No copies will be made of any materials relating to transcription.

Signed

Date 10-09-2019

Print name DENISE WOMERSLEY

Researcher RACHEL CRANE

Project title STAFF EXPERIENCES OF CARING FOR PEOPLE WITH DEMENTIA WHO ARE DISTRESSED

¹ Very occasionally audio recordings may contain distressing content, in these rare cases the researcher should flag up the possibility with you beforehand. Please contact the researcher to arrange a debriefing with them if you have found any aspect of the material distressing.

² The researcher should contact ISS to arrange for the relevant ~~Network~~ folder to have access restricted to themselves and the transcriber. The folder should only be used for materials relating to transcription, other project materials should be kept in a different folder.