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Doctoral Thesis:

Caring for patients with dementia in a general hospital setting

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Literature Review	8,000	8,025	16,025
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Critical Appraisal	3,976	1,163	5,139
Ethics Section	6,614	-	6,614
Total	26,857	17,026	43,883

Thesis Abstract

This thesis is divided into three sections. Section one, the literature review, considers the experiences of general hospital staff caring for patients with dementia. 14 papers were included in the meta-synthesis. Five key themes were constructed from the analysis: the unknown and undesirable; constraints of the environmental and organisational context; emphasising the physical health of patients; recognising the benefits of person-centred care; and identifying the need for training. The synthesis identified how a lack of knowledge of dementia, particularly regarding behaviours that are considered challenging, can contribute to low staff confidence and negativity towards these patients. This, along with organisational constraints, can impact on ability to provide person-centred care. The benefits of dementia training have been recognised. Clinical and research implications of the findings are discussed.

Section two, the empirical paper, considered the experiences of staff within general hospitals regarding the use of truth and deception when caring for patients with dementia. In particular, it explored their decision making processes when choosing whether to tell the truth or to deceive. A grounded theory methodology was used to construct a theoretical model of this process. The analysis identified how 'triggers' set in motion the need for a response. Various 'mediating factors' (including a lack of communication, the individual's interpretation of their role and responsibility, and their ethical framework) influenced how staff chose to 'respond' to those triggers. Again, clinical and research implications have been recognised.

Section three, the critical appraisal, offers a reflective account of the research journey. These reflections are organised into six categories that consider the researcher's own decision-making processes when carrying out the empirical paper.

Declaration

This thesis records work undertaken for the Doctorate in Clinical Psychology at Lancaster University's Faculty of Health and Medicine from June 2013 to September 2014.

The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Alex Turner

1st September 2014

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I would firstly like to thank the 12 individuals who very kindly, honestly and generously shared their experiences of using truth and deception when caring for patients with dementia. For their time and commitment to this research I am deeply grateful.

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Section One: Literature Review

**The experience of caring for patients with dementia within a general hospital setting: A
meta-synthesis**

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Prepared for submission to Aging & Mental Health (see Appendix A for author guidelines).

Abstract

Objectives: The experiences of staff caring for persons with dementia in long-term residential care settings are well documented. However, more recently, qualitative studies have begun to consider staff caring for patients with dementia in general hospitals. This review aimed to synthesise the findings from these studies, to develop our knowledge of how general hospital staff experience caring for patients with dementia.

Method: A systematic search of the literature was conducted, and inclusion/exclusion criteria applied. A total of 14 qualitative papers were included within the meta-synthesis, which utilised a meta-ethnographic approach (Noblit & Hare, 1988).

Results: Five key themes were constructed from the analysis: the unknown and undesirable; constraints of the environmental and organisational context; emphasising the physical health of patients; recognising the benefits of person-centred care; and identifying the need for training. These themes explored the challenges associated with caring for this group of patients, as well as suggestions to improve staff experiences and patient care.

Conclusion: In considering the experience of general hospital staff, the synthesis has identified a lack of knowledge and understanding of dementia, particularly with regard to communication and managing behaviours that are considered challenging. This, along with organisational constraints, can contribute to low staff confidence, negative attitudes towards these patients and an inability to provide person-centred care. The benefits of dementia training have been recognised.

Introduction

Dementia in hospital settings

Dementia is an umbrella term for a range of degenerative processes known to cause a progressive decline in memory, reasoning, functional ability and communication skills (World Health Organisation [WHO], 2012). Such changes in cognitive ability may also be accompanied by changes in behaviour and personality (Stokes, 2000). Currently, it is estimated that 35.6 million people live with dementia worldwide, which generally, although not exclusively, affects older individuals (Prince et al., 2013). This number is expected to almost double in the next twenty years (Knapp, Prince, & Albanese, 2007).

Our aging population means that the number of older people being admitted into general hospitals is increasing, with older people being the primary users of healthcare services (Victor, Healy, Thomas, & Seargeant, 2000). This is likely to have implications for the number of people with dementia being cared for on general hospital wards. In the UK more than 97% of hospital staff report having cared for patients with dementia (Alzheimer's Society, 2009) and this finding appears to be indicative of such experiences worldwide (Alzheimer's Disease International, 2013). It has been suggested that older adults are admitted into hospital more frequently and for longer periods (Trueland, 2014) with over half of those patients having some form of cognitive impairment (Herman, 2010).

Among health care professionals, hospital is commonly believed to be the safest place for a person with dementia with a physical health complaint (Cunningham & Archibald, 2006). For example, it is more likely that an older person will be admitted into hospital following a fractured wrist if they have dementia, because of the perceived risks to their wellbeing (Archibald, 2003). However, risks associated with being in acute care with a co-morbid diagnosis of dementia have also been identified. Dementia has been associated with

longer hospital admissions (Bynum et al., 2004; Gutterman, Markowitz, & Lewis, 1999), loss of independence (Zekry et al., 2009) and an increase in disruptive behaviours (Kolanowski, Richards, & Sullivan, 2002). Therefore, the medical problem that initiated admission not only becomes harder to treat, but the individual may be adversely affected in other, more irreversible, ways (Chrzescijanski, Moyle, & Creedy, 2007). Governments in many countries have developed national action plans on dementia, identifying the need to improve dementia care received within general hospital settings (e.g. the National Dementia Strategy for England, 2009; Alzheimer's Australia, 2011).

Caring for persons with dementia

The challenges associated with caring for someone with dementia are well documented from the perspective of relatives (Croog, Burleson, Sudilovsky, & Baume, 2006; La Fontaine & Oyebode, 2013) and staff in long-term care settings (Brodsky, Draper, & Low, 2003; Edberg et al., 2008; Kuremyr, Kihlgren, Norberg, Astrom, & Karlsson, 1994). The majority of research looking at the experiences of families caring for a relative with dementia focus upon the emotional strain associated with this role (Bordaty & Donkin, 2009; Croog et al., 2006; La Fontaine & Oyebode, 2013). High rates of burden and psychological distress, as well as social isolation, poor physical health and financial difficulties have been identified (Brodsky & Donkin, 2009). Many of these studies discuss the need for support and psychosocial intervention for this vulnerable group of caregivers.

Caring for people with dementia professionally has been described as emotionally and physically draining (Morgan, Semchuk, Stewart, & D'Arcy, 2002), with high physical and psychological demands (Fjelltun, Henriksen, Norberg, Gilje, & Normann, 2009). Studies looking at staff experiences in long-term care settings tend to focus upon factors associated with job satisfaction and burnout. Common themes reflect challenges associated with 'the

system', with care staff feeling unable to balance competing demands while meeting the complex needs of persons with dementia (Edberg et al., 2008; Kuremyr et al., 1994). Staff often report feeling guilty for being unable to form relationships with their residents, given the varied and exhaustive demands of the job (Jenkins & Allen, 1998; Kuremyr et al., 1994). Both qualitative and quantitative studies highlight the need for further training in order to improve confidence and self-efficacy, factors suggested to impact upon performance and job satisfaction (Hughes, Bagley, Reilly, Burns, & Challis, 2008; Leung et al., 2013).

Research around the care of people with dementia from the perspectives of family members and long-term care staff has steadily developed over many years. However, it is only more recently that the experiences of professionals in general hospital settings have started to be considered, as the increasing prevalence rates of patients with dementia have been recognised. This previous lack of consideration is consistent with the lack of dementia training available for general hospital staff.

Dementia training for general hospital staff

The lack of dementia training provided to general hospital staff has been recognised within many international dementia strategies. For example, the National Dementia Strategy for England (DH, 2009) highlights "marked deficits in the knowledge and skills of general hospital staff caring for people with dementia" (p. 51). Similarly, a report for Alzheimer's Australia (2014) identified that "hospital staff often do not receive adequate training on dementia" (p. 9).

Pulsford, Hope, and Thompson (2006) completed a survey of all UK universities offering nursing degrees. They identified that adult nurse training courses provide an average of three hours teaching on dementia over three years. Some universities have no dementia provision whatsoever. The need to improve dementia education for medical students has also

been acknowledged (Hasselbalch et al., 2007; Tullo & Allan, 2011). In response to this, Health Education England (HEE) plans to review the content of pre-registration nurse and medical education to ensure all new nurses and doctors have the right skills to work with older people, with a focus on dementia (DH, 2014).

Post-qualification, training is described as “variable across different providers...because of the nature of local flexibility and decision making in developing curricula” (Doherty and Collier 2009, p. 28). Indeed, a report by the Royal College of Psychiatrists (RCP) (2013) suggests that 41% of hospitals do not include dementia awareness training in their staff inductions and training that is available is variable in content and intensity. Additionally, a recent study identified that where training was available, ward managers were largely unaware of this and reported difficulties in releasing already pressured staff (Griffiths, Knight, Harwood, & Gladman, 2014). Recognising this deficit, recent policy is being implemented to increase the amount of training received by staff caring for people with dementia (DH, 2014).

Considering the experiences of general hospital staff

Policy has recognised the need for better acknowledgement of staff perspectives in the continuing strive for high quality acute care for patients with dementia (e.g. DH, 2009; Cook, Fay, & Rockwood, 2012). The quantitative research looking into experiences of staff in hospital settings primarily focuses upon the management of aggressive behaviour, the challenge of high workloads and low staff levels, as well as the perceived need for dementia training (Bradshaw, Goldberg, Schneider, & Harwood, 2013; Gandesha, Souza, Chaplin, & Hood, 2012; Nnatu & Shah, 2009; Weiner, Tabak, Bergman, 2003). While this provides useful insights, such research is also constrained by the limitations of structured questionnaires which do not necessarily permit the exploration of participants’ views in

depth. A body of qualitative research now exists which considers staff experiences more broadly and arguably can permit greater understanding of some of the complexities of working with patients with dementia. Therefore, a thorough meta-synthesis of these studies is timely to bring together their findings and develop a greater theoretical understanding of this area.

To date, one review has considered the experiences of caring for patients with dementia in an acute setting (Doherty & Collier, 2009). However, this was an overview of the literature, rather than a true synthesis of the qualitative findings. Additionally, Doherty and Collier's (2009) review is more specifically concerned with educational issues for adult nurses. While the current lack of training is concerning, it is important to consider experiences as a whole, rather than potentially losing important insights by making the focus too specific. Finally, their review focuses upon the perspectives of nurses, rather than considering other staff groups. Given that a range of acute care professionals have direct contact with patients with dementia, where possible, it is important to consider perspectives from a range of disciplines.

Consequently, this paper seeks to explore and synthesise the literature relating to the experiences of staff caring for people with dementia in general hospital settings. Using a meta-ethnographic approach (Noblit & Hare, 1988), overarching themes will be developed and the implications of these findings for dementia care will be discussed.

Method

Various methods exist for synthesising qualitative research, all of which use existing research as their primary data (Barnett-Page & Thomas, 2009). For the current review, a meta-ethnographic approach was selected (Noblit & Hare, 1988). Meta-ethnography, unlike meta-analysis, focuses on synthesising interpretations across studies rather than aggregating the data. Following a process of induction and interpretation, this approach resembles the qualitative methods of those studies it seeks to synthesise (Britten et al., 2002). Noblit and Hare's (1988) seven step process was utilised to conduct the current meta-synthesis.

Searching for relevant studies

The search strategy augmented electronic database searches along with manual searching of references from relevant articles. Five databases (CINAHL, Embase, Medline, PsycINFO and Web of Science) were used. A Boolean search was conducted to allow the following terms to be combined:

- [dement* OR Alzheimer's disease* OR cognitive impair* OR vascular* OR confus* OR memory*]
- AND [general hospital* OR acute* OR ward* OR medical*]
- AND [staff* OR nurs* OR physician* OR practi* OR care* OR profession* OR health care*].

Given that no thorough meta-synthesis had been completed previously, date specifications were not implemented in the searches, conducted in January 2014. Five of the papers included in Doherty and Collier's (2009) review were included, along with nine additional papers which both predated and followed their review.

The following inclusion and exclusion criteria were applied. Papers were included if they (1) were written in English; (2) used qualitative methods of data collection and analysis; (3) included participants identified as a member of staff in a general hospital setting with experience of caring for patients with dementia or cognitive impairment (suspected or diagnosed). Studies were excluded if they (1) were quantitative studies with no qualitative data; (2) were not supported by raw data such as quotes, described as a fundamental selection criterion when conducting a meta-synthesis (Finfgeld, 2003); (3) were specific to palliative care and artificial feeding or hydrating; (4) were not published in a peer-reviewed journal.

Studies focussing upon palliative care or artificial feeding and hydrating were excluded as a number of research papers have been specifically dedicated to these topics. Therefore, it may be more appropriate for these papers to be considered for separate review. Within the studies included for the current synthesis, palliative care and artificial feeding or hydrating were not discussed. After the inclusion and exclusion criteria were applied, 14 papers were found suitable for meta-synthesis. To ensure transparency, the search strategy adopted has been detailed in Figure 1 (Bondas & Hall, 2007).

Figure 1 here

Findings from two papers were drawn from the same group of participants (Baille, Cox, & Merritt, 2012a; Baille, Merritt, & Cox, 2012b). However, given that the focus of each paper varied, looking at challenges (Baille et al., 2012a) and strategies (Baille et al., 2012b), both were included for review.

Quality appraisal

Including studies with flawed methodologies within a meta-synthesis may lead to an equally flawed end product (Walsh & Downe, 2006). Although some authors suggest using quality appraisal as part of their inclusion/exclusion criteria, this risks excluding relevant data (Barbour, 2001). There is also potential for confusing the “adequacy of a description of something in a report with the appropriateness of something that occurred in the study itself” (Sandelowski & Barroso, 2007, p. 136). As noted above, the only exception was to exclude studies where findings were not supported by raw data. This step was taken to ensure the interpretations presented within the meta-synthesis were as valid as possible.

The 14 papers from the 13 research studies were all published in peer reviewed journals, where quality has generally been assessed. However, a full appraisal was conducted, to allow description of the range of quality within the studies and reflect upon their contribution to the final synthesis (Atkins et al., 2008). The Critical Appraisal Skills Programme [CASP] (2013) was utilised. However, as well as referring to qualitative comments from the CASP (2013), comments were quantified to obtain an overall quality score (Duggleby et al., 2010). A strong score of ‘3’ denoted extensive justification and meeting of criteria, a moderate score of ‘2’ denoted addressing, but not elaborating on the issue, and a weak score of ‘1’ denoted a substantial lack in meeting criteria or presenting justification. For each study, comments and total scores were collated (Table 1). The papers varied in their quality with scores ranging from 15 to 27. Items such as reflexivity and ethical concerns were commonly not fully met. Additionally, although studies employed an appropriate research design, they did not always explicitly discuss their rationale for its use. While all papers were reflected in the synthesis, those that scored weakest on the CASP (2013) contributed least to the final themes.

Table 1 here

Characteristics of selected studies

Detailed descriptive, demographic and methodological data were extracted from the 14 papers, as shown in Table 2 and Table 3. Papers included data from nurses, healthcare assistants, student nurses, medical officers, managers, occupational therapists, social workers, physiotherapists, domestic staff, receptionists and doctors (job titles may differ in different countries). However, the majority came solely from the perspective of nursing staff. The number of participants ranged between 7 and 87. However, this larger number originates from a study gathering data from quantitative questionnaires as well as qualitative comments. The papers were published across a 12 year period, between 2002 and 2014. Studies selected for inclusion originated from the UK (Atkin, Holmes, & Martin, 2005; Baille, Cox, & Merritt, 2012a ; Baille, Merritt, & Cox, 2012b ; Calnan et al., 2012; Charter & Hughes, 2012; Cowdell, 2010; Fessey, 2007; Smythe et al., 2014), Ireland (Nolan, 2006; Nolan, 2007), Sweden (Eriksson & Saveman, 2002; Nilsson, Rasmussen, & Edvardsson, 2013) and Australia (Borbasi, Jones, Lockwood, & Emden, 2006; Moyle, Borbasi, Wallis, Olorenshaw, & Gracia, 2010). Most data was gathered using focus groups or semi-structured interviews. While the studies utilised a number of methodological approaches, thematic analysis accounted for the majority.

Tables 2 & 3 here

Analysis of the papers

As previously outlined, a meta-ethnographic approach was followed in order to achieve a synthesis while preserving the data within (Noblit & Hare, 1988). The seven steps described by Noblit and Hare (1988) are an iterative, rather than discrete, linear process (Pope, Mays, & Popay, 2007). They include ‘getting started’; ‘deciding what is relevant’; ‘reading the studies’; ‘determining how studies are related’; ‘translating studies into one another’; ‘synthesising translations’; and ‘expressing the synthesis’. Steps one and two were achieved through completing a thorough literature search and implementing set inclusion and exclusion criteria (as described above). With repeated reading, the original findings, including key phrases, metaphors, ideas or concepts were noted. By separating the data in this way it became easier for the author to identify relationships, similarities and differences between the studies. At this stage, an “initial assumption about the relationship between studies can be made” (Noblit & Hare, 1988, p. 28). This provided the author with the raw data to be synthesised.

Table 4 demonstrates the ideas and concepts presented by authors, which led to the key theme ‘The unknown and undesirable’. Table 5 identifies the themes from each study that contributed to the final five key synthesised themes.

Table 4 & 5 here

Studies were then translated into one another by comparing and synthesising the themes emerging in one account with those in other accounts, in a step-by-step way, keeping an open mind for new themes as they emerged. In this way, it was possible to establish relationships between the 14 papers. Translations were compared to one another and overarching themes were formulated that were able to encompass those of the initial studies

while offering a new interpretation of the findings (Sandelowski & Barroso, 2007). Finally, the synthesis was expressed in terms of the five key themes identified.

Table 6 demonstrates the studies that contributed to each of the five themes.

Table 6 here

Results

The findings of this meta-synthesis are presented in terms of the five key themes: The unknown and undesirable; constraints of the environmental and organisational context; emphasising the physical health of patients; recognising the benefits of person-centred care; and identifying the need for training.

“We just don’t know what we’re dealing with”: The unknown and undesirable

A number of studies suggested the ability of staff to identify possible dementia was inadequate in the general hospital setting (Atkin et al., 2005; Baille et al., 2012b; Borbasi et al., 2006; Moyle et al., 2010; Nilsson et al., 2013). However, reasons for this lack of recognition varied from limited knowledge and understanding of the condition (Borbasi et al., 2006) to patients’ ability to conceal their difficulties: “We’re overlooking patients with cognitive impairment because many of them are fantastic at hiding their handicap” (Nilsson et al., 2013, p. 1685).

When cognitive impairment had not been previously diagnosed but was suspected, patients were rarely exposed to appropriate assessment to confirm diagnosis or establish understanding of need (Atkin et al., 2005; Borbasi et al., 2006; Moyle et al., 2010; Nilsson et al., 2013). Assessments were likely to be made on subjective judgements rather than systematic tools. One participant in Borbasi et al.’s (2006) study indicated, “Nurses would say ‘this patient is a bit off or a bit confused’, but no one actually sat down and completed a thorough assessment to find out why” (p. 303). Again, this often related to a lack of knowledge of appropriate screening methods as well as limited tools, time training:

The root of the problem is basically our education, we don’t know enough about the condition for us to screen, identify and therefore treat, that’s our problem, resources aren’t available for us to be able to do that (Atkin et al., 2005).

Additionally, when patients were admitted with a known diagnosis, many staff felt uncertain about how to manage more challenging behaviours (Atkin et al., 2005; Baille et al., 2012a; Borbasi et al., 2006; Cowdell, 2010; Eriksson & Saveman, 2002; Smythe et al., 2014), predominantly related to communication, aggression and disorientation:

Sometimes I think, there's a confused patient, do I re-orientate them? Do I explain they're in hospital? Or do I just let them think they're in the middle of the Sahara desert? I don't know what's best...I hate that feeling of not knowing what to do (Atkin et al., 2005, p. 1082).

Participants appeared to respond to these situations differently. Some questioned their own competency, anxious about whether they were communicating and providing care in the most appropriate way (Baille et al., 2012a; Borbasi et al., 2006; Eriksson & Saveman, 2002).

Participants in Baille et al.'s study (2012a) identified that "nurses hate caring for people with dementia because they feel so out of their depth" (p. 35). Others perceived it to be less associated with their own skills, instead directing their frustrations towards the individual with dementia (Fessey, 2007; Moyle et al., 2010; Smythe et al., 2014): "I was saying the same thing over and over and I wasn't getting anywhere no matter what I did...as far as I was concerned, it was like talking to a brick wall" (Smythe et al., 2014, p. 21). Both left participants frustrated that the care they were providing was based upon "guess work" (Cowdell, 2010, p. 88).

Consequently, patients with dementia could often be perceived negatively (Baille et al., 2012a; Borbasi et al., 2006; Cowdell, 2010; Eriksson & Saveman, 2002; Smythe et al., 2014) and assigned powerful and pervasive labels, such as being deemed "difficult" (Cowdell, 2010, p. 87). It was suggested that these ideas became entrenched within ward culture and impacted upon how staff interacted with patients: "Attitude is an issue...people with dementia are treated as second class citizens" (Baille, et al., 2012a, p. 35). Additionally,

providing their care was viewed as less prestigious compared to other disciplines (Coddell, 2010; Moyle et al., 2008). Studies therefore highlighted the need to improve the perceived status of people with dementia as well as the role of their caregivers.

“I often worry about them being in this system”: Constraints of the environmental and organisational context

Participants suggested that patients with dementia were commonly admitted to hospital due to underlying social problems, without clear medical need (Borbasi et al., 2006; Eriksson & Saveman, 2002; Baille et al., 2012a). Often this was because family had become unable to cope:

Several demented people come here with no medical diagnosis but they come because their situation at home is untenable. In most cases it is the wife who cares for the demented husband and waiting time for nursing home is too long (Eriksson & Saveman, 2002, p. 82).

Similarly, patients admitted for medical reasons often remained on the ward if their presenting condition improved until appropriate community support could be put in place (Baille et al., 2012a; Borbasi et al., 2006, Eriksson & Saveman, 2002, Calnan et al., 2013). Referrals to residential care could reportedly take up to 12 weeks, making participants question whether patients with dementia were unjustifiably taking up beds (Borbasi et al., 2006).

Furthermore, the ward environment was considered inappropriate for confused individuals (Baille et al., 2012a; Borbasi et al., 2006; Eriksson & Saveman, 2002; Moyle et al., 2010; Nilsson et al., 2013; Nolan, 2007) as high levels of noise and stimulation often increased confusion and agitation: “The activity on the ward makes them more anxious, more

worked up” (Nolan, 2007, p. 420). Additionally, it was identified that “the methods by which we need to ensure patient safety often compounds the problem” (Borbasi et al., 2006, p. 302). Doors would have to be locked at all times or alternatively, ‘wandersome’ patients required “excessive and unnatural monitoring” (Moyle et al., 2010, p. 423) and were continuously being redirected to bed. Again, this was described as frustrating and time consuming for staff.

Lack of time along with inappropriate staffing levels questioned the ability of staff to provide even basic care, let alone care for more challenging patients (Baille et al., 2012a; Borbasi et al., 2006; Eriksson & Saveman, 2002; Fessey, 2007; Moyle et al., 2010; Nolan, 2006; Nolan, 2007). This was despite constant demand from the top of the organisation to “get the job done” (Nolan, 2006, p. 211):

I’ve been told ‘you don’t have time to do that’ I was like ‘I was talking to the patient while I was helping with this, trying to calm them down a bit’...there are certain managers who perceive that you don’t have time for that (Baille et al., 2012a, p. 34).

Given these added pressures, patients with dementia were often ignored as staff felt they did not have time to meet their needs adequately (Baille et al., 2012b).

I don’t feel like they were treated with dignity because of time constraints...wards are very busy environments and people with dementia can take time for you to give them care...a lot of people would become frustrated and wouldn’t bother (Baille et al., 2012a p. 34).

“You don’t die of confusion”: Emphasising the physical health of patients

A number of studies identified that patients with purely physical health needs were commonly given greater priority than those also exhibiting cognitive difficulties (Atkins et al., 2005; Baille et al., 2012a, 2012b; Borbasi et al, 2006; Calnan et al., 2012; Cowdell, 2010;

Eriksson & Saveman, 2002; Moyle et al., 2001; Nolan, 2007). Cowdell (2010) and Baille et al. (2012a; 2012b) suggested that the lack of knowledge and confidence around how to communicate with and care for those with dementia led staff to focus on other patients. Others argued that physical need was simply considered more important (Borbasi et al., 2006; Atkin et al., 2005; Moyle et al., 2001; Nolan, 2007). Caring for and managing behaviours associated with dementia were not seen as part of their role: “Patients with dementia require constant attention when we have other priorities” (Borbasi et al., 2006, p. 303).

Given this hierarchy of need, one student identified a common belief that patients with dementia should not be cared for in a general hospital setting, commenting “They [other staff] see them as a nuisance ‘why are they here’...the attitude of staff is often that these people are just in the way, so they usually get ignored and left to the end” (Baille et al., 2012a, p 35). Methods were used to try and reduce the amount of time nurses were required to spend with these patients. Students or healthcare assistants were used as “babysitters” (Moyle et al., 2010, p. 424), allowing nurses to focus on patients with a “greater priority of care” (Moyle et al., 2010, p. 424). Alternatively, disruptive patients with dementia were “put in corridors so that others could sleep” (Eriksson & Saveman, 2002, p. 82) or given high doses of sedatives to minimise their behaviours (Eriksson and Saveman, 2002). Participants expressed that patients with dementia did not receive the same quality of care for their mental or physical condition as those in need of medical care without dementia (Atkin et al., 2005).

“We don’t always see the person behind the confusion”: Recognising the benefits of person-centred care

Despite the sometimes negative attitudes towards patients with dementia, in all but one study (Smythe et al., 2014) participants acknowledged the importance of providing person-centred care and recognising the individual rather than simply their dementia: “It’s

alright having the medical info, but...people deserve more than that. They're real people...you know, they've got a personality" (Charter & Hughes, 2012, p. 584).

Important in providing individualised care was building a good relationship with patients (Baille et al., 2012b; Borbasi et al., 2006; Nilsson et al., 2013; Nolan, 2006; Nolan, 2007): "You have to build up a kind of friendship...trust...the confused patient needs trust as much as anyone else" (Nolan, 2006, p. 211). Promoting this relationship was suggested to make a "real difference to patient well-being" (Borbasi et al., 2006, p. 304). However, only one student in all 14 papers gave a specific example of relationship building, explaining "When I give personal care I tend to ask the patient about their life, what they did when they were younger etc." (Baille et al., 2012b, p. 23). More common were discussions regarding the barriers to building relationships. It was recognised that establishing a bond took time and "authenticity" on the part of the staff member (Nolan, 2006). However, a pervasive narrative running through all studies was that time was limited and communication was considered difficult.

Team reflection was considered a useful way of sharing ideas about how best to care for patients, as well as documenting relevant information (Baille et al., 2012b; Borbasi et al., 2006; Charter & Hughes, 2012; Eriksson & Saveman, 2002). This was because "everyone's had experiences with the same patient and some people have built up a relationship with them...is that something other people can learn from?" (Charter & Hughes, 2012, p. 586). It was also considered important to maintain a person's independence (Baille et al., 2012a; Baille et al., 2012b; Fessey, 2007; Nolan, 2006). Examples included encouraging patients to complete their own activities of daily living and giving patients a role on the ward e.g. folding laundry.

I've got an extra half hour here... I wonder whether they'd have a bath today or who'd like to go out as it's a sunny day... people don't think like that because it's a one off and it's too depressing because they realise they can't achieve that on a daily basis... it's like a defence against that (Calnan et al., 2013, p. 474).

As the quote suggests however, time pressures again made it difficult to regularly engage with patients. Therefore, staff preferred to avoid these additional aspects of care rather than be unable to maintain them.

***“I could never say I know what I'm doing”*: Identifying the need for training**

Given over-arching feelings of uncertainty and sometimes reluctance to care for patients with dementia, all studies highlighted a need for better education and training. While only two papers (Baille et al., 2012a; Baille et al., 2012b) discussed this need prior to qualification, most wanted training once in post. It was identified that this should be delivered to all members of staff “because everyone interacts with them” (Charter & Hughes, 2012, p. 587). In fact, nursing assistants who arguably provide the greatest amount of direct care felt they had the least preparation “I mean as much as I love my job... I could never say I know what I'm doing” (Smythe et al., 2014 p. 20). Despite this resounding need, in-service training appeared to be infrequent and often considered inappropriate.

The most common criticism of limited training was that it relied too much on theoretical principles that did not always transfer to a ward environment (Charter & Hughes, 2012; Borbasi et al., 2006; Cowdell, 2010): “It's just slide after slide... somebody talking away and you switch off... when there's stuff to act out, that's the way I learn best” (Charter & Hughes, 2012, p. 583). A difficulty applying theoretical principals to an acute environment was again linked to a shortage of time and resources: “It's all good and well when you're

sitting in a class room, but when you're actually putting it into practice, you don't have a lot of time, you know, or the staff" (Smythe et al., 2014, p. 21).

Participants suggested various methods that might assist their understanding of dementia. It was considered that learning from and reflecting with colleagues would provide support and might facilitate techniques that had proved successful with certain patients (Charter & Hughes, 2012). Additionally, observation of those with more experience was commonly requested. One participant commented "How do you teach for dementia? The range is so huge...you need to observe someone doing it" (Smythe et al., 2014, p. 21). Alternatively, meeting people in the early stages of dementia, not experiencing acute medical illness, might help staff understand the effects of the condition and better relate to the patients for whom they cared: "To speak to someone with early onset dementia, that would be really good training, for them to explain how they sometimes feel" (Charter & Hughes, 2012, p. 584).

Staff members who had received training with both a theoretical and psychosocial element were often pleased with the confidence it had given and the increased understanding it provided: "I think it gave me more patience, more confidence in how to talk to them and more understanding that they don't always mean to do things that they do" (Smythe et al., 2014, p. 23).

Discussion

In the continuing strive for high quality hospital care, the need for a better understanding of how staff experience caring for patients with dementia within general hospital settings has been recognised (e.g. DH, 2009; Cook, Fay, & Rockwood, 2012). Synthesising the research to date has helped to strengthen our knowledge of this issue. The present analysis identified five key themes each of which was contributed to by at least eight of the papers, indicating that all provided beneficial insights to the focus of the review. None of the themes relied solely on lower quality papers, thus giving confidence in the strength of each. While the majority of studies focussed upon the challenges associated with caring for patients with dementia, there were also optimistic findings indicating a desire for the care for this group of patients to improve.

Staff attitudes towards patients with dementia

A key theme reflected within many of the studies was the lack of knowledge staff felt they had, both in terms of communication with patients with dementia and management of the challenging behaviours they can display. The lack of knowledge was generally associated with limited training and resources. This reflects concerns raised in previous research literature and policy (DH, 2009; Doherty & Collier, 2009; Holmes, Bentley, & Cameron, 2003) adding to the argument that general hospital staff are currently ill-prepared to care for this group of patients. As articulated by a participant in Cowdell's (2010) study, much of the care provided is currently based upon "guess work" (p. 88).

Beliefs about challenging behaviours were identified within this synthesis as important in determining staff attitudes towards patients with dementia. In some studies, the difficulties associated with managing challenging behaviour and communication encouraged staff to question their own skills and competence as care providers. However, despite

attributing these difficulties to their own perceived short-comings, it could still result in negative feelings towards these patients. Consistent with this, Zimmerman et al. (2005) suggested a link between perceived competence and attitudes towards dementia, with level of knowledge arguably linked to that competence (Hughes, Bagley, Reilly, Burns, & Challis, 2008). If staff felt insecure about their own abilities, this may contribute to the negative labels commonly assigned to patients with dementia.

In contrast, other staff members attributed the challenges and frustrations associated with caring as being the “fault” (Smythe, 2014, p. 23) of the person with dementia. Again, the examples given were often related to the frustrations of communicating with those who were unable to understand or provide information. While this idea was less prominent and generally came from studies of lower quality, it raises important considerations regarding how challenging behaviours are perceived. Research in the field of learning disabilities has shown significant correlations between perceived responsibility for ‘challenging behaviour’ and the responses of those providing care (Dagnan & Cairns, 2005; Stanley & Standen, 2000). Similarly, attributional theory predicts that ‘helping behaviour’ is less likely to occur if cause is attributed to the person being helped (Weiner, 1985). These findings appear to fit with the experiences of staff in acute settings. Interestingly, Smythe et al. (2014) identified that attributions of responsibility were minimised following dementia training. This suggests that blaming the person with dementia for their behaviour may again be associated with a lack of knowledge about the condition.

Two papers focussing upon the experiences of student nurses, identified how negative attitudes could become entrenched within ward culture and impact upon the care patients received (Baille et al., 2012a; 2012b). These perspectives may not have been captured by incorporating studies solely interviewing permanent members of staff. While these papers drew upon the same sample of participants, both were high quality and experiences are likely

to have come from varied placements. This suggests that the findings are representative of a number of wards caring for patients with dementia.

Hierarchy of care

In particular, students identified the tendency amongst staff to consider those with dementia as lower priority. Instead, attention was often directed to patients with more clearly identifiable physical health needs. Emphasising physical health, a domain in which staff felt confident and competent (Cowdell, 2010; Baille et al., 2012a), may be a way of compensating for a lack of knowledge of dementia and maintaining identity as a skilled professional. This may account for why students and health care assistants were utilised as “babysitters” for these “low priority” patients. Of note, it appears paradoxical that despite highlighting a lack of training as contributing to the challenge of caring for patients with dementia, their care was often passed to those with arguably less knowledge and experience.

Alternatively, this finding may corroborate previous suggestions that dementia care is often perceived as less prestigious than other disciplines (Ashburner et al., 2004; Health Advisory Service, 2000; Parsons, 1951). The Parsonian model (1951) identifies that health professionals have an obligation to bring individuals out of the ‘sick role’ so that they can maintain their social responsibilities within society. However, caring for those with long-term conditions threatens these obligations, as the patient’s health may not be expected to improve. Therefore, the usually privileged position of the health professional is considered less esteemed. By focussing upon what were considered the more skilled aspects of their role, staff may have felt able to escape the negative associations of caring for patients with dementia.

Constraints of the organisational and environmental context

Participants also suggested that the organisational and environmental constraints of the ward setting made it unsuitable for patients with dementia. The review raised particular concerns regarding the inappropriate use of beds, associated with unnecessary admissions as well as delayed discharges (Baille et al., 2012a; Borbasi et al., 2006, Eriksson & Saveman, 2002, Calnan et al., 2013). Consequently, participants considered themselves to be caring for patients with dementia because of a social, rather than medical, need when community support was not available. This perceived “bed-blocking” and belief that their medical skills were not being effectively utilised, may add to the negative attributions placed upon these patients.

Additionally, high levels of noise and stimulation were suggested to increase agitation and many ‘wandersome’ patients attempted to leave the ward un-supervised. Again, staff often felt they were monitoring patient behaviour rather than providing physical care. Initiatives to improve hospital environments have suggested incorporating dementia friendly designs, such as subdividing large open spaces to reduce noise as well as enhancing areas for purposeful walking (Tadd et al., 2011; Waller, 2012). However, while the RCP (2011) found that most wards in the UK had suitable space for patients to walk around safely, data from the more recent UK studies incorporated within the synthesis indicate otherwise (Baille et al., 2012a; Calnan et al., 2012). Interestingly, previous observation based research has shown that hospital staff consider it ‘unacceptable’ for patients with dementia to walk around the wards (Norman, 2006). Therefore, while the ward setting was considered inappropriate, it is questionable whether the review has highlighted an issue with the hospital environment, or again, an issue with staff attitudes towards the behaviours of those patients.

Barriers to person-centred care

Despite the findings discussed so far, it is important to acknowledge that the majority of those in caring professions are likely to be caring individuals. However, there was an overarching sense that participants did not feel they were able to provide adequate care for patients with dementia, either because of a lack of knowledge or the organisational and resource constraints placed upon them. Additionally, pressures identified from the top of the organisation to “get the job done” (Nolan, 2006, p. 11) were likely to contribute to feelings of inadequacy and thus potentially exacerbate negative feelings towards patients with dementia. However, such feelings may be cognitively dissonant with staff’s core beliefs about themselves as caring individuals (Dagnan, Trower, & Smith, 1998).

Participants in all but one study (Smythe et al., 2014) identified the importance of ensuring individualised, person-centred care. The ‘VIPS’ framework¹ (Brooker, 2004), summing up elements of Kitwood’s (1997) philosophy of person-centred care, recognises that getting to know the person helps staff understand their perspectives and meet individual needs. Although this was recognised by a number of staff, only one participant gave an example of putting this into practice; attempting to communicate with patients about their lives while providing personal care (Baille et al., 2012b). This may be representative of the supernumerary position of most students on placement (Royal College of Nursing, 2007). Indeed, for the majority of participants, time and resource limitations were considered barriers to taking time to talk to patients and building relationships.

Participants also acknowledged the need to maintain patient independence in the promotion of person-centred care. Models attest to the centrality of the need to work *with*

¹ V – valuing people with dementia and those who care for them

I – treating people as individuals

P – looking at the world through the perspective of the person with dementia

S – a positive social environment in which the person with dementia can experience relative well-being

people with dementia, rather than *for* them (Cheston & Bender, 2003; Edvardsson et al., 2010). Despite this, dementia within general hospitals has been associated with a loss of independence (Zekry et al., 2009). Again, the synthesis highlights how staff did not feel they had the time or resources to encourage patients to maintain their abilities. For example, it was considered quicker to wash someone than to assist them in washing themselves (Borbasi et al., 2006).

These findings correspond with previous research suggesting that working within a medical culture works against person-centred care and contributes to feelings of inadequacy in relation to meeting patients' needs (Goff, 2000; Wolf, Ekman, & Dellenborg, 2012). Even when staff acknowledged how person-centred care might be achieved, for the majority, putting this into practice was not deemed possible. To avoid further feelings of inadequacy, this may account for why staff preferred to avoid these aspects of care rather than feel guilty for being unable to maintain them.

Identifying the need for training

Perhaps not surprisingly given the challenges identified in caring for people with dementia on general hospital wards, all studies highlighted a need for further training. The review supports the wealth of evidence that dementia education for healthcare professionals from all disciplines should be improved (DH, 2009; Doherty & Collier, 2009; Tullo & Allan, 2011). Although the need for pre-registration training was only mentioned in studies including students in their data collection (Baille et al., 2012a; 2012b), this supports Pulsford et al.'s (2006) survey highlighting the continued lack of dementia teaching available for students specialising in adult nursing.

Training for qualified staff was also perceived to be lacking (Charter & Hughes, 2012; Cowdell, 2010; Smythe et al., 2014). However, recent national training programmes have

been mandated to ensure that all NHS staff looking after patients with dementia receive foundation level training to spot the early symptoms of dementia and have a better understanding of how to interact with those with dementia (DH, 2014; RCN, 2013). HEE has already ensured that 100,000 NHS staff have received foundation level training and aim to roll it out to a further 250,000 staff by March 2015 (DH, 2014).

While there remains a paucity of work looking at the *impact* of dementia training in general hospitals, the limited research available appears promising. Galvin et al. (2010) and more recently Elvish et al. (2014) found that training for general hospital staff led to immediate improvements in staff knowledge and confidence in caring for people with dementia. The training covered aspects such as encouraging and recognising the importance of communication, providing person-centred care and the impact of the hospital environment. Importantly, Elvish et al.'s (2014) training promoted small shifts towards a more person-centred perspective regarding behaviours that challenge. These elements appear to address many of the issues identified as problematic for general hospital staff.

Clinical implications

Overall, the synthesis identifies that greater consideration needs to be given to general hospital staff caring for patients with dementia. A lack of knowledge and understanding around communication and challenging behaviours runs throughout a number of studies and can result in reduced confidence and an increase in negative attitudes towards these patients. This has been shown to impact upon the reluctance of staff to provide their care. In response, the need for dementia training for all acute care professionals is paramount. This may have positive implications in improving knowledge, confidence, attitudes and therefore patient care. As suggested, the research to date has shown positive outcomes (Elvish et al., 2014; Galvin et al., 2010; Hughes et al., 2008).

The review has also highlighted that getting to know the patient and encouraging the maintenance of their abilities is important in ensuring person-centred care. However, organisational constraints, such as time and resources, as well as uncertainty around how to communicate and build relationships make this challenging to uphold within a ward context. While in the current economic climate it is unlikely that these organisational constraints will reduce, it is possible that group supervision or team reflection might allow staff to share knowledge and generate ideas for best achieving person-centred care. Similarly, dementia passports have been implemented in a number of hospitals as a communication tool enabling staff to learn more about the patients for whom they care (RCN, 2013).

Limitations of review

Given the time and resource constraints of the project, quality appraisal of the studies included within the review were only completed by the researcher and not validated by supervisors. Therefore it is possible that others may interpret the quality of the individual studies differently.

Additionally, the literature search strategy was conducted solely by the researcher. Although the strategy was discussed with supervisors, it is possible that the search terms used could have been more refined (e.g. to include ‘experiences’). This is likely to have reduced the number of initial abstracts to review and may therefore make the literature search easier to replicate.

Limitations of studies and future research

The range of countries from where the papers originated is relatively small. Therefore, it is unclear at this stage to what extent the findings are representative of the situation internationally. Additionally, the majority of studies came from the perspectives of those in

nursing professions with a smaller number including participants from other disciplines. Only Calnan et al.'s (2013) study included participants who had direct contact with patients with dementia but not in a clinical capacity, such as domestic staff and receptionists. Given that "everyone interacts with them" (Charter & Hughes, 2012, p. 587), it would add further interest to the meta-synthesis to gather perspectives from the range of professionals who have contact with these patients.

Finally, although all participants had experience of caring for people with dementia, it was often not made clear what wards they were recruited from and how much contact they had with these patients. For example, some wards predominantly held older adults which might suggest a higher proportion of patients with dementia, whereas others were more general e.g. A&E. This might impact upon how experienced staff become in caring for patients with dementia. Only one study (Moyle et al., 2010) emphasised the difference ward speciality had on experiences, suggesting surgical wards and surgical nurses were least sympathetic towards people with dementia. It might be interesting to take this finding further to determine the reasons behind this distinction.

Conclusion

The synthesis has considered how staff in general hospital settings experience caring for patients with dementia. In particular, it has identified a common lack of knowledge and understanding, particularly with regard to communication and behaviours that are considered challenging. This has been identified as contributing to low staff confidence and often negative attitudes towards these patients. The organisational and resource constraints placed upon hospital staff can also contribute to feelings of inadequacy and an inability to provide person-centred care. The benefits of dementia training have been recognised. This may have

positive implications in improving knowledge, confidence, attitudes and therefore the care that is provided to patients with dementia.

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Figure 1: Process of searching and identifying relevant papers for synthesis

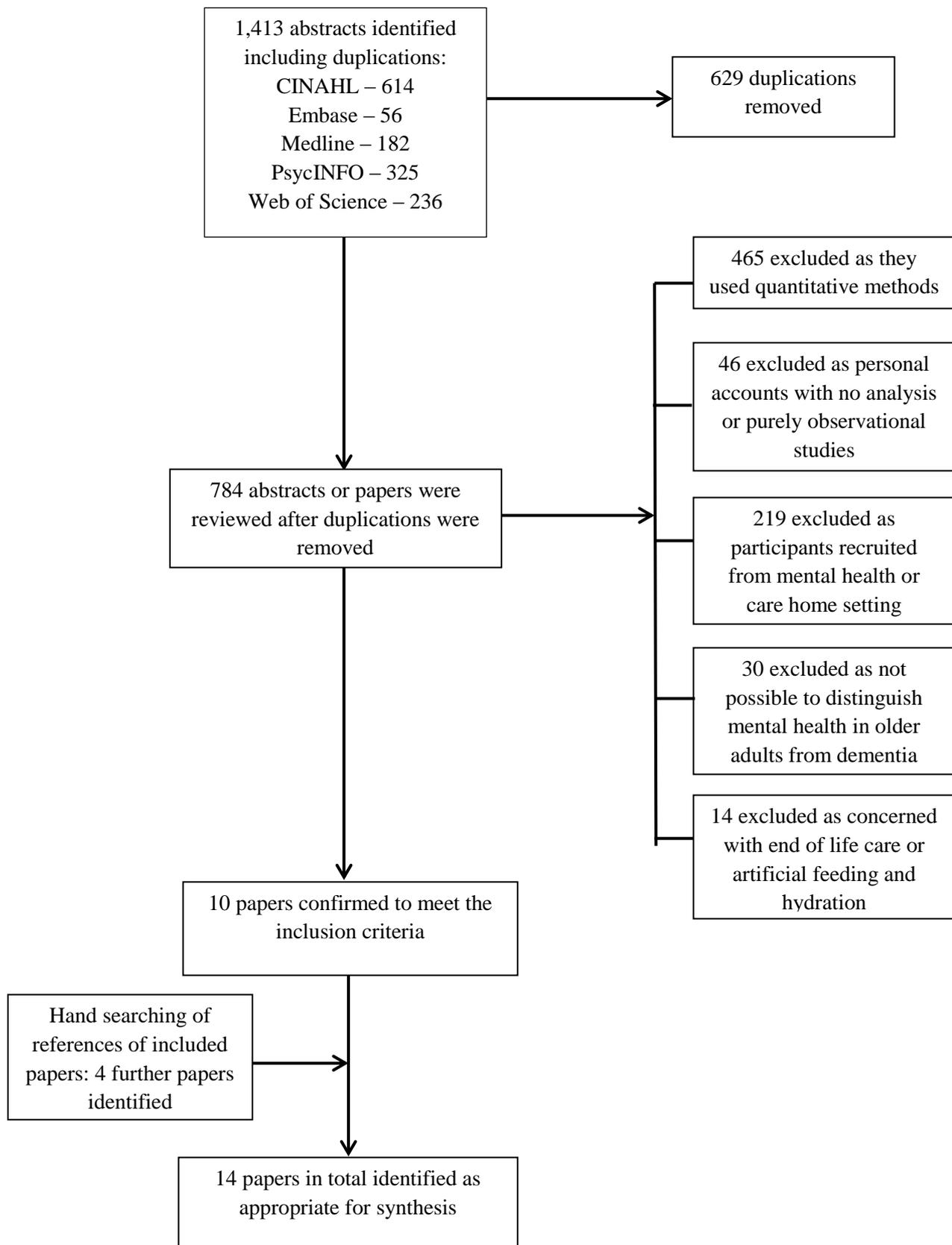


Table 1: Quality appraisal using the CASP (2013)

Studies	Statement of aims	Appropriate for qualitative research	Appropriate design	Recruitment strategy	Data collection	Reflexivity of researcher	Ethical issues	Data analysis	Findings	Value of the research	Final score
Atkin, K., Holmes, J., & Martin, C. (2005).	3 – clear rationale and statement of aims	2 – appropriate methodology but not clearly explained	2 – limited justification for research design used	2 – brief explanation of sample, not of recruitment strategy	2 – brief explanation of data collection	1 – no description of role and position of authors or potential influence	1 – no explicit discussion of ethical considerations	2 – description of process but not clear how researcher arrived at themes	2 – findings explicit but limited, useful discussion of evidence and numerous quotes provided to support findings	2 – contributions to existing knowledge and implications for future practice briefly discussed, but not future research	19
Baille, L., Cox, J., & Merritt, J. (2012).	3 – clear rationale and statement of aims	3 – clear and appropriate explanation of methodology chosen	3 – clear rationale and justification for research design used	3 – clear explanation of how and why participants recruited	3 – data collection fully detailed and justified	1 – no description of role and position of authors or potential influence	3 – ethical approval detailed as well as measures to ensure ethical standards	2 – some description of process but no demonstration	2 – findings explicit with useful discussion of evidence, numerous quotes provided but no discussion of contradictory findings	2 – contributions to existing knowledge and implications for future practice discussed, but not future research	25
Baille, L., Merritt, J., & Cox, J. (2012).	3 – clear rationale and statement of aims	3 – clear and appropriate explanation of methodology chosen	3 – clear rationale and justification for research design used	3 – clear explanation of how and why participants recruited	3 – data collection fully detailed and justified	1 – no description of role and position of authors or potential influence	3 – ethical approval detailed as well as measures to ensure ethical standards	2 – some description of process but no demonstration	2 – findings explicit with useful discussion of evidence, numerous quotes provided but no discussion of contradictory findings	2 – contributions to existing knowledge and implications for future practice discussed, but not future research	25
Borbasi, S., Jones, J., Lockwood, C., & Emden, C. (2006).	3 – clear rationale and statement of aims	3 – clear and appropriate explanation of methodology chosen	2 – limited justification for research design used	3 – clear explanation of how and why participants recruited	3 – data collection fully detailed and justified	1 – no description of role and position of authors or potential influence	3 – ethical approval detailed as well as measures to ensure ethical standards	3 – clear description of process and thematic summary provided	3 – findings explicit, numerous and useful quotes provided and exploration of contradictory findings	2 – describes contribution to existing knowledge and clinical implications but no reference to future research	26

Studies	Statement of aims	Appropriate for qualitative research	Appropriate design	Recruitment strategy	Data collection	Reflexivity of researcher	Ethical issues	Data analysis	Findings	Value of the research	Final score
Calnan, M., Tadd, W., Calnan, S., Hillman, A., Read, S., & Bayer, A. (2012).	3 – clear rationale and statement of aims	3 – clear and appropriate explanation of methodology chosen	2 – limited justification for research design used	3 – clear explanation of how and why participants recruited	3 – data collection fully detailed and justified	1 – no description of role and position of authors or potential influence	2 – brief ethical approval detailed with measures to ensure ethical standards	3 – clear description of analytic process	2 – findings explicit and useful quotes provided to back them up. No exploration of contradictory findings	3 – contributions to existing knowledge and implications for future practice discussed as well as brief discussion of future research	25
Charter, K. & Hughes, N. (2012).	3 – clear rationale and statement of aims	3 – clear and appropriate explanation of methodology chosen	2 – limited justification for research design used	3 – clear explanation of how and why participants recruited	3 – data collection fully detailed and justified	1 – no description of role and position of authors or potential influence	2 – ethical approval detailed, but no discussion of measures to ensure ethical standards	3 – in-depth description of analytic process	2 – findings explicit, quotes useful but difficult to follow. Some exploration of contradictory findings	2 – describes contribution to existing knowledge and clinical implications but no reference to future research	24
Cowdell, F. (2010).	3 – clear rationale and statement of aims	2 – appropriate methodology but not clearly explained	3 – clear rationale and justification for research design used	2 – brief explanation of sample, not of recruitment strategy	3 – data collection fully detailed and justified	3 – assumptions and experience of authors detailed and how managed	3 – ethical approval detailed as well as measures to ensure ethical standards	2 – some description of process but no examples of how themes developed	3 – findings explicit, numerous and useful quotes provided and contradictory findings explored	2 – contributions to existing knowledge and implications for future practice discussed, but not future research	27
Eriksson, C. & Saveman, B. (2002).	3 – clear statement of aims of study	2 – appropriate methodology but not clearly explained	2 – limited justification for research design used	3 – clear explanation of how and why participants recruited	3 – data collection fully detailed and justified	1 – no description of role and position of authors or potential influence	3 – ethical approval detailed as well as measures to ensure ethical standards	2 – process detailed but no examples of how themes developed	3 – findings explicit, limited but useful quotes provided and contradictory findings explored	2 – describes contribution to existing knowledge and clinical implications but no reference to future research	24
Fessey, V. (2007).	2 – brief explanation of rationale	2 – appropriate methodology but not clearly explained	1 – no justification for design used	1 – very limited description of sample	2 – brief description of data collection	1 – no description of role and position of	1 – no explicit ethical considerations	2 – some description of process but no examples of	1 – qualitative findings briefly discussed, very few quotes	2 – contributions to existing knowledge and implications for	15

Studies	Statement of aims	Appropriate for qualitative research	Appropriate design	Recruitment strategy	Data collection	Reflexivity of researcher	Ethical issues	Data analysis	Findings	Value of the research	Final score
	and aims					authors or potential influence		how themes developed	provided to support findings	future practice briefly discussed, but not future research	
Moyle, W., Borbasi, S., Wallis, M., Olorenshaw, R., & Gracia, N. (2010).	3 – clear rationale and statement of aims	2 – appropriate methodology but not clearly explained	3 – clear rationale and justification for research design used	2 – full explanation of sample but limited recruitment strategy	3 – data collection fully detailed and justified	1 – no description of role and position of authors or potential influence	2 – brief ethical approval detailed with limited detail of measures to ensure ethical standards	2 – process detailed but no examples of how themes developed	3 – findings explicit, numerous and useful quotes provided and contradictory findings explored	3 – contributions to existing knowledge and implications for future practice discussed. Brief suggestions for future research	24
Nilsson, A., Rasmussen, B. H., & Edvardsson, D. (2013).	3 – clear rationale and statement of aims	2 – appropriate methodology but not clearly explained	2 – limited justification for research design used	2 – limited description of sample and recruitment strategy	3 – data collection fully detailed and justified	2 – limited reference to reflexivity of researchers	3 – ethical approval detailed as well as measures to ensure ethical standards	3 – in-depth description of analysis process	3 – findings explicit, numerous and useful quotes provided and contradictory findings explored	3 – contributions to existing knowledge and implications for future practice discussed as well as suggestions for future research	26
Nolan, L. (2006).	3 – clear rationale and statement of aims	2 – appropriate methodology but not clearly explained	2 – limited justification for research design used	2 – limited description of sample and recruitment strategy	2 – brief description of data collection	2 – limited description of use of reflective journal but not of authors position	2 – brief ethical approval detailed with limited detail of measures to ensure ethical standards	2 – some detail of process but no examples provided	2 – findings and credibility discussed, numerous and useful quotes provided but limited discussion of contradictory findings	2 – some discussion of relevance of findings and implications	21
Nolan, L. (2007).	3 – clear rationale and statement of aims	2 – appropriate methodology but not clearly explained	2 – limited justification for research design used	2 – limited description of sample and recruitment strategy	2 – brief description of data collection	2 – limited description of use of reflective journal but not of authors position	2 – brief ethical approval detailed with limited detail of measures to ensure ethical standards	2 – some detail of process but no examples provided	2 – findings and credibility discussed, numerous and useful quotes provided but limited discussion of contradictory	2 – describes contribution to existing knowledge and clinical implications but no reference to future research	21

Studies	Statement of aims	Appropriate for qualitative research	Appropriate design	Recruitment strategy	Data collection	Reflexivity of researcher	Ethical issues	Data analysis	Findings	Value of the research	Final score
Smythe, A., Jenkins, C., Harries, M., Wright, J., Dee, P., Bentham, P., & Oyeboode, J. (2014).	3 – clear rationale and statement of aims	2 – appropriate methodology but not clearly explained	1 – no justification for design used	1 – very limited description of sample	3 – data collection fully detailed and justified	1 – no description of role and position of authors or potential influence	2 – brief ethical approval detailed with limited detail of measures to ensure ethical standards	2 – limited detail of analysis process, no examples provided	findings 2 – qualitative findings briefly discussed with small number of useful quotes. Brief discussion of evidence and contradictory findings	2 – discussion of relevance of findings, limited attention to future research or clinical implications	19

Table 2: Demographic information of the participants included within the meta-synthesis

Study	Sample	Gender	Location	Country
Atkin, K., Holmes, J., & Martin, C. (2005).	19 registered staff nurses	Female $n = 17$ Male $n = 2$	Sites within an acute hospital trust	United Kingdom
Baille, L., Cox, J., & Merritt, J. (2012a).	20 2 nd and 3 rd year students, 6 in each focus group	Not stated	Recruited from one university in England	United Kingdom
Baille, L., Merritt, J., & Cox, J. (2012b).	20 2 nd and 3 rd year students, 6 in each focus group	Not stated	Recruited from one university in England	United Kingdom
Borbasi, S., Jones, J., Lockwood, C., & Emden, C. (2006).	4 senior medical officers, 5 clinical nurse consultants, 3 clinical nurses, 3 nurse unit managers, 1 registered staff nurse, occupational therapists, 3 social workers, 1 assistant director of nurses, 1	Not stated	3 large teaching hospitals	Australia

	physiotherapist			
Calnan, M., Tadd, W. Calnan, S., Hillman, A., Read, S., & Bayer, A. (2012).	Ward managers, registered staff nurses, healthcare assistants, domestic staff, receptionists, doctors, physiotherapists, occupational therapists	Not stated	Four wards in four clinical areas in four trusts	United Kingdom
Charter, K. & Hughes, N. (2012).	4 registered staff nurses, 3 healthcare assistants	Not stated	Mixed gender acute elderly medical ward	United Kingdom
Cowdell, F. (2010).	18 interviews with registered staff nurses and healthcare assistants	Not stated	3 wards in one acute hospital	United Kingdom
Eriksson, C. & Saveman, B. (2002).	12 registered staff nurses	Female $n = 12$	5 acute wards, 1 A&E department	Sweden
Fessey, V. (2007).	87 registered staff nurses	Not stated	“Acute hospital wards”	United Kingdom

Moyle, W., Borbasi, S., Wallis, M., Olorenshaw, R., & Gracia, N. (2010).	1 medical doctor, 2 acute care nursing directors, 1 clinical nurse consultant, 3 nursing unit managers, 2 clinical nurses, 1 registered staff nurse, 3 healthcare assistants	Not stated	Acute medical or surgical wards in large hospital	Australia
Nilsson, A., Rasmussen, B. H., & Edvardsson, D. (2013).	3 licensed practical nurses, 4 registered staff nurses, 2 doctors	Not stated	20 bed cardiology ward	Sweden
Nolan, L. (2006).	7 registered staff nurses	Female $n = 7$	Unit caring for acutely ill older persons in large acute hospital	Ireland
Nolan, L. (2007).	7 registered staff nurses	Female $n = 7$	Specialist unit caring for older persons in a large acute hospital	Ireland
Smythe, A., Jenkins, C., Harries, M., Wright, J., Dee, P., Bentham, P., & Oyeboode, J. (2014).	15 participants from nursing and service settings	Not stated	3 wards within acute hospital	United Kingdom

Table 3: Descriptive information of the studies included within the meta-synthesis

Study	Focus	Sampling strategy	Data collection	Data analysis
Atkin, K., Holmes, J., & Martin, C. (2005).	Training needs of general nurses to care for patients with dementia	Not stated	Focus groups	Framework Analysis
Baille, L., Cox, J., & Merritt, J. (2012a).	Explore adult nursing students' experiences of the challenges of caring for older people with dementia in hospital	Self-selection following receipt of information packs	Focus groups	Thematic Analysis
Baille, L., Merritt, J., & Cox, J. (2012b).	Explore adult nursing students' experiences of appropriate strategies for caring for older people with dementia in hospital	Self-selection following receipt of information packs	Focus groups	Thematic Analysis
Borbasi, S., Jones, J., Lockwood, C., & Emden, C. (2006).	Health care professionals' experiences of managing patients who have	Purposive sampling – healthcare professionals identified by key	Semi-structured interviews	Thematic Analysis

	dementia but are in hospital for treatment of non-dementia related illness	personnel. Self-selection if they wished to participate		
Calnan, M., Tadd, W. Calnan, S., Hillman, A., Read, S., & Bayer, A. (2012).	To identify aspects of the ward environment and activity, processes and organisation that maintain and challenge dignity of older people from the perspective of staff (as well as patients and relatives)	Self-selection	Semi-structured interviews	Thematic Analysis
Charter, K. & Hughes, N. (2012).	To consider dementia education for healthcare workers in hospital from the perspective of staff nurses and healthcare assistants	Self-selection following receipt of information sheet	Focus groups	Grounded Theory

<p>Cowdell, F. (2010).</p>	<p>To explore the experiences of nursing staff (and patients) of the care received by older people with dementia in acute hospitals</p>	<p>Not stated</p>	<p>Semi-structured interviews</p>	<p>Grounded Theory</p>
<p>Eriksson, C. & Saveman, B. (2002).</p>	<p>To describe nurses' experiences of difficulties related to caring for patients with dementia in acute care settings</p>	<p>Possible participants selected by managers and consent given</p>	<p>Semi-structured interviews</p>	<p>Thematic Analysis</p>
<p>Fessey, V. (2007).</p>	<p>To explore the knowledge, understanding and implications for care of adult nurses working with patients with dementia in general hospital wards</p>	<p>Not stated</p>	<p>Qualitative comments taken from questionnaire</p>	<p>Thematic Analysis</p>
<p>Moyle, W., Borbasi, S., Wallis, M., Olorenshaw,</p>	<p>To explore the management of older</p>	<p>Senior management asked staff to voluntarily</p>	<p>Semi-structured interviews</p>	<p>Phenomenologically informed thematic analysis</p>

R., & Gracia, N. (2010).	people with dementia in an acute hospital setting from perspective of staff	participate in the study if fit criteria		
Nilsson, A., Rasmussen, B. H., & Edvardsson, D. (2013).	To develop an understanding of the processes hindering person-centred care for older people with cognitive impairment in acute care settings	Theoretical sampling but recruitment method not specified	Semi-structured interviews (as well as observations)	Grounded Theory
Nolan, L. (2006).	To explore nurses' experiences of caring for older persons with dementia in an acute hospital setting	Purposive sampling to identify set of participants who fit criteria but recruitment method not specified	Non-directive conversational interviews	Thematic Content Analysis
Nolan, L. (2007).	To consider the experiences of nurses caring for people with dementia within an acute	Purposive sampling	Non-directive conversational interviews	Thematic Content Analysis

	hospital setting			
Smythe, A., Jenkins, C., Harries, M., Wright, J., Dee, P., Bentham, P., & Oyeboode, J. (2014).	To evaluate psychosocial training from the perspective of staff working with people with dementia in an acute hospital setting	Self-selecting by signing up to study following advertisement	Focus groups	Thematic analysis

Table 4: Ideas and concepts presented within studies which led to the key theme ‘The unknown and undesirable’

Ideas	Concepts	Theme
<p>Need for dementia to be identified early for treatment to be effective</p> <p>Dementia overlooked due to lack of time and knowledge</p> <p>Patients with dementia “fantastic at hiding their handicap”</p> <p>Need for more thorough assessment</p> <p>No routine to assess cognitive status</p> <p>Assessments made on subjective judgements</p> <p>Lack of resources available to screen</p> <p>Use and application of screening instruments</p> <p>Staff with knowledge about dementia asset but minority</p> <p>Special extended practice role created</p> <p>Specialist recommended to give pastoral and occupational support</p> <p>Engage with patients independent of nursing need</p> <p>Someone to call up to spend time with patient and assess them</p> <p>Require staff with awareness of need</p> <p>Specialists available but not for dementia</p>	<p>Identifying dementia</p> <p>Screening for cognitive status</p> <p>Developing a dementia specialist role</p>	<p>The unknown and undesirable</p>

<p>patients</p> <p>Entrenched stereotypes</p> <p>Attitude as much an issue as time</p> <p>Treated as second class citizens</p> <p>Seen as additional work</p> <p>Assigned powerful and pervasive labels</p> <p>Influenced by and influencing ward culture</p> <p>Labels impact interaction</p> <p>Pwd blamed for behaviour rather than management technique</p> <p>Focus on moving patient on</p>		
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Table 5: Themes from each study that contributed to the five key synthesised themes

Synthesised Themes	Original Study Themes
The unknown and undesirable	<ul style="list-style-type: none"> - Older people with mental illness are identified through their behaviour (Atkin et al., 2005) - General nurses perceive themselves as lacking the skills needed to recognise and manage mental illness (Atkin et al., 2005) - General nurses perceptions of their training needs (Atkin et al., 2005) - Organisational culture (Baille et al., 2012a) - Deficits in knowledge, skills and attitudes of staff and students (Baille et al., 2012a) - The struggle to provide care (Baille et al., 2012a) - Emotional needs and communication (Baille et al., 2012a) - The acute care built environment (Borbasi et al., 2006) - The acute care operational system (Borbasi et al., 2006) - Key players within the acute care system (Borbasi et al., 2006) - Role of staff (Borbasi et al., 2006) - Current dementia care practice in the acute setting (Borbasi et al., 2006) - Skills and training (Calnan et al., 2012) - The ward culture (Calnan et al., 2012)

	<ul style="list-style-type: none">- Learning about dementia (Charter & Hughes, 2012)- Learning from specialists (Charter & Hughes, 2012)- Philosophies of caring for people with dementia (Cowdell, 2010)- The value that staff attach to their work (Cowdell, 2010)- The ability of staff to provide care (Cowdell, 2010)- Ethically difficult situations which can lead to abuse (Eriksson & Saveman, 2002)- Difficulties related to disorderly conduct among patients with dementia (Eriksson & Saveman, 2002)- Difficulties related to the organisation of acute care as an obstacle to good nursing care of dementia patients (Eriksson & Saveman, 2002)- Knowledge and understanding (Fessey, 2007)- Attitudes towards dementia and implemented care (Fessey, 2007)- Defining confusion (Moyle et al., 2010)- Everyday challenges (Moyle et al., 2010)- The physical environment (Moyle et al., 2010)- Specialising as care management (Moyle et al., 2010)
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	<ul style="list-style-type: none"> - Falling behind in meeting the needs of older patients with cognitive impairment (Nilsson et al., 2013) - Working without consensus about the care of older patients with cognitive impairment (Nilsson et al., 2013) - Caring as an ethical way of being (Nolan, 2006)
<p style="text-align: center;">Constraints of the environmental and organisational context</p>	<ul style="list-style-type: none"> - Physical environment (Baille et al., 2012a) - Organisational culture (Baille et al., 2012a) - Mobility (Baille et al., 2012a) - Flexible and creative care approaches (Baille et al., 2012b) - The acute care built environment (Borbasi et al., 2006) - Current dementia care practice in the acute setting (Borbasi et al., 2006) - Recommendations for dementia care practice in the acute setting (Borbasi et al., 2006) - The environment of care (Calnan et al., 2012) - Skills and training (Calnan et al., 2012) - The organisational context (Calnan et al., 2012) - The ward culture (Calnan et al., 2012) - The value that staff attach to their work (Cowdell, 2010) - Ethically difficult situations which

	<p>can lead to abuse (Eriksson & Saveman, 2002)</p> <ul style="list-style-type: none"> - Difficulties related to disorderly conduct among patients with dementia (Eriksson & Saveman, 2002) - Difficulties related to the organisation of acute care as an obstacle to good nursing care of dementia patients (Eriksson & Saveman, 2002) - Focus on acute problems (Moyle et al., 2010) - The physical environment (Moyle et al., 2010) - Specialising as care management (Moyle et al., 2010) - Working in a disease orientated and efficiency driven organisation (Nilsson et al., 2013) - Working within a busy and inflexible environment (Nilsson et al., 2013) - Caring as an ethical way of being (Nolan, 2006) - The reality of caring (Nolan, 2007) - The meaning of caring (Nolan, 2007)
<p>Emphasising the physical health of patients</p>	<ul style="list-style-type: none"> - Older people with mental illness are identified through their behaviour (Atkin et al., 2005) - General nurses perceive themselves as lacking the skills needed to recognise and manage mental illness (Atkin et al., 2005)

	<ul style="list-style-type: none">- General nurses do not believe older people with mental illness get a good service in general hospitals (Atkin et al., 2005)- Organisational culture (Baille et al., 2012a)- Deficits in knowledge, skills and attitudes of staff and students (Baille et al., 2012a)- Emotional needs and communication (Baille et al., 2012a)- Key players within the acute care system (Borbasi et al., 2006)- The organisational context (Calnan et al., 2012)- Philosophies of caring for people with dementia (Cowdell, 2010)- The ability of staff to provide care (Cowdell, 2010)- Ethically difficult situations which can lead to abuse (Eriksson & Saveman, 2002)- Difficulties related to disorderly conduct among patients with dementia (Eriksson & Saveman, 2002)- Focus on acute problems (Moyle et al., 2010)- Focus on safety (Moyle et al., 2010)- Specialising as care management (Moyle et al., 2010)- Optimal care practices (Moyle et al., 2010)
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	<ul style="list-style-type: none"> - Falling behind in meeting the needs of older patients with cognitive impairment (Nilsson et al., 2013) - Working in a disease orientated and efficiency driven organisation (Nilsson et al., 2013) - The meaning of caring (Nolan, 2007)
<p>Recognising the benefits of person-centred care</p>	<ul style="list-style-type: none"> - Deficits in knowledge, skills and attitudes of staff and students (Baille et al., 2012a) - Getting to know the patient and building a relationship (Baille et al., 2012b) - Flexible and creative care approaches (Baille et al., 2012b) - Comfort and communication (Baille et al., 2012b) - The acute care operational system (Borbasi et al., 2006) - The role of staff (Borbasi et al., 2006) - Current dementia care practice in the acute setting (Borbasi et al., 2006) - Recommendations for dementia care practice in the acute setting (Borbasi et al., 2006) - The organisational context (Calnan et al., 2012) - The ward culture (Calnan et al., 2012) - Learning about the person (Charter & Hughes, 2012) - The ability of staff to provide care (Cowdell, 2010)

	<ul style="list-style-type: none"> - Difficulties related to the organisation of acute care as an obstacle to good nursing care of dementia patients (Eriksson & Saveman, 2002) - Attitudes towards dementia and implemented care (Fessey, 2007) - Challenging behaviours (Fessey, 2007) - Defining confusion (Moyle et al., 2010) - Focus on safety (Moyle et al., 2010) - Specialising as care management (Moyle et al., 2010) - Optimal care practices (Moyle et al., 2010) - Caring as an ethical way of being (Nolan, 2006) - Embracing each other – bonding (Nolan, 2006) - Working with relatives/carers in this process (Nolan, 2006) - The reality of caring (Nolan, 2007) - Caring for people with dementia who are agitated or aggressive differs from caring for people with dementia who are not agitated or aggressive (Nolan, 2007) - The meaning of caring (Nolan, 2007)
<p>Identifying the need for training</p>	<ul style="list-style-type: none"> - General nurses perceive themselves as lacking the skills needed to recognise and manage mental illness (Atkin et al., 2005)

	<ul style="list-style-type: none">- General nurses perceptions of their training needs (Atkin et al., 2005)- Deficits in knowledge, skills and attitudes of staff and students (Baille et al., 2012a)- Flexible and creative care approaches (Baille et al., 2012b)- Recommendations for dementia care practice in the acute setting (Borbasi et al., 2006)- Skills and training (Calnan et al., 2012)- Learning about dementia (Charter & Hughes, 2012)- Learning about the person (Charter & Hughes, 2012)- Learning from each other (Charter & Hughes, 2012)- Learning from specialists (Charter & Hughes, 2012)- The ability of staff to provide care (Cowdell, 2010)- Difficulties related to the organisation of acute care as an obstacle to good nursing care of dementia patients (Eriksson & Saveman, 2002)- Attitudes towards dementia and implemented care (Fessey, 2007)- Knowledge and understanding (Fessey, 2007)- Defining confusion (Moyle et al., 2010)- Optimal care practices (Moyle et al.,
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	<p>2010)</p> <ul style="list-style-type: none">- Working without consensus about the care of older patients with cognitive impairment (Nilsson et al., 2013)- Caring as an ethical way of being (Nolan 2006)- The meaning of caring (Nolan 2007)
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Table 6: Description of which studies contributed to each of the key themes:

(1) The unknown and undesirable; (2) Constraints of the environmental and organisational context; (3) Emphasising the physical health of patients; (4) Recognising the benefits of person-centred care; and (5) Identifying the need for training

Papers	Themes				
	1	2	3	4	5
Atkin, Holmes, & Martin, 2005	X		X	X	X
Baille, Cox, & Merritt, 2012a	X	X	X	X	X
Baille, Merritt, & Cox, 2012b	X			X	X
Borbasi, Jones, Lockwood, & Emden, 2006	X	X	X	X	X
Calnan, Tadd, Calnan, Hillman, Read, & Bayer, 2012			X	X	X
Charter & Hughes, 2012	X			X	X
Cowdell, 2010	X	X	X	X	X
Eriksson & Saveman, 2002	X	X	X	X	X
Fessey, 2007		X		X	X
Moyle, Borbasi, Wallis, Olorenshaw, & Gracia, 2010	X	X	X	X	X
Nilsson, Rasmussen, & Edvardsson, 2013	X	X		X	X
Nolan, 2006	X	X		X	X
Nolan, 2007		X	X	X	X
Smythe, Jenkins, Harries, Wright, Dee, Bentham, & Oyeboode, 2014		X			X

*Appendix A. Author guidelines from Aging & Mental Health***Instructions for authors****SCHOLARONE MANUSCRIPTS™**

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Use these instructions if you are preparing a manuscript to submit to *Aging & Mental Health* . To explore our journals portfolio, visit <http://www.tandfonline.com> , and for more author resources, visit our [Author Services](#) website.

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

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

1. General guidelines

- Manuscripts are accepted only in English. Any consistent spelling and punctuation styles may be used. Please use single quotation marks, except where ‘a quotation is “within” a quotation’. Long quotations of 40 words or more should be indented without quotation marks.
- Manuscripts may be in the form of (i) regular articles not usually exceeding **5,000 words** (under special circumstances, the Editors will consider articles up to 10,000 words), or (ii) short reports not exceeding **2,000 words** . These word limits **exclude** references and tables. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate Funding paragraph, as follows:
For single agency grants :
This work was supported by the <Funding Agency> under Grant <number xxxx>.
For multiple agency grants :
This work was supported by the <Funding Agency #1> under Grant <number xxxx>; <Funding Agency #2> under Grant <number xxxx>; and <Funding Agency #3> under Grant <number xxxx>.
- Structured Abstracts of not more than 250 words are required for all manuscripts submitted. The abstract should be arranged as follows: Title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion.
- Each manuscript should have 3 to 5 keywords .
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance [here](#) .
- Section headings should be concise. The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content.
- All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.
- All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.
- Biographical notes on contributors are not required for this journal.

- Authors must also incorporate a Disclosure Statement which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.
- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.
- Authors must adhere to SI units . Units are not italicised.
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- Description of the Journal's reference style.
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- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
- All figures must be numbered in the order in which they appear in the manuscript (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).
- Figure captions must be saved separately, as part of the file containing the complete text of the manuscript, and numbered correspondingly. The captions should include keys to symbols, and should make interpretation possible without reference to the text.
- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

Section Two: Empirical Paper

**The use of truth and deception in dementia care: Constructing the experiences of staff
on general hospital wards**

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Prepared for submission to Aging & Mental Health (see Appendix K for author guidelines).

Abstract

Objectives: Deceptive practice has been shown to be endemic in dementia care, particularly within long-term care settings. However, deception remains controversial and there is no clear consensus regarding its use. Given the aging population, increasing numbers of patients within general hospitals have a diagnosis of dementia and recent research suggests hospital staff face similar dilemmas regarding the acceptability of deceiving their patients. The current study aimed to gather a greater understanding of the experiences of hospital staff, in particular exploring their decision-making processes when choosing whether to deceive.

Method: This qualitative study drew upon a constructivist grounded theory approach (Charmaz, 2006) to analyse data gathered from semi-structured interviews with a range of hospital staff. A model, grounded in participant experiences, was developed to describe their decision-making processes.

Results: Participants identified particular ‘triggers’ that set in motion the need for a response. Various ‘mediating factors’, including lack of guidance and communication, relationship with the patient and consideration of ethical framework, influenced how staff chose to ‘respond’ to these ‘triggers’. These factors were often affected by whether the participant was a qualified or non-qualified member of staff. When possible, participants would generally avoid lying or telling the truth to patients. Instead, distracting or ‘passing the buck’ to another member of staff were preferred.

Conclusion: The study adds to the growing research regarding the use of lies in dementia care by considering the decision-making processes for staff in general hospital settings. Various factors have been identified as influencing how staff choose to respond to patients and whether deception is used. However, many staff remain uncertain of what is acceptable and would welcome further discussion and guidance on the issue.

Introduction

Dementia

Dementia is a term used to describe a range of neurodegenerative processes including memory loss, a decline in functional ability and difficulties in communication (World Health Organisation [WHO], 2012). Cognitive decline associated with dementia can also result in disorientation and confusion, often leading to those with dementia inhabiting different realities to those around them (Stokes, 2000).

It is estimated that 35.6 million people worldwide live with dementia, which typically, although not exclusively, affects individuals over the age of 65 (Prince et al., 2013). In the UK, approximately 5% of people over 65 live with dementia and by the age of 80 that prevalence increases to approximately 20% (Department of Health, 2009). The challenges associated with caring for someone with dementia are well documented, particularly in long-term care settings (Brodaty, Draper, & Low, 2003; Edberg et al., 2008). Ballard et al. (2001) found standards of care in such settings to be poor, predominantly due to the low quality interaction between staff and residents. Indeed, Kitwood (1997) described the resulting culture that develops within these settings as ‘malignant social psychology’, suggesting one of the hallmark features of such cultures was deception.

Defining deception

‘Deception’ and ‘lies’ are concepts that have been studied in a number of social contexts, described as “a feature of everyday life found in personal, occupational and political interactions” (Hunt and Manning, 1991, p. 65). It is suggested that lies may be used in a number of different ways, but are most commonly employed to control information being given and received within conversations (Turner, Edgley, & Olmstead, 1975). However,

Blum (1994) suggested that lying in relation to dementia differs to that in other contexts. Rather than being to control the information received, it is used more as an aid for daily living to assist with the accomplishment of tasks and to manage behaviour.

Within dementia research, it is acknowledged that defining a response as either a 'truth' or a 'lie' is overly simplistic (Blum, 1994; Cunningham, 2005; Hasselkus, 1997). As such, there have been many variations in how deception is categorised and labelled. For example, Hasselkus (1997) categorised the deceptive practices of care home staff as either 'benign manipulation' or 'pretending', when the situation was perceived to be minor or manageable, and 'white lies' used when the situation became more challenging. More recently, Cunningham (2005) distinguished between 'blatant lies', the 'truth' and a 'grey area', which included terms such as 'bending the truth' and 'white lies'. Furthermore, Blum's (1994) research with family members differentiated between 'going along', 'not telling', 'little white lies' and 'tricks'. Such studies highlight a lack of consensus about what constitutes a lie and the challenges that arise when trying to define the practice of lying within dementia care (Wood-Mitchell, Cunningham, Mackenzie, & James, 2007).

Deception in dementia care

Despite the lack of consensus around definition, deceptive practices have been shown to be endemic in dementia care (James, Powell, Smith, & Fairbairn, 2003). James, Wood-Mitchell, Waterworth, Mackenzie, and Cunningham (2006) found that 96% of care staff report using lies when caring for residents with dementia. The most common reason given for lying was to ease the distress of the person with dementia e.g. when asking to see a deceased family member. Other reasons were to ease the distress of the carer, to get the person with dementia to comply with treatment, or to save time.

Cunningham (2005) developed a theoretical model from interviews with staff in long-term dementia care settings which encapsulated the factors affecting whether they chose to tell the truth or deceive residents in their care. She found that most decisions regarding the use of truth and lies were talked about in relation to being in the best interests of the person with dementia. Complementing this research, Day, James, Meyer, and Lee (2011) interviewed people with dementia about their perspectives on the use of lies. Again, participants felt that lying was acceptable if done in their best interests; however, level of acceptability was influenced by the person lying, the person with dementia and the nature of the lie.

The research undertaken to date has sparked contrasting opinions around deceptive practices. Some argue that lying is “an easy way out” (Sherratt, 2007, p. 12) and indicates “poverty of the imagination” (Walker, 2007, p. 30). Pool (2007) suggests that in order to be person-centred one must be genuine, honest and respectful; without this, a therapeutic relationship cannot be successful. Those against the use of deception suggest that in most cases lies are for the benefit of the staff member placed in the difficult situations, rather than the person being cared for (Kitwood, 1997).

Conversely, others have suggested that using deception can be seen as more caring if it gives the person with dementia reassurance and confidence (Zeltzer, 2003). It has been argued that lies are predominantly used for the benefit of the person with dementia (Wood-Mitchell et al., 2007) and can be a useful communication strategy to encourage those with dementia to open up and explore their past (Walker & Dale, 2004). Bender (2007) highlights that professionals who raise issue with the use of lying are generally not those who have to manage situations where lying might be considered. It is generally front line care staff placed in those difficult positions.

Professionals involved in the direct care of people with dementia identified the need for further guidance around the use of lies (James et al., 2003). James et al. (2006) generated a list of guidelines where deception might be employed in care settings, based upon recommendations by nursing home staff. More recently, a revised version of these guidelines was utilised to obtain the views of psychiatrists (Culley, Barber, Hope, & James, 2013). While three quarters of respondents felt the guidelines could improve communication skills if used in training, only half felt they provided an ethical guide to practice. As highlighted by the research to date and a recent review by the Mental Health Foundation (2014), there is currently little agreement among carers, practitioners or people living with dementia on the ethical acceptability of the use of 'lies' in dementia care.

Deception in general hospital settings

In the UK, more than 97% of hospital staff report having experience of caring for patients with dementia (Alzheimer's Society, 2009) but with minimal dementia training (WHO, 2012). Perhaps unsurprisingly, recent research suggests general hospital staff face similar dilemmas to those documented in current literature when it comes to using deception with patients in their care, but with possible added pressures associated with a medical setting, such as giving health diagnoses (Elvish et al., in preparation). These initial findings come from a qualitative strand of a larger quantitative study evaluating a training programme for general hospital staff which included the topic of deception (Elvish et al., 2014). As this is the only work to consider deception specifically in general hospitals, there is a need to develop work in this area.

Aims of the current study

The current study aimed to gather an understanding of the views and experiences of staff within general hospital settings regarding the use of truth and deception when caring for

patients with dementia. In particular, it aimed to explore their decision making processes when choosing whether to tell the truth or to deceive. A grounded theory (GT) methodology was used to construct a model of this process, grounded in participants' accounts (Charmaz, 2006).

Method

Design

This qualitative study drew upon a constructivist GT methodology, based primarily on Charmaz's (2006) approach. More traditional GT approaches adopt a realist perspective (e.g. Glaser & Strauss, 1967), suggesting there are objective truths that are testable and verifiable. In contrast, a constructivist approach to GT suggests no objective reality exists (Mills, Bonner, & Francis, 2006) and instead attempts to construct an *interpretation* of participants' perceived reality. Additionally, while data are grounded in the experiences of participants, the approach acknowledges the personal and professional experience of the researcher (Charmaz, 2006).

Ethical considerations

Ethical issues were considered in consultation with project supervisors. Particular consideration was given to confidentiality, ensuring that staff members felt comfortable discussing a potentially challenging topic. However, while openness was to be encouraged, participants were informed of procedures put in place to address any practice discussed within the interviews that the researcher felt was unsafe.

The research was reviewed and approved by the Lancaster University Faculty of Health and Medicine Research Ethics Committee. Research governance approval was then sought and given by NHS Research and Development departments for the two NHS Trusts that took part (see 'Ethics section' of this report).

Sampling and Participants

The current study was conducted in two National Health Service (NHS) sites in the North of England. Participants were recruited from 13 general wards that held patients² predominantly over the age of 65. Participants were staff members with direct experience of working with patients with diagnosed or suspected dementia. Those taking part were fluent in English. There were no sex or age restrictions. In total, 12 participants from 8 wards were interviewed, details of whom are provided in Appendix A. While job roles have been included to differentiate participants, ward names have been excluded to maintain anonymity.

In line with GT methodologies (Charmaz 2006), a theoretical sampling strategy was adopted. Following the initial six interviews, further participants (highlighted in italics in Appendix A) were recruited based on their particular characteristics, such as job role, to explore ideas that had emerged as part of the ongoing process of theory development.

Recruitment procedures

Dementia lead nurses were approached and informed of the study and facilitated access to appropriate wards. Once ethical approval had been received, meetings were set up between the researcher and ward managers to provide further information. Ward managers subsequently distributed information packs to staff on their respective wards. The packs contained information sheets (Appendix B) and contact details forms (Appendix C).

Recipients were informed that the researcher could be contacted via post, e-mail or telephone. Where recruitment via information packs alone proved difficult, the researcher attended handover meetings so that staff could raise any potential queries. On one Trust site, the researcher also attended a meeting for doctors and medical students, in order to

² The term 'patient' is used throughout, rather than client or service user, reflecting the language predominantly used by participants.

specifically recruit these professionals (in line with theoretical sampling). Once a potential participant had made contact with the researcher, an interview was arranged.

Interview schedule

The initial interview schedule (Appendix D) was developed using findings from previous research regarding deception in dementia care, primarily in long-term care settings (e.g. Cunningham, 2005). In this way, initial areas of interest or ‘sensitizing concepts’ (Blumer, 1969) were developed. Using a semi-structured approach ensured questions could be modified in light of responses from participants. Therefore, the role of the interviewer was to guide, rather than dictate the direction of the interview. Following coding of initial interviews, the interview schedule was adapted to pursue possible gaps in the data.

Interview procedures

All interviews were held in rooms on the Trust sites. Prior to the interview commencing, interviewees were reminded that participation was voluntary and they could withdraw at any time up to two weeks following interview (after which transcription and analysis may have started). Consent forms (Appendix E) were signed by participant and researcher, stating they were happy to proceed. After the interview, participants were given the opportunity to raise any questions. All were provided with a debrief form (Appendix F), thanking them for their participation. Interviews ranged between 36 minutes and 65 minutes. They were digitally recorded and transcribed verbatim.

Data analysis

Initially, transcribing interviews and re-reading transcripts generated familiarity with the data (Bird, 2005). Charmaz (2006) identified GT as an iterative process, whereby analysis and sampling take place concurrently. Therefore, the researcher began the coding

stage of analysis while continuing with data collection. The first stage of ‘open coding’ summarised participant accounts in line by line detail.

Following open coding, codes that were considered more frequent or significant were combined to produce ‘focussed codes’. Focussed coding allowed the researcher to separate, sort and synthesise the data, explaining larger segments of transcript (Charmaz, 2006) (Appendix G). Charmaz (2000, 2006) recommends moving from focussed coding directly to the process of raising conceptual categories. However, she also emphasises that the approach is not prescriptive and allows for flexibility. The researcher therefore chose to include an additional level of analysis, arguably similar to the ‘theoretical coding’ described by Glaser and Strauss (1965, 1967). This helped to identify similarities, differences and links between the focussed codes and to identify the conceptual relationships between developing categories (Appendix H).

In order for ideas to be explored, analysis was done in stages using a ‘constant comparative method’ (Charmaz, 2006; Glaser & Strauss, 1967). Initially, the first four interviews were analysed as described. During this stage, data was compared both within and between those first few interviews. As theory developed and similarities and contradictions were identified, this informed further investigation in subsequent interviews. By selecting participants gradually, emerging theory could be explored to further elucidate and define the developing categories. This process continued until the final participant was interviewed, whereby it was felt that theoretical sufficiency had been reached (Dey, 1999). While ‘sufficiency’ does not mean full exhaustion of all possible sources, it proposes there are data sufficient enough to ‘suggest’ the developed theory.

Memos were recorded throughout, developing ideas or observations that felt relevant to the researcher. In the later stages of analysis, memos also helped to develop more abstract

and analytical concepts in the emerging theory (Tweed & Charmaz, 2011, cited in Thompson & Harper) (For example see Appendix I). This analytic process formed the basis of an emerging theoretical model (Charmaz, 2006).

Credibility of analysis

To ensure credibility of the analysis, recommendations on conducting qualitative research were employed (Elliot, Fischer, & Rennie, 1999; Yardley, 2008). In order to show sensitivity to existing work (Yardley, 2008), the study used previous literature to help generate a relevant research question. Participants were recruited with consideration of this research question and any ethical implications. To ensure credibility checks were completed (Elliot et al. 1999), two supervisors carried out initial coding on the first two transcripts. The codes were compared with those of the researcher to ensure consistency regarding interpretation of the data. If there were any inconsistencies in interpretation e.g. around perceived tone or meaning or with regard to the developing iterations of the model, these were discussed further and a consensus was reached. Additionally, after the first four interviews, the emerging theoretical model was discussed to ensure it remained grounded in the data. While participant validation can be an element of GT, a pragmatic decision was made not to include it, given the limited time and resources available for a thesis project of this size and the time constraints for participants. As Bryant and Charmaz (2010) state, “unfortunately, conducting member checking with respondents is often not a realistic option due to time constraints, limited resources...” (p. 486).

To ensure coherence (Elliot et al., 1999), the methods used have been described in detail and examples have been provided. Finally, both Elliot et al. (1999) and Yardley (2008) suggest the researcher’s own experiences and assumptions around dementia care are considered. A reflective diary was utilised, to avoid imposing preconceptions upon the data. An example can be found in Appendix J.

Results

Figure 1 here

Figure 1 represents the decision-making process of staff when choosing whether to deceive patients with dementia. Within this process, ‘**triggers**’ set in motion the need for a response. Various ‘**mediating factors**’ (including a lack of communication, the individual’s interpretation of their role and responsibility, and their ethical framework) influence how staff ‘**respond**’ to those triggers. However, in specific situations, participants might have to ‘**adapt their desired response**’.

Triggers

Participants described three types of situation where the use of deception might be considered: i) in response to difficult questions; ii) when attempting to manage challenging behaviour or provide personal care; and iii) when sharing medical information. A common example of a difficult question included asking for a deceased relative: “She always asks ‘When is Bobby coming?’ ...but I think Bobby’s dead...what are you meant to say to that?” (CSW2, 98). Common examples of managing challenging behaviours included patients refusing to accept medication and personal care, or when they attempted to leave the ward independently: “They constantly go to the doors and try to get out, so you have to think of a way to get them back to their bay” (Domestic, 129). Finally, common examples of providing medical information included discussing diagnosis, discharge plans and end of life care. When faced with these ‘triggers’, staff were required to make a conscious decision of how to respond. The process of coming to that decision was influenced by a number of ‘mediating factors’.

Mediating Factors

Mediating Factor 1: Poor Communication and Lack of Guidance

A key mediating factor in the decision making process, appeared to be the lack of communication amongst staff. All participants reported they had never openly discussed the use of deception with their colleagues. As highlighted by CSW1, “it’s not really something we talk about, you’re kind of just left to get on with it” (47). Non-qualified staff (ward clerk, housekeeper, domestic and CSWs) felt that more formal discussion would provide clarity and direction around what they were expected to do in difficult situations. However, these participants did not feel comfortable raising the topic of deception for discussion. More senior nurses (staff nurse, ward manager, ward sister) acknowledged that they did not always tell the truth but were uncomfortable directing other staff to deceive for fear of leaving themselves “open to blame” (Ward Manager, 220). As the ward sister explained, “Even though I might sometimes do it, I wouldn’t feel comfortable telling others to... it’s their job, their PIN number...we are all accountable for our own actions” (130). This finding highlights the difficulty for staff in knowing how to respond as it appears unlikely they would receive advice from those in more senior positions.

Both the ward clerk and CSW2 suggested that in a “perfect world” everyone would be “singing from the same hymn sheet”. However, this was considered impossible, predominantly because time and resources provided little opportunity for all staff to be involved in necessary discussions. Additionally, a number of participants were not routinely included within formal information sharing opportunities, such as handover, where it was felt these discussions could be initiated. As the domestic explained “I don’t get included, so I don’t get the opportunity to ask for advice.” (217). Therefore, many resorted to doing “what I think is best until someone tells me I’m doing it wrong” (Housekeeper, 573). This lack of

communication prompted staff to independently evaluate how best to respond in a given situation.

Mediating factor 2: Staff interpretations of role/responsibility and 'knowing the person'

All participants discussed the importance of developing a relationship with the patients they cared for in order to know how best to respond. As CSW1 described, "If I knew them better, I like to think I would know what would work for them, what would help calm them down" (106). Having relevant and accurate information about that individual was also deemed necessary. Without these things, it was considered difficult to give an informed response:

If you don't know the patient it's hard to know the right thing to tell them. You don't know what's right and what's wrong, like if a family member has died or something, you don't know...you're kind of just guessing (Domestic, 95).

Likewise, it was considered important that patients had trust in what was being said to them and for this to occur, a good relationship was essential: "If they don't know you and you're telling them that their mum's dead, they would be like 'who are you telling me'... if they know you, they would be happier to hear it" (Staff Nurse, 257).

While acknowledging the benefits of both building a relationship and having accurate information, participants identified obstacles inherent in their job roles that made these things difficult to achieve. A distinction was particularly evident between qualified and non-qualified staff. Non-qualified staff were often excluded from handover and access to patient documentation. Thus, although they spent large amounts of time with patients, they felt they didn't really have appropriate information about them:

Even though we spend most of the time with them, day in day out, we don't really get to hear anything about them....you just have to pick up what you can...and if it's coming from them [patients], you don't know if it's true (CSW1, 75).

Additionally, most non-qualified staff considered it was not their responsibility to cause potential upset. Again, this was attributed to their 'non-qualified' status: "I don't know if I should be the one to upset them...I don't think I'm in the best position to do that" (Housekeeper, 316).

Interestingly, qualified nurses who had access to handover and patient documentation described themselves as too busy to spend quality time with patients and build good relationships. Although they had more information about the patient, they felt they did not have capacity to support them should their response result in distress: "If what I said upset them, I don't have time to sit with them and make them feel better, there's just too much other stuff to do" (Staff Nurse, 211). Paradoxically, this meant both qualified and non-qualified participants believed the other to be in a better position to tell the truth.

Finally, the doctor and physiotherapist also believed that others were in a better position to give potentially upsetting news, if the issue was not directly relevant to their medical condition:

I don't see that as my role to be honest, they won't want to hear that from me. I don't know the ins and outs of that patient's life. Unless it is something to do with the medical complication it's down to the nurses to sort out (Doctor, 147).

Their sporadic time on the ward meant they did not have opportunity to form relationships. Similarly, they were not made privy to personal information: "I come on, see a patient and

then leave again...it doesn't really give me time to get to know much about them. I know what I need to know" (Physiotherapist, 201).

In summary, the overarching finding within this factor was that responding truthfully to certain trigger situations was often considered 'somebody else's job'.

Mediating factor 3: Referring to ethical framework

The third mediating factor involved staff assessing a situation against a framework of ethical conduct. Again, this was often influenced by whether the participant was a non-qualified or qualified member of staff. For non-qualified staff, responses were generally governed by 'personal ethics'; their own moral beliefs of what was right and wrong. For qualified staff, responses were more often driven by drawing upon professional ethical guidelines.

Personal Ethics. Non-qualified staff tended to focus upon what were termed "moral dilemmas" (Housekeeper, CSW3, Domestic). These were situations not related to the medical condition of the patient, but where emphasis was placed on personal questions, such as whether a deceased relative was coming, or challenging behaviours. In these situations, many non-qualified staff responded to patients based upon the rule of "treating others as you would want to be treated" (CSW2, 376). The majority suggested that if roles were reversed they would not want to be told the truth if it caused them upset: "If I got dementia, I wouldn't know if they were telling me the truth...so if it makes me happier, don't tell me" (Student Nurse, 334). Of note, personal ethics often left staff in a conundrum rather than helping them to make a clear decision about how to respond. For example, many suggested that their personal ethics prevented them from wanting to cause distress but also prevented them from wanting to 'lie': "I think it's probably wrong to lie about something like that [death of

relative], but at the same time, if I was to tell the truth, it would upset them loads. I just couldn't do that" (Ward Clerk, 20).

Professional Ethics. Qualified participants appeared to give less concern to "moral dilemmas", instead referring to situations where they might be considered unprofessional if they were to give the wrong response. Specific examples were concerned with administering medication or discussing diagnosis and end of life care. In these situations, participants were generally clear on when they would and would not deceive, believing the decision to be more "black and white" (Ward Manager, 383). For example, qualified participants suggested they would "lie through their teeth...and drop it in their tea" (Ward Sister, 227) to ensure patients took the correct medication, as it was felt the ends justified the means.

What would be considered worse, that you've dropped a tablet in their tea or that person has become unwell because they're not getting the medication you're supposed to give them? I know what I'd rather be held accountable for (Staff Nurse, 247).

However, adhering to their professional ethical code meant that they had to remain truthful when discussing diagnosis or end of life care. This was generally because it was felt patients needed to be given the opportunity to make advanced decisions.

Regardless of the ethical framework underpinning their decision, all staff suggested that the response given was done so in what they perceived to be the patient's best interests. Consequently, the majority of participants showed clear discomfort if questioned whether their own needs influenced their actions: "I shouldn't really go by my feelings, I should go by the patient's feelings" (CSW3, 222), suggesting this went against both personal and professional ethics.

Responding

Responding to the Situation

As depicted in Figure 1, participants predominantly relied upon four types of response; telling the truth, passing the buck, distracting or lying.

Telling the Truth. While most participants considered truth-telling to be the “right option on paper” (CSW2, 89), when faced with ‘triggers’ this was generally the least preferable response. Participants often felt that their relationship with the patient, their responsibilities on the ward, and their ethical framework made it inappropriate for them to respond truthfully. Non-qualified staff felt they were not privy to accurate information or were not in a position that made upsetting the patients acceptable: “I can’t make someone upset like that, who am I to do that? I’m here to keep it clean!” (Domestic, 207).

Additionally, qualified staff felt they did not have the time to support patients if giving potentially upsetting news. Therefore, the truth was only told when interpretation of professional ethical guidelines indicated such a response was necessary, for example, when giving a diagnosis. In these situations “you need to tell them if there are important decisions to be made” (Staff Nurse, 119).

“Passing the Buck”. For non-qualified staff, “passing the buck” (CSW1, 78) to those considered more qualified enabled them to maintain their position of not wanting to cause distress or resort to the use of lies: “I’ll often say ‘I’m not sure if he’s [husband] coming, we can ask the nurse when she comes” (Housekeeper, 79). In this way, staff felt they were offering a form of support to patients without having to provide a concrete answer. Additionally, when questions unrelated to the physical needs of patients were directed towards the doctor or physiotherapist, they too chose to pass responsibility to qualified nurses: “I’m here for ward-round, then I’m off somewhere else...I leave those kinds of

questions to the nurses” (Doctor, 75). For qualified nurses therefore, “the buck” often stopped with them. In these instances, if distraction was not possible, another response was required.

Distracting. For all participants, both qualified and non-qualified, distracting patients was considered the most favourable response as it did not require using outright lies or causing potential upset: “if you can just get them thinking about something else, that’s often best” (CSW3, 198). However, distraction was often a time consuming process and was not always successful. For non-qualified staff, when distraction was unsuccessful they might then resort to “passing the buck”. However, for some staff “passing the buck” was not an option: “they [non-qualified staff] might say to me ‘so and so wants to know if she can go home’, she won’t be going home, but I’ve got other things to get on with...you’ve just got to do what works” (Staff Nurse, 227). It was predominantly in these situations that lies might be used.

Lying. As discussed, the majority of participants were reluctant to lie, preferring to use the other “tactics” (Staff Nurse, 98) described. It was only very rarely that non-qualified staff alluded to the use of lies when they felt there was no other option. Qualified staff were more likely to lie in order to ensure medication was given or when distraction was not considered possible. However, suggesting they were adhering to their professional ethical guidelines made this deception more acceptable: “It’s about remembering why we are telling these porkies...to keep that patient relaxed...it’s OK as long as we maintain those boundaries of when to tell that little fib” (Ward Sister, 427).

Interestingly, as the above quotation suggests, participants were reluctant to describe their response as lying, no matter how inaccurate the information. There were a number of different terms used such as “telling a little white lie”, “humouring the patient”, “bending the truth” or “going along with it”. Within the interviews, the term ‘lie’ was only ever used by

qualified nurses, when suggesting medication was given deceptively. Here, staff were confident in using the word 'lie' because deceiving was considered justified.

Adapting Desired Response

The mediating factors described generally allowed participants to respond in what they perceived to be the most appropriate way. However, in specific situations; i) when being observed by relatives; and ii) when a patient showed *significant* distress or agitation, it was felt these desired responses needed to be adapted. Adapted responses have been considered separately from other mediating factors because they contradict the usual decision-making process.

When observed by relatives, the majority of participants suggested they were more likely to give what was perceived a 'socially acceptable' response, such as telling the truth. This was to avoid the possibility of triggering a complaint (Housekeeper, 203). As the domestic explained, "When relatives are there, you just want to do what they [relatives] think is right, you don't want them making complaints about you" (167). This highlights how staff often believed that deceiving patients would be perceived by others as wrong.

Conversely, participants suggested they were more likely to lie when faced with a patient who was *significantly* distressed or agitated. This was often based upon experience of patients becoming physically aggressive and concern for other patients on the ward: "they can be so unpredictable when they get like that...you need to think about the safety of other patients" (Housekeeper, 301). In these situations, it was considered more important to calm patients down in whatever way possible.

Discussion

The present study adds to the growing research regarding the use of lies in dementia care by considering the decision-making processes of staff in general hospital settings. In the current study, participants identified particular ‘trigger’ situations that often left them uncertain of how best to respond to patients with dementia. Generally, this was in response to difficult questions, when attempting to manage challenging behaviour or personal care, and when sharing medical information.

Lack of communication and guidance

The overarching finding was that staff showed little clarity on how they *should* respond. Generally, participants suggested that they would prefer not to lie. However, they were equally reluctant to tell the truth. This ambiguity was initially associated with a lack of communication on the issue of deception. Irrespective of their position or experience on the ward, no participants discussed the possible use of deception with their colleagues or how best to respond in difficult situations. This is despite all identifying these triggers as problematic. Although non-qualified staff felt that more discussion around the use of deception would provide clarity and direction, none felt comfortable raising the issue. This is contrary to James et al.’s (2003) finding that 83% of staff in care home settings felt comfortable telling their managers about the lies they told. However, the acknowledgement of the use of lies within care homes has been established for some years. Open discussion about deception within general hospitals may not yet have reached that level of acceptance.

Interestingly, qualified staff appeared more reluctant than non-qualified staff to initiate or support deception, for fear of being “left open to blame” (Ward Manager, 220). Given that those in positions of authority were reluctant to acknowledge the issue, it is not surprising that it remains somewhat of a taboo subject. During a conference aimed at

professionals working in dementia care, a workshop encouraging communication around the topic of deception helped to change prior negative attitudes (Elvish, James, & Milne, 2010). Given that some participants in the current study were reluctant to initiate these discussions, similar opportunities to encourage communication within a hospital setting may prove beneficial.

As discussed, controversy around the use of lies is long standing (Kitwood, 1997; Bender, 2007). Therefore, it may be understandable that participants were reluctant to lie, or suggest they lie, to their patients. However, it was interesting to discover that so many were also reluctant to tell the truth. In the previous literature, participants have suggested that telling the truth should be attempted first, with more deceptive responses utilised if this proved unsuccessful (Cunningham, 2005; Tuckett, 2012; Wood-Mitchell et al., 2007). However, participants in the current study suggested that truth-telling was rarely attempted.

Role and responsibility

Reluctance to tell the truth appeared to be influenced by their relationship with the patient as well as their position on the ward. While much research discusses the importance of knowing the person with dementia (Cunningham, 2005; Day et al., 2011; Kitwood & Bredin, 1992), participants in the present study suggested that their job role affected their ability to obtain this knowledge. Non-qualified staff felt that being excluded from relevant information about the individual made it difficult to tell the truth. They also believed that their non-qualified status meant it was not their responsibility to cause upset. Conversely, qualified staff considered themselves too busy to build up good therapeutic relationships or spend time with patients should they become distressed. Interestingly, participants therefore perceived others to be in a 'better position' to tell the truth.

This finding raises the question of what is more important in choosing how to respond; having a good relationship or having factual information about the individual. Of course, one needs to know the truth in order to tell the truth. However, a person with dementia may no longer share the reality of everyday life (Vittoria, 1998). Validation therapy (Feil, 1992) proposes that a person should be accepted in whatever time or place they are experiencing as real. Therefore, factual information may be less important than the ability to acknowledge the patient's reality when choosing a response. This is of particular relevance given that a lack of information about a patient left many staff uncertain about how to respond. If factual information can, at times, be considered less important, then this may be significant when developing guidelines regarding the use of deception in general hospitals.

Ethical frameworks

Reference to ethical frameworks often led staff, particularly those non-qualified, to consider truth-telling as inappropriate. Non-qualified staff tended to focus upon 'personal ethics', whereby responses were based upon the rule of "treating others as you would want to be treated" (CSW2, 376). Many suggested that if the truth would cause them upset, they would rather this was avoided. Furthermore however, it was reportedly their personal ethics that prevented staff from wanting to lie. For many, deceiving patients contradicts longstanding beliefs that "lying is wrong" (Ward Clerk, 24). Again, this dichotomy probably emphasised the feelings of uncertainty regarding how best to respond.

Alternatively, qualified staff tended to refer to professional ethical guidelines. Nurses are commonly called to act under the principals of beneficence, of doing good; non-maleficence, of doing no harm; autonomy, to encourage the ability to make decisions; and justice, treating people fairly and equally (Four Principals of Bioethics, Beauchamp & Childress, 2009). Reference to these principals possibly allowed qualified staff to be clearer

on instances of when they would tell the truth or lie. For example, providing medication covertly may fit with the principals of beneficence or non-maleficence, whereas ensuring patients were made aware of diagnoses and end of life plans may fit with the principal of autonomy.

No matter what framework participants used, all suggested that their responses were given in the best interests of the patient. This corroborates a number of previous studies suggesting that lies are used only in the best interests of the person with dementia (Cunningham et al., 2005; Day et al., 2011; Elvish et al., 2010; James et al., 2006; Tuckett, 2012). However, as we have seen, decisions around ‘best interests’ appear to be subjective and reliant upon different ethical frameworks. This raises the question “how do we really know that it’s in that patients best interests? [...] someone else might think different” (Ward Manager, 349). Given the lack of communication identified and the idea that opinions regarding best interests may differ, it might arguably be more appropriate to suggest that responses are currently being given with good intentions, rather than knowingly in the patient’s best interests (Higgs, 1998; Tuckett, 2012).

Responses and definitions of lying

The overall reluctance to lie or tell the truth (other than in specific medical situations) reportedly resulted in the favouring of other responses, such as distracting or ‘passing the buck’. The idea that responses are not categorised simply into truth or lies fits with previous research (Blum, 1994; Cunningham, 2005; Hasselkus, 1997 etc.). In the current study, distracting was generally identified as the preferred option, as this was believed to allay the anxieties of the patient without resorting to truth-telling or lying. In their four stage communication strategy, Wood-Mitchell et al. (2007) proposed that distraction should be used as a ‘third option’, after attempting to meet the individual’s need or identifying the

unmet need and substituting with an alternative. However, given the limited dementia training and the time restraints placed on hospital staff (WHO, 2012), it is possibly unrealistic to expect them to be able to identify and substitute an unmet need. Models developed for this purpose take time that may not be available within a hospital context for staff to implement effectively (James & Stephenson, 2007). Therefore, distraction may be the best available option.

For non-qualified staff, ‘passing the buck’ was also suggested to be a preferred option which reduced the need to either tell the truth or lie. This appears to be a new concept within the lying research, where there has previously been no reference to handing responsibility over to another member of staff. The ability to do so may be more evident within a general hospital setting due to the hierarchical staff structure and clearly defined roles. Other studies have identified ‘avoiding’ as a common response (e.g. Cunningham, 2005; Day et al., 2011). Arguably, passing the buck could be considered another form of avoidance. However, participants believed that rather than ignoring the question completely, passing the buck was more acceptable because it provided brief relief to patients without requiring a concrete answer. Indeed, it would be interesting to determine whether patients found this type of response supportive or whether it was simply a way of relieving staff anxieties.

On the rare occasions that participants reported lying, they did so believing it to be consistent with their ethical frameworks. However, it appeared evident that staff felt uncomfortable discussing their use of lies, as deceptive practices were reframed using expressions such as telling ‘little fibs’ (Housekeeper) or “bending the truth” (CSW1). Using such terms possibly helped to reduce cognitive dissonance, given that lying was generally considered “wrong” (Cunningham, 2005; Festinger, 1962). Additionally, it may also have helped to allay any anxieties that the researcher might think negatively of them for lying to their patients.

The way in which responses are categorised calls into question how deception is defined. While some suggest that withholding the truth is not lying (Hertogh, The, Miesen, & Eefsting, 2004), alternatively, lies of omission may be seen as equally deceptive as lies of commission (Backhurst, 1992; Bender, 2007). In the current model, the boxes representing 'lying', 'passing the buck' and 'distracting' have been coloured grey, taking the perspective that all represent deception, albeit of different magnitudes. However, the researcher identifies that while 'passing the buck' has been considered a form of deception, this is arguably dependent upon the specifics of the situation. If a member of staff passes over responsibility because they are unsure of the answer, this may not be intentionally deceptive. However, if it is because they feel uncomfortable upsetting the patient, this is more representative of deception. Perhaps, if all responses are being given with good intentions, what is more important is how they are received by the patient. For example, if lying, distraction and passing the buck all withhold the truth, it may be that lying is preferable if it most effectively relieves patient distress. Therefore, while the current study goes some way to identifying the different responses given to patients with dementia in a hospital setting, perhaps it is important to identify how these responses directly impact upon those for whom they care.

Clinical implications

A significant finding from the current study was the lack of communication regarding how best to respond to patients with dementia. As discussed, this is likely to leave staff in a state of uncertainty and reliant upon their own subjective decision-making process. Non-qualified staff would welcome further guidance on the topic. However, qualified staff appear reluctant to do so. Training that incorporates discussion around deception in dementia care has previously proved beneficial in reducing negative attitudes (Elvish et al., 2010). Therefore, incorporating similar training within general hospital settings might encourage communication and attitudes around the use of deception to improve.

Participants also identified the need for better information sharing. Confidentiality may question whether all staff can have access to patient documentation. However, implementation of peer supervision groups might provide opportunity for all staff members to discuss individual patients and encourage consistency in how they respond. This would also help to ensure that best interests are considered collaboratively. Additionally, encouraging consistency might help to reduce the extra burden placed on qualified nursing staff where currently the 'buck' is being passed to them.

So far, James et al. (2006) have gone furthest in developing specific guidelines around how to approach the use of deception in dementia care settings. These guidelines were developed for staff within care settings and include principals such as 'once a lie has been agreed upon it must be used consistently across all people and all settings' (p. 800) and 'lies should only be told if in the best interests of the person with dementia' (p. 800). While hospital staff may welcome similar recommendations, findings from the current study suggest that changes need to be made in the culture of general hospitals, particularly around communication, before such guidelines could be developed in this environment.

Limitations

Given that the current study was completed as a part of a doctoral thesis, it was conducted within a relatively small geographical area of the UK. Therefore, it would be beneficial to conduct this study on a much larger scale to identify whether staff use similar decision-making processes in general hospital settings elsewhere. Additionally, certain staff groups were under-represented due to recruitment difficulties. Both the doctor and the physiotherapist provided interesting data. However, because they varied from other participants in a number of ways e.g. their limited time on the ward and both being male, it is difficult to unpick exactly how their job roles impacted upon decision-making. Unfortunately,

it proved challenging to find professionals in similar roles willing to take part, possibly because they were not attached to a specific ward.

Future research

Given that the current study was conducted in a relatively small geographical area, it would be beneficial for it to be repeated on a larger scale to further explore hospital staff views. Additionally, interviews were focussed more on participants professional lives, although they did occasionally refer to personal factors when decision making. Aspects such as previous employment, cultural influences or personal experiences of caring for a relative with dementia would be interesting to explore in greater detail for future research.

While the current study has helped identify the different responses used when caring for patients with dementia, it does not go as far as to consider how these responses might impact upon patients. Before one can justify one response as better than another, it is important to determine how they are received by those being cared for. This could potentially be studied by questioning patients with dementia, or alternatively through observation. However, given participants suggested they might alter their response when being observed, overt observations might be influenced by social desirability effects (Rosenbaum, 2002).

It would be beneficial to identify the impact of different types of response on hospital staff. The majority of participants were reluctant to suggest they considered their own well-being when choosing how to respond. In contrast, James et al. (2006) found that approximately 30% of staff in care settings anonymously reported lying for their own benefit. This contradiction may be attributed to methodological differences. However, given that staff well-being can impact upon patient care (Skovhold & Trotter-Mathison, 2001) it is important to consider the needs of those providing that care.

Conclusion

The current study adds to the growing research regarding the use of lies in dementia care. Staff in general hospital settings are often unclear about whether to use the truth, a lie, or “something else”; often leaving them in an uncertain place when trying to decide how to respond to a patient with dementia. Various factors influence their decision-making process, but these factors can often leave them in a conundrum rather than providing them with clear guidance on how to respond. Many staff would welcome further discussion on the issue and it is hoped that future work within research and clinical practice will lead to further exploration of the use of deception with people in general hospitals.

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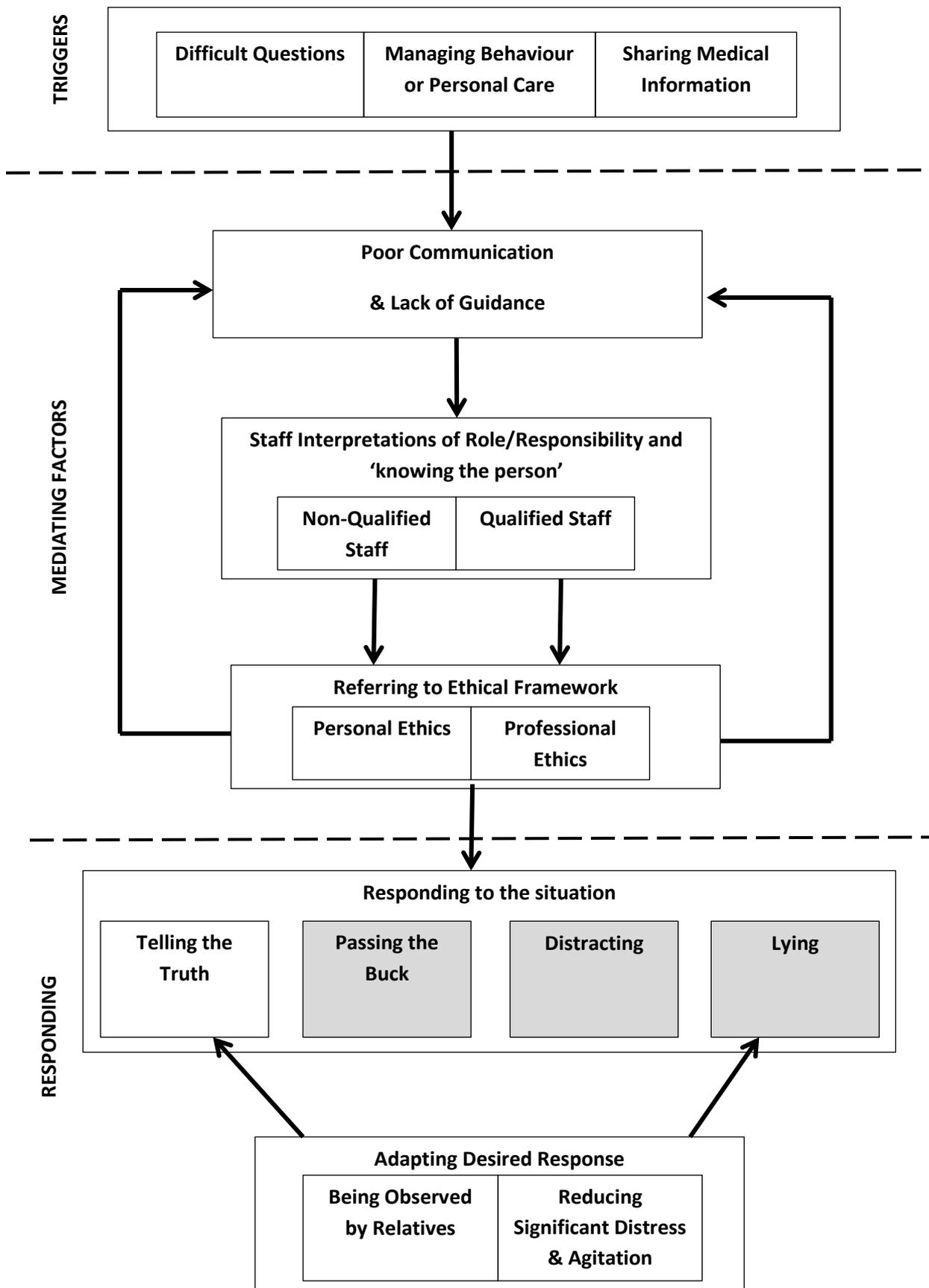
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Figure 1: Theoretical model of decision-making process

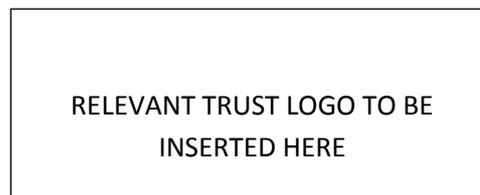


Appendix A. Participant details (in order of recruitment)

Job Role	Job Description (as described by participants)	Gender	Ethnicity	Experience of Working in Elderly Care Settings	Time Working on Current Ward
Staff Nurse	Providing care for patients. Recording vital signs, assessing medical conditions and administering medication	Female	White British	8 years	8 years
Clinical Support Worker (CSW1)	Looking after the general well-being and comfort of patients. Assisting with feeding and washing and general personal care.	Female	White British	16 years	5 years
Domestic Staff	Ensuring ward is clean and hygienic. Sometimes assisting with changing beds.	Female	White British	21 years	6 years
House Keeper	Co-ordinating a range of ward services such as catering, cleaning and equipment. Also co-ordinating transport and linen services.	Female	White British	10 years	4 years
Ward Clerk	Running the reception desk, handling phone calls and greeting visitors and patients. Booking in patient appointments,	Female	White British	23 years	3 years

	filing patient records and chasing up reports.				
Clinical Support Worker (CSW2)	Looking after the general well-being and comfort of patients. Assisting with feeding and washing and general personal care.	Female	White British	5 years	5 years
Ward Sister	<i>Managing care of patients. Promoting and monitoring safe and effective environment. Assessing medical conditions and administering medication</i>	<i>Female</i>	<i>White British</i>	<i>10 years</i>	<i>10 years</i>
Clinical Support Worker (CSW3)	Looking after the general well-being and comfort of patients. Assisting with feeding and washing and general personal care.	Female	White British	15 years	7 years
Ward Manager	<i>Organising and managing MDT and day to day running of the ward – managing staff, rota, appraisals, budgets, recruitment etc.</i>	<i>Female</i>	<i>White British</i>	<i>13 years</i>	<i>10 years</i>
Student Nurse	<i>Supernumerary member of staff. Assisting qualified staff members as well as clinical support workers.</i>	<i>Female</i>	<i>White British</i>	<i>5 weeks</i>	<i>5 weeks</i>
	<i>Treating and rehabilitating physical</i>				

<i>Physiotherapist</i>	<i>difficulties that have resulted from the illness or injury that caused admission. Helping patients to improve movement and function.</i>	<i>Male</i>	<i>White Irish</i>	<i>4 years</i>	<i>4 years</i>
<i>Doctor</i>	<i>Assessing and treating medical condition of patient.</i>	<i>Male</i>	<i>Indian British</i>	<i>13 years</i>	<i>13 years</i>

Appendix B. Participant information sheet**Participant Information Sheet****Date: 21.06.2013****Version: 2****The use of truth and deception in dementia care: Constructing the experiences of staff on general hospital wards.****Purpose of the study**

The aim of the current study is to gather the views and experiences of staff in general ward settings regarding the use of deception when caring for patients with dementia. Previous research within residential/care homes, found that 96% of staff reported using deception when caring for dementia residents. An example of a situation when deception might be considered is when a person with dementia asks to see a deceased family member because they cannot recall that they have passed away. Whilst some people think that staff should never lie to their patients, others suggest that using deception in certain situations is in the best interests of a patient. Currently, there is little understanding of how staff on general hospital wards feel about this. Given the large number of patients with dementia on hospital wards, it is important to understand this area further.

Who is conducting the study?

The study is being conducted by Alex Turner, a trainee clinical psychologist at Lancaster University, as part of her doctoral thesis. The study is being supervised by [REDACTED]

[REDACTED] and [REDACTED]
[REDACTED]
[REDACTED] will be an advisor for the study.

Why have I been approached?

You have been approached because the research aims to interview staff within general ward settings who have direct contact with patients with dementia.

What is involved in the study?

If after reading this information you would like to hear more or feel that you would like to take part, you can send the Contact details form (see enclosed) in the freepost envelope provided, agreeing that you are happy to be contacted. Alternatively you can contact me (Alex Turner) directly on [REDACTED] or email on [REDACTED]

If you agree to take part, we can meet at a time and location convenient to you. This is most likely to be in a private room within the Trust site. At this meeting I will conduct an interview with you, to discuss your own views and experiences of using truth and deception in your care of patients with dementia. The meeting is likely to last approximately one hour and will be on a one-to-one basis. The interview will be recorded, and later transcribed. However, your name and other potentially identifiable details will not appear in the transcript. The information gathered will be analysed and written up in a report.

Do I have to take part?

Taking part in this study is completely voluntary; you may decline or withdraw at any time without having to give reason. Should you decline at any point, this will have no impact on your legal rights or employment within the Trust. Once your data has been anonymised and incorporated into themes it might not be possible for it to be withdrawn. However, every attempt will be made to extract your data, up to the point of publication, should you wish to withdraw. If you choose to take part, I will ask you to sign a consent form stating that you are happy to proceed.

It may be possible for interview to take place during work hours. However, if you would rather take part in the study out of work hours and this requires you to travel to the Trust specifically to take part, travel and parking expenses will be reimbursed up to the amount of £10. To receive these expenses back, please bring with you any tickets and receipts of your costs. Petrol expenses will be reimbursed on a mileage basis.

Are there any risks?

There are no risks anticipated in taking part in this study. However, if you experience any difficulty following participation you are encouraged to inform the researcher who will be able to discuss this with you.

Are there any benefits?

There are no direct benefits to participants as a result of taking part in the study.

What will happen to the results?

The results will be summarised and reported in my thesis and may be submitted for publication in an academic or professional journal or presented at conferences.

Will my taking part in the study be kept confidential?

The information you provide in the interview will remain confidential. The data collected for this study will be stored securely and only the researcher and supervisors will have access:

- Audio recordings will be encrypted (that is no-one other than the researcher will be able to access them) onto a password protected computer. These recordings will be destroyed following examination of the report.
- Interview transcripts will be kept securely on the university network during the analysis stage.
- Following write up and publication, interview transcripts will be kept securely in the possession of Lancaster University. After ten years they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study.

If what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality. Wherever possible, I will tell you if I need to do this.

Who has reviewed the study?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University. It has also been approved by the Research and Development department for this Trust.

Where can I obtain further information about the study if I need it?

If you have any questions about the study or would like more information before deciding to take part, please contact the main researcher:

Alex Turner, Trainee Clinical Psychologist

████████████████████
████████████████████

Or the academic supervisor:

████████████████████ Contact number ██████████,
e-mail: ██████████

Or the field supervisor:

████████████████████ Clinical Psychologist, Contact number: ██████████
e-mail: ██████████

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher who will do their best to answer your questions (see contact details above). If you remain unhappy or wish to complain formally, you can do this by contacting [REDACTED] at Lancaster University on:

[REDACTED], Acting Research Director, Doctorate in Clinical Psychology, Division of Health Research, Faculty of Health & Medicine, Furness Building, Lancaster University, Lancaster, LA1 4YT, Contact number: [REDACTED], e-mail: [REDACTED]

If you wish to talk to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Professor [REDACTED], Associate Dean for Research, Faculty of Health and Medicine, Lancaster University, Lancaster, LA1 4YD, Contact number: [REDACTED];

Thank you again for taking time to read this information. Please do not hesitate to contact me if you would like further information.

Appendix C. Contact details form



RELEVANT TRUST LOGO TO BE
INSERTED HERE

Contact Details Form

Date: 21.06.2013

Version: 2

Title of Project: **The use of truth and deception in dementia care: Constructing the experiences of staff on general hospital wards.**

Name of Chief Investigator: **Alex Turner**

Contact number: [REDACTED]

Email: [REDACTED]

Address: **Clinical Psychology, Faculty of Health & Medicine**
Furness Building
Lancaster University
Lancaster, LA1 4YF

Having read the information sheet provided, I am happy to be contacted by the researcher of the study, to be given more information about what is involved and to answer any questions I might have.

I understand that being contacted by the researcher does not mean I am obliged to take part in the study.

Name: Ward:

Job role:

Contact number:

E-mail address:

Please return the contact details form in the pre-paid envelope provided, or leave with your ward manager for the chief investigator to collect. If you would prefer, you can contact the researcher directly on [REDACTED], or via e-mail ([REDACTED]).

Recruitment will end once enough participants have agreed to take part in the study.

Thank you for your time.

Appendix D. Interview schedule

RELEVANT TRUST LOGO TO BE
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Interview Schedule**Date: 28.05.2013****Version: 1**

Title of Project: **The use of truth and deception in dementia care: Constructing the experiences of staff on general hospital wards.**

Can you tell me a bit about your role within the hospital and in particular your contact with patients who have dementia?

Can it be a challenge on a busy ward?

Is there a time when you have considered lying to a patient who has dementia (e.g. when they have been confused/upset)?

Can you describe the situation (ask for more than one situation if participant suggests it has happened often)?

Prompt: is there anything specific to hospital where lying is an issue?

How did you decide whether to lie or not?

Prompt: what was your thought process/ what were you thinking about?

Prompt: what helped you make the decision?

Prompt: what were your biggest concerns (if any)

Prompt: did it make a difference how well you knew the patient?

Prompt: is it something that you discuss with anyone?

Prompt: is there a difference in the type of patient

How long did you have to make the decision?

Prompt: did you make the decision straight away?

Prompt: did you go away to think about what to do?

Prompt: was there the opportunity for this?

Prompt: do you think you would have made the same decision if you had longer to think about it?

Prompt: have you seen others in the same situation?

How did you feel after the event?

How did the patient seem after the event?

What do you think now about the decision?

Prompt: Have you ever regretted your decision to lie/not lie?

Prompt: Were you pleased with your decision?

Prompt: Do you think your way of handling the situation had the effect you wanted?

Prompt: What was this effect?

Prompt: how did you know if it helped in the short term/the long term?

Prompt: what was the effect on you?

Are there times when you feel that deceiving patients or not telling the truth is more acceptable?

Prompt: were there any situations that you thought lying was OK and others when you felt that it wasn't?

Prompt: Are there different kinds of lies?

Prompt: When might you use different kinds of lies?

Do you worry that deceiving patients might be considered wrong?

Prompt: Do you feel that you are able to talk to your colleagues about it?

Prompt: Do you know if others do the same?

Prompt: Do you think its easier for some to lie than others e.g. different professions?

Prompt: Does talking about lying change your opinion about it (with colleagues if applicable or chief investigator during study)?

Prompt: Has your opinion about lying changed at all with time/working within the hospital longer?

Do you feel you are given enough support or guidance when making these decisions?

Appendix E. Consent form

RELEVANT TRUST LOGO TO BE
INSERTED HERE

Date: 28.05.2013**Consent Form****Version: 1**

Study Title: The use of truth and deception in dementia care: Constructing the experiences of staff on general hospital wards.

The aim of the current study is to gather the views and experiences of general hospital staff on the use of truth and deception when caring for patients with dementia. Before you consent to taking part in the study we ask that you read the participant information sheet and initial each box below, stating that you agree. If you have any questions or queries before signing the consent form please speak to the chief investigator, Alex Turner.

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study.
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.
4. I understand that audio recordings will be kept until the research project has been completed and examined.
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my employment or legal rights being affected.
6. I understand that once my data has been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication should I wish to withdraw from the study.
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.

8. I consent to information and anonymised quotations from my interview being used in reports, conferences and training events.

9. I understand that if it is thought that there is a risk of harm to myself or others, the chief investigator may need to share this information.

10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.

11. I consent to take part in the above study.

Name of Participant _____ **Signature** _____ **Date** _____

Name of Researcher _____ **Signature** _____ **Date** _____

I would like to receive an a summary of the final report to my e-mail address
e-mail address:

Appendix F. Debrief form

RELEVANT TRUST LOGO TO BE
INSERTED HERE

Debrief Form**Date: 28.05.2013****Version: 1**

Thank you very much for taking part in this study, I very much appreciate your time and expertise. I hope that you found it interesting to discuss your own experiences of working with patients with dementia. However, if after leaving our meeting, you feel that further support is needed it may be beneficial to:

- Contact me on the details below. I will be able to discuss your concerns with you and, if necessary, signpost you to relevant services.
- Speak to your line manager about how you are feeling.
- Speak to someone from Occupational Health within your Trust. They will be trained in dealing with staff concerns.
- The Alzheimer's Society provide factsheets covering a wide range of dementia related topics. These can be found at <http://www.alzheimers.org.uk/factsheets>

Following completion of the study a summary of the report will be provided to the ward. Additionally, a copy of the report can be e-mailed to you on the details you provided on the consent form if requested.

My details:

Alex Turner

Number: [REDACTED]

e-mail: [REDACTED]

Appendix G: Example of open and focussed coding for clinical support worker 2 (CSW2)

	Transcript Excerpt	Open Coding	Focussed Coding
1	R: Could you tell me a little bit about your role within the hospital?		
2 3	P: well, I'm clinical support and quite hands on with patients...erm...we are the ones that deal with their everyday care and well-being I suppose.	Providing every day care	
4	R: Right, OK, so you have quite a lot of direct contact with the patients?		
5	P: yes, we do a lot of washing and dressing and feeding, things like that	Direct contact with patients – hands on	Direct contact with PwD despite limited experience
6	R: and how long have you worked on this ward?		
7	P: about 5 years.	Minimum experience on ward compared to other participants	
8	R: and in the trust generally, how long have you been here?	First ward experience	
9	P: no, no, I came to this ward and I stayed.		
10	R: and have you had a lot of contact with patients that have dementia?		
11	P: yes, the majority of the patients we see have dementia.	Identifying large number of patients with dementia	Identifying large number of patients with differing presentations
12	R: right, and can that be a challenge?	Challenge of caring for PwD	
13 14 15 16 17	P: yeah it can be, when the ward is really busy it can be because they do need that extra help. There's lots of things that come into play with people with dementia, you can get one whose very subdued, and then you can get the complete opposite where they're very wandersome, or those that get really agitated so erm... and we have both, we can have both at the same time. We've had...lately there was 17 patients at one time out of 25 that had dementia. So there's lots of things that come into play.	Identifying different presentations of dementia Subdued, wandersome, agitated	
18 19	R: and how do you feel about caring for people that have dementia? Is it something you feel quite confident about?	majority of patients with dementia	Lacking confidence

<p>20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42</p>	<p>P: oh gosh no, it's hard because I don't really have a lot of experience. I used to work in catering before this job. So when I came here I thought I would just be helping people with feeding and stuff, I hadn't had any experience of looking after someone with dementia and it's very different. So I don't really know what I'm doing half the time, you just have to do what you thinks best.</p> <p>R: and how do you do what you thinks best?</p> <p>P: I suppose I just try and spend as much time as I can with the patients so that they know who I am. I don't know if they really remember me from day to day, but I think if they know me, they might feel a bit more comfortable around me and then I might know them better.</p> <p>R: and do you think it's important to know them better?</p> <p>P: I think it's important to have a relationship with them, a professional one of course, but you are caring for them after all, so you can't really be a total stranger to them, you have to try and make it nice for them. It's not always easy though, I mean, I can spend time with them when I'm washing them and stuff, but then you have a whole bay of other patients so you have to be quite quick with it...but I like to try and get to know them as best as I can.</p> <p>R: but you mentioned that can be quite difficult?</p> <p>P: yeah, I mean, it's hard with patients that have dementia, because you don't always know what's right do you. They might tell you something but it don't always mean it's right! Sometimes they'll tell you something like they have kids who are young, like 12 or 13 or something...but you know that cant be true...you know, if they are like 80 odd! So sometimes you have to take everything they say with a pinch of salt. But that makes it hard to know what to say to them sometimes. Do you nod along and agree with them or do you say, no, I think your kids must be a bit older than that now.</p> <p>R: and what do you think you would do in that situation?</p> <p>P: God knows!</p>	<p>Lacking confidence and lacking experience Expecting role to be different Doing what thinks best</p> <p>Trying to spend time with patients Suggesting patients will feel more comfortable with staff they know Uncertain if patients remember</p> <p>Importance of having a relationship Needing to know patient to care for them Getting to know PwD restricted by time and other patients Doing your best</p> <p>Uncertainty of what is correct Information from PwD not always correct Assuming information isn't</p>	<p>and guidance so 'doing what thinks best'</p> <p>Developing relationship with PwD aids care but restricted by time</p> <p>Going off guesswork</p>
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43	R: is there any times when you have thought it best to lie to a patient with dementia?	correct	
44	R: erm...I don't know if I would lie lie like that. I think if someone asked me a difficult question, I would	Taking with a pinch of salt	
45	try and find a way around it.	Nod and agree or correct?	
46	P: and what kinds of difficult questions might they ask?:	Uncertain of response to give	
47	R: well they often ask for their mum and dad or something like that, or a husband, yeah, they quite	Wouldn't "lie lie"	Lying language
48	often ask to see their husband.	Finding ways around lying	Avoiding lying
49	P: and what might you say if someone asked for their parents?	Requesting deceased relatives	
50	R: well, I don't know really. I mean, I guess you would assume that their parents are no longer with us,		
51	especially some of the people we get in here, most of them are quite elderly. But you never know do		
52	you. You might have someone who's 75 or something in here and you would assume their mum or		
53	whatever is dead, but they might not be, they might be hitting 100, but that doesn't mean they're		
54	dead! Not nowadays! So its hard in those situations to know what to say.		
55	R: what specifically makes it hard?	Assuming elderly relatives no longer alive	Going off
56	P: well, I mean, I don't know do I. I might spend time with that patient, but I don't actually get to	Acknowledging guess work may be incorrect	guesswork may be incorrect
57	know much actual information about them. I don't do handover and I don't read their notes, so its not	Difficulty 'knowing what to say'	
58	like I can even say "hold on one second", then go and check their notes to see if they do still have		
59	family that are still alive. I cant do that, so I'm kind of just guessing. It makes it hard to know what to		
60	say to them.	Spending time with pt doesn't provide accurate information	Feeling excluded
61	R: and what do you think that you would say, given that you don't always get all the information	Being excluded from information sharing	
62	about that person?	Guessing makes responding	
63	P: well if they wanted their mum or whatever, I might just try and change the subject or distract them		
64	with something else.		

<p>65 66 67 68 69 70</p>	<p>R: and does that generally work?</p> <p>P: Sometimes, not all the time. Depends how het up they are and things. Sometimes there’s just no distracting them, they want what they want and they want it now...they can get quite angry about it. Then it doesn’t normally work, but if I can try and distract them somehow I will do.</p>	<p>difficult</p> <p>Changing the subject Distracting</p> <p>Distracting not always successful Distracting less successful when patient agitated Acknowledging patient anger Distracting first option</p>	<p>Distracting as preferable option</p> <p>Distracting less successful with limited time and agitated patients</p>
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Appendix H. Example of focussed codes and theoretical codes that led to conceptual category: 'Staff interpretations of role/responsibility and 'knowing the person''

Example of focussed codes	→ Theoretical codes	→ Conceptual category
<ul style="list-style-type: none"> • Developing relationship with patient assists care • Knowing the patient and how they might react • Gathering knowledge of patients and their trust helps to tell the truth • Being able to identify what will calm patient down • Understanding their challenging behaviour • Gathering information about patients facilitates engagement • Changing tactic to find what works • Avoid lying or telling the truth when don't know patient • Building rapport • Learning how patient will react • Need to know everything or nothing 	Getting to know the patient	Staff interpretations of role/responsibility and 'knowing the person'
<ul style="list-style-type: none"> • Feeling information is not shared • Unable to attend handover • Unable to read documentation • Left to fend for self • Us and them (qualified and non-qualified) • Nobody to ask – so 	Feeling excluded from care role	

<p>do what thinks best</p> <ul style="list-style-type: none"> • Information only shared with some • Responding based on guess work 		
<ul style="list-style-type: none"> • Somebody else’s responsibility • Handing responsibility over to the nurses • ‘Passing the buck’ • Irrelevance of experience • Not in a place to cause upset • Avoiding confrontation • considering other patients • I’m only a... • Patients want to talk to those in charge • A family’s responsibility • Keeping out of their way • Doing what I’m here to do • Playing dumb 	<p>Excluding self from responsibility</p>	
<ul style="list-style-type: none"> • Feeling restricted by time pressures • Other patients to care for • Attending wards for brief periods • Getting to know patients takes unavailable time • Needing to calm down quickly • Truth takes time • Distracting takes time 	<p>Lacking the time</p>	

<ul style="list-style-type: none"> • Time restricted care • Time for the necessities of care, not the desirables • Passing the buck adds to nurses time pressures 		
<ul style="list-style-type: none"> • Building rapport facilitates trust • Truth should come from staff they trust • Challenge of shift work in building trust • Shift work – confusing for patients • Lying can ruin trusting relationship • Not believing truth can ruin relationship • Needing consistency in response to maintain patient’s trust • Distracting maintains trusting relationship 	<p>Building Trust</p>	

Appendix I. Example of memos relating to 'Lying' in 'Responding to the situation'

Memos from 'Lying' Found in 'Responding to the Situation'	Date of Memo & Part of Transcript to Refer to (if applicable):
<ul style="list-style-type: none"> • When thinking about different kinds of lies, participants had different perspectives on what was a “lie lie” and what was a “white lie”. Generally, they suggested they would only tell “white lies” (or similar language), but for some, that included telling a patient that a deceased relative might be coming to see them. I wonder whether the language used allowed participants to move the boundaries of what they thought was acceptable (and maybe what I will think is acceptable). • The Domestic has an embedded word for lying. Instead of lying she says she is “humouring them”. This is possibly her way of making her response feel acceptable. Maybe identify other terminology used by other participants. Is this something they all do? • It appears as though it can take participants a while within the interviews to consider for themselves what constitutes a lie. Towards the end of interviews, it seems that they are more accepting to suggest that what they are doing is a form of deception. Maybe they are becoming more comfortable with me or maybe it is not something they have considered in depth before and therefore takes time within the interview to get to that stage of acceptance? • During the interviews, if I use the word ‘lie’, participants will often reframe my question and insert a 	<p>Date noted: 21/01/14 For specific examples see CSW 2 and Housekeeper</p> <p>Date noted: 19/12/13 See Domestic interview, line 341</p> <p>Date noted: 03/03/2014 See Staff Nurse and Ward Manager</p> <p>Date noted: 11/02/13 See CSW 1, Ward Clerk, & Student Nurse</p>

<p>different word for lie. For example, in the interview with the ward clerk I asked her “Do you worry then that they will think lying is wrong?”, to which she replied “yes, I do worry, but I don’t think it is, I don’t think a little white lie in that situation is wrong, it just calms them down”</p> <ul style="list-style-type: none"> • In another situation where I used different language to that used by the participant, it felt as though it shut her response down. In future interviews, I should try and stick to the language of that participant. This might also help them to feel more comfortable with me and feel as though I understand where they are coming from. However, when I made the same mistake with the housekeeper, she felt confident in arguing that she did not see what she was doing as ‘lying’. Maybe this depends on the character of the participant. • Participants seem to suggest that to ensure medication is taken, it is OK to lie. This is the only example so far where participants have been very clear that this is an example of deceiving patients and that they are happy to do so. The ward sister suggested she would “lie through her teeth” to make sure a patient was taking appropriate medication. This might be because she feels she will get into more trouble if that patient became unwell, than she would if she were seen to be lying. Are some things more acceptable to lie about? Is that because they are in a medical setting where the aim is to improve the physical health of patients so that they can be discharged? • It is interesting what participants perceive to be deception. It seems that they only see blatant lies as deception whereas other tactics such as distracting the patient is not. I wonder 	<p>Date noted: 18/01/14 See Domestic and Housekeeper</p> <p>Date noted: 03/04/14 See Ward Manager, Doctor and Ward Sister</p> <p>Date noted: 11/04/14</p>
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whether anything but telling the truth is deceptive? Do they feel guilty for distracting or is that a way to reduce the guilt?	
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Appendix J. Excerpt from reflective dairy 07/02/2014

It was interesting to see how the clinical support workers found it frustrating that they were not included in a number of information sharing opportunities on the ward. When I worked as a nursing assistant, I myself found this particularly frustrating, not only because it meant that you did not feel as though you knew that background to the individuals you were caring for, but also because it felt difficult to share important information with the rest of the team. As a nursing assistant, particularly one that was part time, you were not encouraged to make entries in patient documents. Therefore, although you could pass information on to the nurse in charge, it was common that this was either not documented or not shared e.g. in handover. Given that as a nursing assistant (or clinical support worker) you spent the most amount of one to one time with patients, it felt as though useful information that could help to improve the care or experience of that person was not being utilised.

However, in this research, while the clinical support workers and other non-qualified staff talked about the frustrations of not being able to receive information about their patients, they did not really talk about the frustrations of not being able to share their own information. Therefore, it is important in my write up that I do not assume my own reflections on to the participants. This might be because they didn't feel particularly comfortable sharing information about lying, and instead wanted to receive information and advice.

*Appendix K. Author guidelines from Aging & Mental Health***Instructions for authors**

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1. General guidelines

- Manuscripts are accepted only in English. Any consistent spelling and punctuation styles may be used. Please use single quotation marks, except where ‘a quotation is “within” a quotation’. Long quotations of 40 words or more should be indented without quotation marks.
- Manuscripts may be in the form of (i) regular articles not usually exceeding **5,000 words** (under special circumstances, the Editors will consider articles up to 10,000 words), or (ii) short reports not exceeding **2,000 words**. These word limits **exclude** references and tables. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate Funding paragraph, as follows:
For single agency grants :
This work was supported by the <Funding Agency> under Grant <number xxxx>.
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- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

Section Three: Critical Appraisal

My Research Process

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Overview of the findings

Deceptive practice has been shown to be endemic in dementia care, particularly within long-term care settings (James, Powell, Smith, & Fairbairn, 2003). The empirical paper adds to the growing literature by developing an understanding of the decision-making processes of general hospital staff when choosing how to respond to patients with dementia. The findings corroborate certain aspects of the research conducted within long-term care settings, suggesting that staff commonly engage in what might be deemed deceptive practices or avoidance of the truth. However, rather than suggesting they lie, participants were more likely to attempt other methods such as distracting the patient or “passing the buck” (CSW1, 78) to another member of staff.

The findings also identify differences between qualified and non-qualified staff in the process of coming to that decision. Both staff groups referred to their relationship with the patient and perceived responsibilities on the ward. However, in doing so, identified challenges inherent in their job roles that placed the other in a better position to tell the truth. Additionally, both referred to different ethical frameworks as part of the decision making process, which again influenced how they might choose to respond.

This critical appraisal aims to reflect upon key aspects of my research journey, including decisions made and challenges overcome. These reflections are organised into six categories that consider my own decision-making process: choosing and reflecting upon the research area, choosing an appropriate methodology, recruiting participants, conducting the interviews, analysing the data, impact of the research on self and future practice, and disseminating the findings.

Category one: Choosing and reflecting upon the research area

My interest in the use of deception in professional practice arose from several previous experiences. Prior to clinical psychology training, I worked as an assistant psychologist within a Memory Assessment Service (MAS). This was predominantly working with people with suspected or diagnosed dementia and their family members. Early on in this role, when observing supposed ‘diagnostic’ appointments, I was often left confused as to what the outcome had been for that client. Understandably, the disclosure of a diagnosis is a difficult part of a clinician’s practice (Bamford et al., 2004; Iliffe, Menthorpe, & Eden, 2003), particularly when the diagnosis is not clear (Alzheimer’s Society, 2014). However, there were occasions when consultants appeared reluctant to provide a known diagnosis or even suggest the word dementia. I wondered how a lack of clarity would impact upon those receiving this information and why an individual so qualified in their field might be reluctant to provide a clear and honest answer.

The hesitancy of psychiatrists and geriatricians to provide a diagnosis of dementia is reflected in the literature. Two reviews have suggested that disclosure of a dementia diagnosis is not standard practice (Bamford et al., 2004; Carpenter & Dave, 2004). Indeed, a survey of old age psychiatry consultants showed that the majority “rarely” or only “sometimes” informed their patients about the diagnosis and almost never about the prognosis (Marzanski, 2000). This is likely to improve given the current strive to close the diagnosis gap (Benbow, Jolley, Greaves, & Walker, 2013). However, having now considered this in light of my own data, it may seem more paradoxical that participants, with limited experience in dementia care, unanimously reported that they would remain truthful when giving health diagnoses to patients with dementia. Taking the research further, it would be interesting to identify whether consultants within MAS’ consider the withholding of

diagnostic information as a form of deception and how this might fit with their own ethical frameworks.

I also worked as a nursing assistant within an acute psychiatric ward for older adults. Here, I gained first-hand experience of some of the difficult questions or situations that were identified by participants within the empirical study. I found it particularly challenging when patients were distressed and asking for a loved one that I knew would not be visiting. I noticed I would often resort to deceiving patients or attempting to turn that person's attention to something else. However, I regularly questioned whether this was an appropriate way to respond. While I would have considered it to be in the interests of the person for whom I was caring, I also believe my choices to deceive were due to my own personality and desire to "rescue" people rather than see them upset. Such traits are often exhibited by those in caring professions (Gabbard, 2010).

Throughout this research, I felt it important to note and reflect upon this experience as I was conscious that it might influence the questions I asked or responses I expected to hear from participants (Murray, 2003). Given my own assumptions that self can impact upon the way we choose to respond, I was surprised that participants did not report similar considerations. I question whether this represents a reluctance to identify one's own needs within a face to face interview and whether a quantitative methodology would have uncovered contrasting perspectives (James, Wood-Mitchell, Waterworth, Mackenzie, & Cunningham, 2006). This may be one of the limitations of doing face to face interviews when discussing a challenging topic.

Overall, these pre-training experiences made me question whether others consider it acceptable to deceive, and how that decision is made. Given the current strive to improve the care of patients with dementia in general hospitals (Department of Health, 2012), it felt

timely to consider whether the issue of deception transferred to these settings. I also had a personal interest, given my understanding of some of the challenges associated with working on a ward environment.

Category two: Choosing an appropriate methodology

As discussed, the purpose of the research was to identify the decision-making processes of general hospital staff when choosing whether to deceive patients with dementia. Initially, I was tempted to revert to methodologies I had more familiarity with, such as IPA (interpretive phenomenological analysis). However, the purpose of IPA is to examine the lived experience of a phenomenon (Smith & Osborn, 2003). Therefore, while this may have provided interesting data, I questioned whether this approach would fully support the research aims and consider the process of *how* and *why* general hospital staff chose to respond in a particular way. Alternatively, Grounded Theory (GT) aims to develop an explanatory theory of basic social processes within a particular context (Starks & Trinidad, 2007). It also gives way to a conceptual model, moving away from a purely descriptive process, to develop a more theoretical understanding of the findings. Again, this appeared to provide a better fit with the research aims.

Additionally, given my novice status, it was important to consider the methodological approaches used in prior research. Much of the qualitative research has used a GT approach (Cunningham, 2005; Day, James, Meyer, & Lee, 2011; Tuckett, 2012). Cunningham (2005) developed a theoretical model from staff in long-term dementia care settings which encapsulated the factors affecting how they chose to respond to residents. Given that this resembled the purpose of my own research, albeit within a different context, it felt appropriate to consider using a similar methodology that might allow comparison of the

findings. For example, Cunningham (2005) similarly identified that knowing the person with dementia was important, however, differed in how willing participants were to tell the truth.

With only a limited understanding of GT, I was faced with the challenge of navigating my way through the methodological options in order to identify which version of GT to use. GT comes in various forms, along a continuum of a more positivist perspective (e.g. Glaser & Strauss, 1967) to a social constructivist approach (Charmaz, 2006). As well as considering the needs of the research, it is also important to consider one's own epistemological stance when making methodological decisions (Breckenridge & Jones 2009). My personal view is that every perceived truth is open to interpretation and that an individual's own values and beliefs impact upon their experiences. Therefore, as researchers, we can at best aim to develop an *interpretive* understanding of participant accounts. As an epistemological stance, constructivism (Charmaz, 2006) asserts that reality is constructed by individuals as they assign meaning to the world around them (Appleton & King 2002). Therefore, contrary to some of the more positivist approaches, it challenges the belief that there is an *objective* truth that can be captured by the researcher (Crotty 1998). I believed my own epistemological stance married well with the Charmazian position.

Category three: Recruiting participants

Initially, my supervisors and I discussed whether it would be appropriate to focus upon recruiting only qualified nurses, as it was felt they were likely to have the most direct contact with patients and would provide a relatively large recruitment pool. However, given my prior experience, particularly as a nursing assistant, I felt strongly that it was important for anyone with direct patient contact to have the opportunity to take part. As suggested in my reflective diary extract (Appendix J of empirical paper), it is easy for these voices to be lost within a ward context.

My primary concerns regarding recruitment were that professionals may be reluctant to discuss their use of deception, or take part in a study that they may feel questioned them ethically (Shaw, 2003). Indeed, in the initial stages of recruitment, ward managers suggested that staff were reluctant to be involved. In the participant information sheet (Appendix B of empirical paper) I had attempted to reduce anxieties by acknowledging the extent of lies within different settings. However, having taken the time to consider my own practice for the purposes of this research, I can acknowledge the difficulty in talking candidly about lying. This was also reflected in the current findings where a number of participants suggested they were reluctant to lie because of long-standing beliefs that “lying is wrong” (Ward Clerk, 24).

Although recruitment started slowly, a range of staff members soon expressed an interest in taking part. As I conducted the interviews it became apparent that participants had spoken to one another about the purpose of the research. I initially questioned whether this would have any implications for confidentiality. However, given that participants were choosing to share this information, there was little that I as a researcher could do to prevent it (Barreteau, Bots, & Daniell, 2010). On a positive note, hearing the experiences of those interviewed may have allowed others to feel more confident in engaging with the research. Additionally, a lack of communication was identified as a particular issue in need of addressing within the empirical paper. Therefore, discussing the research with one another may have helped initiate communication regarding the use of deception with patients with dementia.

Recruiting participants who were more transient on the ward, such as doctors, physiotherapists and occupational therapists, continued to prove challenging throughout the process. I have continued to question what made recruitment of these professionals so difficult. Firstly, being transient members of staff, they may spend such limited time on each ward that, logistically, taking part is difficult. Indeed, within the interviews, the doctor and

physiotherapist alluded to their busy schedule and the brief time they spend in each location. Additionally, as discussed, a number of participants signed up to the study after having spoken to other colleagues. It may be unlikely that transient professionals had opportunity for similar discussions. Finally, given that the doctor and physiotherapist suggested they would “pass the buck” or remain truthful to patients, similar professionals may have felt the study was not relevant to their practice as they do not consider themselves to use deception.

Consequently, given that I considered this one of the main limitations to the study, it feels important to question whether interviewing other professionals in these transient roles would have provided further insights. It is possible that additional interviews would have simply cemented some of the ideas that already started to emerge. Interestingly two participants (domestic and ward clerk), suggested that “females were more caring than males” and were therefore more likely to avoid telling the truth to prevent upset. Both the doctor and physiotherapist were male, and while they suggested they would remain truthful when discussing medical aspects of patient care, they also commonly “passed the buck” to qualified nurses in response to more “trivial” (Doctor, 99) questions. Through further interviewing, possibly with female professionals in these roles, it may have been possible to ascertain whether their responses were related to their sex, their transient positions on the ward or their medical training and focus upon physical health (Borbasi, Jones, Lockwood, & Emden, 2006; Moyle, Borbasi, Wallis, Olorenshaw, & Gracia, 2010).

Category four: Conducting the interviews

When conducting the interviews, I was initially apprehensive about the potential for participants to disclose professional practice that might be considered unsafe or unethical. Indeed, the risk of interviewees revealing more than they intended, in response to a rapport with the researcher has been identified (Kvale, 1996). However, I was also conscious that

facilitating participant disclosures was an important part of the interviewer role (Dickson-Swift, James, Kippen, & Liamputtong, 2007). As with most research, it was made clear within the participant information sheet that confidentiality might have to be broken if “what is said in the interview makes me think that you, or someone else, are at significant risk of harm” (Appendix B of empirical paper). However, given the ambiguity of the research area, I was uncertain of what practice might be considered ‘unsafe’. As has been highlighted within the empirical paper and previous research, perspectives around the use of lies are subjective and often open to interpretation (Bender, 2007; Hertogh, The, Miesen, & Eefsting, 2004).

Early on in the research process, I raised these concerns with my supervisors. It was agreed that if participants discussed situations that I found questionable, I would terminate the interview, cautiously inform the participant of my concerns and contact a supervisor immediately. Fortunately, no such concerns were raised. With hindsight, I was particularly relieved that participants suggested they would attempt to tell the truth to patients with regard to health diagnoses. This made me consider my own ethical framework and whether I would have considered any other type of response as ‘ethical’.

Additionally, I was cautious of participants asking me to divulge my own experiences regarding the use of deception in dementia care. While I do have a stance on lying, I was conscious that I did not want this to influence what participants chose to disclose or encourage them to become ‘complicit’ with my own way of thinking. The guidance around self-disclosure is varied (Abell, Locke, Condor, Gibson, & Stevenson, 2006; Hill & Knox, 2001; Rapley, 2004). It has been suggested that a neutral researcher can sometimes be seen to treat participants simply as “research objects” (Rapley, 2004, p. 19). On the other hand, other authors suggest that anything other than a neutral stance will bias the story (Weiss, 1994) and therefore researchers should refrain from any form of self-disclosure (Abell et al., 2006).

Personally, while acknowledging the need for certain boundaries within a therapeutic setting, I find the concept of being a “blank canvas” (Martin, Gaske, & Davis, 2000) challenging. I was also conscious of feeding into a culture that is already reluctant to communicate about the use of deception. This feeling became particularly prominent as the interviews progressed and themes about the impact of limited communication began to emerge. I therefore tried to draw upon my developing skills as a therapist; attempting to balance a neutral stance whilst facilitating open discussion.

In order to create this balance, it became evident that I needed to utilise language similar to that used by participants (Polkinghorne, 2005). I initially spoke using very concrete terminology such as ‘lie’ and ‘deceive’. However, this had the potential to close discussions down. As data from the empirical study has highlighted, participants were reluctant to use such concrete language, possibly because of the cognitive dissonance it created (Cunningham, 2005). Dwyer and Buckle (2009) suggest that being seen as an “insider” can allow “more rapid and more complete acceptance” (p. 58), therefore facilitating greater openness. A qualitative interview is essentially a “social interaction” between the interviewer and interviewee (Pezalla, Pettigrew & Miller-Day, 2012, p. 166). By adopting a language style that fit with the interviewee, such as “telling a fib” or “humouring them”, I believe this ‘social interaction’ was more readily achieved and participants became more open in sharing their experiences.

Category five: Analysing the data

Having identified what I considered to be the most appropriate methodology, it took much work, both from myself and my supervisors, to ensure I was using GT effectively. Kiesinger (1998) suggests researchers often feel “terrified and overwhelmed” (p. 84) when beginning analysis, considering the vast amount of data collected. Being a novice to GT, I

was also conscious as to whether I was doing it “right”. One of the benefits of the Charmazian approach is that it is not prescriptive and allows for flexibility (Charmaz, 2006). However, during periods of frustration and uncertainty, I was often keen for something more structured and prescriptive to follow. Supervision was an invaluable resource during these times as it enabled me to keep on the ‘methodological track’, especially when I was tempted to engage with the data using more familiar methodologies.

I found the most challenging aspect of the analytic process was attempting to conceptualise data from participants within a range of professional disciplines. While a sample size of 12 is relatively small, it took a long time and a lot of reading and re-reading of the data to feel as though I was representing the nuances of individual accounts within the overall findings (Bird, 2005). On reflection, this was likely to be due to the heterogeneity of the sample. Recruiting a more homogenous sample (e.g. all nurses) may have proved simpler in identifying the decision-making processes of professionals within that one discipline. However, it would not have afforded us the insights that interviewing a range of staff allowed, for example identifying how role influences ones perceived ability to tell the truth or impacts upon the ethical framework one might use.

A number of qualitative researchers identify the benefits of encouraging respondent validation, in helping to refine participant explanations (Barbour, 2001). However, as well as potentially being unrealistic given time constraints for both researcher and participants, validation can also result in discrepant accounts (Mays & Pope, 2000). Given the somewhat controversial nature of the research topic, I questioned whether respondent validation would be appropriate. It took time for many participants to feel confident in opening up within the interviews. Therefore, hearing or seeing their transcripts at a later date may have made them concerned about their disclosures. Consequently, while I wanted the research to remain as

collaborative as possible, I believed it would be less anxiety provoking for participants to see their accounts in combination with that of other participants, within the final feedback report.

Category six: Impact of the research on self and future practice

It is inevitable that research will impact on the researcher in some way (Rager, 2005). Completing such an extensive piece of work and allowing myself to become so close to the emerging data has not only impacted upon me as a researcher, but also as a soon-to-be qualified clinician. In particular, it has encouraged me to think carefully about my own epistemological stance; something I have previously found quite challenging to identify. The process has cemented my assertion that a researcher can never show true objectivity, but by recognising their own assumptions, can work to enhance the integrity of their findings. Through documenting my thoughts throughout the research process, I was able to acknowledge my own experiences and pre-conceptions (Ortlipp, 2008). I found myself surprised at the potential influence these assumptions might have had on how I interpreted the research findings, had I not taken the time to reflect upon them. This is an approach I will take with me when engaging in future research; something I would hope to continue alongside clinical practice.

Engaging in this research has also helped me to consider the impact that a lack of communication can have on practitioners, particularly in care settings where there is often a pressure to act in the “best interests” of those for whom you are caring. As my findings have suggested, “best interests” can be an ambiguous and subjective term, with the potential to leave practitioners in a state of uncertainty. As psychologists, particularly trainees, it is easy to take for granted the luxury of receiving regular supervision. Following completion of the course, I will start my first qualified post within a memory assessment service. Given my previous experiences of working within this setting and the findings from the current study, I

would hope to encourage and facilitate good team reflection and open communication, particularly around topics that might be avoided or considered challenging (BPS, 2010).

The research has also encouraged me to consider how I choose to define deception. As the empirical paper has identified, the definition of 'deception' is subjective and often dependent upon the perspective of the researcher. I have chosen to take the stance that any response or action that intentionally avoids honesty is a form of deception. However, that does not imply that I believe deceptive practices to be wrong. There are a number of instances within therapeutic settings that we are not completely honest towards those with whom we work. For example, part of the process of formulation is often to try and guide clients to come to an understanding of their difficulties themselves, even if we know the direction we are taking (BPS, 2011). Similarly, well established therapeutic approaches, such as validation therapy (Feil, 1992), doll therapy (Godfrey, 1994) and aspects of reminiscence therapy (Woods, Spector, Jones, Orrell, & Davies, 2005) encourage practitioners to accept and engage with the reality of the person with dementia, no matter how far removed from their own. Arguably, such approaches are based upon the concept of deception and support its application. A number of professionals, including psychologists, were found to have negative attitudes towards lying in dementia care (Elvish et al., 2010). However, it may be argued that practices many of us engage in on a regular basis are based on some form of deception.

Category seven: Disseminating the findings

The dissemination of findings is an integral part of the research process. Not only does this honour the time and experiences of the participants, it also informs future research and clinical practice (British Psychological Society, 2006). Following its completion, I plan to feedback the results of the study to the wards where recruitment took place. Summary reports will also be provided. One of the clinical recommendations from the study was that

communication around the use of deception needs to improve within hospital settings. Thus, it will be interesting to identify whether discussions around this topic have increased following the research. This might be an area for future research. Managers from two of the wards that were approached to take part in the study declined to have the results fed back. This possibly reflects the reluctance of those in more qualified positions to initiate or be seen to encourage the use of deception, as identified within the study.

It is hoped that the literature review and empirical paper will both be submitted for publication in peer-reviewed journals. While a number of journals might be fitting, I plan to submit both to the journal 'Aging & Mental health'. This journal produces a number of papers dedicated to dementia research and much of the literature around lying in dementia care is published here. It also has a wide readership worldwide with an impact factor of 1.781. While a limitation of the current study was that it was conducted within a small geographical area of the UK, it is possible that the clinical implications and need for future research may be applied elsewhere. Therefore, encouraging a readership wider than the UK seems important.

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Section Four: Ethics Section

Alex Turner

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Research Protocol



RELEVANT TRUST LOGO TO
BE INSERTED HERE

Date: 21.06.2013

Version: 2

Title

The use of truth and deception in dementia care: Constructing the experiences of staff on general hospital wards.

Chief Investigator

[Redacted]

Supervisor(s)

[Redacted]

[Redacted]

Study Advisor

[Redacted]

Introduction

Dementia is a degenerative process describing a set of symptoms including memory loss, mood changes and problems with communication and reasoning (Alzheimer's society, 2013). Cognitive decline associated with dementia can also result in disorientation and confusion. Currently, around 800,000 people in England are living with dementia, which generally, although not exclusively, effects individuals over the age of 65. Approximately one in twenty people over the age of 65 are living with dementia and by the age of 80, about

one in five people are affected. With an ever aging population, it has been suggested that the number of individuals living with dementia is likely to double over the next twenty years (Department of Health, 2009).

Given that individuals living with dementia can become confused and disorientated, it can result in individuals living in care homes where they may feel better supported. However, it can become increasingly difficult for carers to know how to respond to people's different realities. Sometimes those caring for the person with dementia feel that the best option is to lie to the confused or disorientated person (James, Powell, Smith, & Fairbairn, 2003; Tuckett, 2012). An example of this might be when a person asks to see a deceased family member because they cannot recall that they have passed away. There has recently been an increase in the debate around the ethics of lying in the best interests of the person with dementia. This debate was raised in particular following a pilot study in Newcastle which reported the majority of care home staff used deception with their residents (James, Powell, Smith, & Fairbairn, 2003). More recently, the authors found that 96% of staff reported using lies in their work with dementia residents (James, Wood-Mitchell, Waterworth, Mackenzie, & Cunningham, 2006).

Some argue that using deception is just an easy way out (Sherratt, 2007) and simply "poverty of the imagination" (Walker, 2007, p. 30). It is suggested that in order to be person centred, one must be genuine, honest and respectful (Pool, 2007); without this, a therapeutic relationship cannot be successful. Those against the use of deception suggest that in most cases, such lies are for the benefit of the staff member placed in the difficult situation, rather than the person being cared for (Kitwood, 1997).

Conversely, others have suggested that using deception in certain situations is actually more caring for the individual and could be seen as more ethical if it gives the person with dementia reassurance and confidence (Zeltzer, 2003) and reduces distress e.g. of being repeatedly told that a loved one has passed away. Recent studies have argued that lies are in fact predominantly used for the benefit of the person with dementia (Wood-Mitchell, Cunningham, Mackenzie, & James, 2007) and can be a useful communication strategy to encourage those with dementia to open up and explore more about their past.

As the research suggests, deception in dementia care is clearly a controversial issue, where there is no definitive answer of what is the right course of action to take. Bender

(2007) highlights that professionals who raise issue with the use of lying are not usually those that have to deal with the situations in which lying is sometimes needed. It is generally front line care staff who find themselves in those difficult situations. Arguably therefore, it is those individuals that services need to hear.

Currently, the majority of research into deception in dementia is based in residential and care homes, gathering information and opinions from front line care staff (James et al., 2006; Tuckett, 2012) and residents with dementia (Day, James, Meyer, & Lee, 2012). As has been reported by James et al. (2006), the majority of these staff report using lies when caring for these residents. They have also stated however, that they would welcome further guidance on the use of deception (James et al., 2003). In response to this, Cunningham (2005) generated a model that looked into staff processes when deciding to lie and James et al. (2006) generated a list of guidelines to follow in situations where deception might be employed. Examples of these guidelines include, 'Lies should only be told if they are in the best interest of the resident, e.g. to ease distress' and 'Communication with family members should be required and family consent gained if a lie is to be told to the resident'. However, these guidelines only work if the residency is long-term and the resident and their family are well known to staff. In addition to James et al.'s (2006) study, Day et al. (2012) developed a conceptual model depicting people with dementia's perspectives towards lies in dementia care. Again, they felt that lying was acceptable only if it was done in the best interests of the person with dementia, depending upon the person lying, the person with dementia and the nature of the lie.

As the previous research highlights, there is no clear answer when it comes to the use of deception in dementia care. This is the case even in settings where dementia care is a prominent aspect of staff role, such as within residential homes. Here, it is likely that staff will either be trained in dementia care or have extensive contact or experience of caring for individuals living with dementia. However, it is important to consider that individuals with dementia do not just receive care within these residential settings and that, given our aging population, a large number of patients within general hospital settings might also have a diagnosis of a dementia. This is only going to become more prevalent. Currently, it is suggested that around two thirds of medical beds are occupied by people over the age of 65, with the prevalence of dementia at around 30% (Royal College of Psychiatrists, 2005). As research has suggested, hospital staff face similar dilemmas when it comes to using deception

in their care, with added medical pressures that this may involve, such as whether to share a medical diagnosis with a person with dementia (Elvish et al., in preparation).

The current study therefore aims to gather a greater understanding of the views and experiences of staff within general ward settings, around the use of truth and deception when caring for patients with dementia. In particular, it will examine the decision making processes of staff when choosing whether to deceive. This model may be helpful for services developing future guidelines around this issue for medical staff.

Aims

- The aim of the current study is to explore the issue of truth and deception and the attitudes of staff in general hospital wards when caring for patients who have dementia.
- To develop a model using a grounded theory method of analysis, identifying processes in decision-making by hospital staff when choosing whether to use truth or deception.
- The findings may help to inform the development of guidelines (as are available for staff in long-term care settings) to support general hospital staff in their care of people with dementia.

Overview of the study

Design

A qualitative approach will be used to address the aims of this study. Data will be gathered through the use of semi-structured interviews with a range of staff in general ward settings who have direct contact with patients that also have a diagnosis of dementia. This will include both professional and ancillary staff.

Participants

Participants will be recruited from general ward settings at [REDACTED] and [REDACTED]. If recruitment is difficult, additional Trusts may be approached. Initial inclusion criteria will be as follows:

- Participants will be staff based within general hospital wards.

- Participants will be recruited from wards that generally have a high proportion of older adult patients.
- Participants will have direct experience of working with patients who also have dementia. This will be professional and ancillary staff.
- Participants can be male or female and of any age.
- Due to not having the financial resources to pay for interpreters, participants must be English speaking. It is also considered that as interviews will be with staff members in an NHS setting, they will be English speaking.

Those that do not fit the inclusion criteria will be excluded.

It has been estimated that it will be realistic to expect to recruit between 10 - 15 participants within the time frame available for the project. However, given that a grounded theory method of analysis is intended, the number of participants required may vary depending on saturation.

Again, if it becomes clear that it will be difficult to recruit enough participants from [REDACTED], additional Trusts may be approached. Also, the number of wards approached for recruitment will be increased, however, only wards that have a high proportion of older adult patients will be utilised.

Recruitment Process

In order to gain approval for the study to proceed in the initial stages, contact has been made and authority given from dementia leads in both [REDACTED]. The dementia leads will provide details of wards that have a high proportion of older adult patients and inform ward managers of the study. Once ethical approval has been obtained and the chief investigator has received confirmation that ward managers are happy for staff to be approached, information packs will be given for them to distribute amongst their staff. These information packs will include an information sheet (see additional documentation) and contact details form (see additional documentation). The signed contact details form can be returned by post to the chief investigator in the pre-paid envelope that will be provided, or the chief investigator can be contacted directly using the details provided.

Alternatively, if managers are happy for the chief investigator to enter the ward to present the study and to assist with recruitment, information packs could be distributed by the chief

investigator in person e.g. during staff handover. This would also give staff members opportunity to ask any questions they might have and to sign up to take part if they wish to. Information packs will have contact details for the chief investigator so that potential participants can contact them at a later time if more appropriate.

Posters (see additional documentation) will also be placed in staff rooms advertising the study and advising where further information can be sought.

Materials

A semi-structured interview will be used to explore the views, experiences and decision making processes of staff of using truth and deception when working with patients with dementia in a general ward setting. The questions within the schedule are to be used as a rough guide, therefore they can be removed or modified, or additional questions may be included (in line with grounded theory methods of analysis), depending on the participants' responses (Smith, 2003). This will allow participants to recount their experiences in the way of their choosing, whilst ensuring that relevant areas are covered. Questions in the schedule have been developed based on previous research in care home settings and initial research in hospital settings. Support and advice was also obtained from supervisors ([REDACTED] [REDACTED]), the adviser for the study ([REDACTED]) and from an expert patient in the early stages of dementia.

All interviews will be audio recorded and transcribed for analysis. A reflective log will be kept to allow the interviewer to record their thoughts and feelings on the interview immediately afterwards. This will be used to reflect upon each interview and will be drawn upon during the analysis and write up stage.

Procedure

Once the information sheet has been given and contact details form has been obtained either in person or via participants returning the form, the chief investigator will contact the potential participant to see if they have any further questions about the study. Times and locations for the interview will also be arranged. Interviews will be held in a private room at the hospital, depending on location and availability. If interviews are agreed to take place during work hours, managers will need to know who has agreed to take part so this can be authorised on the rota or during quiet times on the ward. However, participants will also be

informed that they can take part after work hours. Participants will be informed that all information they give throughout the interview will be anonymised.

Each interview will take place for approximately one hour. They will be audio-recorded with the participant's consent (see consent form in additional documentation).

Once the interview has been completed the data will be transcribed and interpreted by the researcher. A summary of the final report will be given to the wards that took part and presented back to ward staff after completion if requested. A summary will also be e-mailed to each participant (if requested).

Proposed analysis

Once data has been gathered through semi-structured interviews, a grounded theory method of analysis will be used (Charmaz, 2006). The aim of grounded theory methods of analysis is to develop a theoretical understanding of a phenomenon that is 'grounded' in the data. It is particularly appropriate when theory is not already available for the specific research area (Strauss & Corbin, 1998). Given that there is limited theoretical understanding of how care-staff in general ward settings conceptualise their experiences of using truth and deception in dementia care, a grounded theory method of analysis is deemed appropriate.

Each transcript will first be subjected to open coding. This involves a line by line analysis of the meaning of the individual accounts in order to generate initial codes. Throughout this process, the researcher will write analytic notes of their initial thoughts on the emerging themes and their link to existing literature. Once complete, axial coding will be adopted, where large amounts of data codes will be separated, sorted and synthesised into core categories or themes. At this stage, the understanding of the data moves from a descriptive level to understanding it in terms of conceptual analytic units. These core categories will then be built into a conceptual model and theory; synthesising them with one another and existing literature.

A core concept of grounded theory methods of analysis is that recruitment, data collection and analysis are not separate stages of the research process but take place concurrently. In this way, analysis of the earlier interviews can inform subsequent recruitment and data collection. This therefore makes it easier in subsequent interviews to focus on areas identified as being particularly important and identify potential participants (eg. particular groups of staff) that may help to thicken the data. To enable this, the interview schedule may require

adaptation or refinement so that future interviews can provide greater information about the concepts identified in the initial stages of analysis.

Grounded theory methods of analysis generally aim to gather enough data from participants so that theoretical saturation is reached (Charmaz, 2006). This means that further data and data analysis would not provide any further insights into the area of study. However, at this stage of the research design, it is difficult to predict when theoretical saturation of the data may be reached and therefore how many participants will be recruited into the study.

However, based on previous research and the experience of the study supervisors and advisor, it is predicted that roughly 10-15 participants will enable theoretical saturation to be achieved.

Data storage

During the study, personal data (including phone numbers and e-mail addresses that were provided by participants on consent to contact forms) will be transferred to a word document and stored on the secure university network. This will be accessible at the chief investigator's home so that interviews can be arranged. Hard copies of contact forms will be destroyed. Personal data stored electronically will only be destroyed once the study is complete and summary reports have been written, so reports can be sent to participants (on email address provided). Consent forms will be kept at the University site, accessible only by the chief investigator, until completion of the study. They will then be stored securely by Lancaster University for ten years before being destroyed. The research director at Lancaster University will be responsible for data storage and deletion of data once the chief investigator has completed the course ([REDACTED]).

All interviews will be recorded onto a portable audio device. As soon as possible following the interview, the audio recording will be transferred from the portable device and encrypted and saved onto a password protected computer. In the meantime, the recorder will be stored securely. The audio recording will then be deleted from the portable device. Audio recordings will be transcribed within three months of the interview taking place. Transcriptions will be anonymised and all identifiable data will be removed. These anonymised transcripts will be stored on the secure university network. Access to transcription data will be restricted to the chief investigator and supervisors ([REDACTED] [REDACTED]). Following completion of the study or publication, transcripts will be stored

securely by Lancaster University for ten years before being destroyed (separate from consent forms). The research director at Lancaster University will be responsible for data storage and deletion of data once the chief investigator has completed the course ([REDACTED] [REDACTED]). Audio recordings will be deleted from the password protected computer following examination of the thesis report.

Potential ethical issues

If interviews are taking place during work hours, managers will need to allow access to staff and therefore may have knowledge of who has agreed to take part. Interviews will also need to take place on hospital premises and therefore staff may be seen taking part. However, all identifiable information given in the interviews will be anonymised and pseudonyms used throughout. Staff will also be given the option to take part in the study out of working hours.

Interviews with participants will be audio recorded and transcribed. All transcripts will be anonymised. Participants will be informed that the supervisors of the research project may see the interview data but will not see the names of those taking part. Every effort will be made to anonymise any quotes that are used directly from the transcripts within the write up (i.e. changing all real names, places and events).

Staff may be concerned about discussing the use of deception when caring for their patients. However, the information sheet will highlight how research has found this to be a common issue for staff and will therefore acknowledge the difficulties associated with it. Participants will be informed that the purpose of the study is to gather the thought processes of general ward staff on the use of deception. This will enable staff to talk about the difficulties and think about their own practice. This may inform future practice.

Participants will be informed that if there is anything said in the interview that suggests risk of harm to anyone including the interviewee or a patient within the service, the researcher might have to speak to their supervisor or other safe-guarding professionals. Participants will be informed if and when this may happen wherever possible.

It will be made clear within the information sheet and consent form that participation is voluntary and participants have the right to withdraw at any time, without their employment of legal rights being affected. However, they will be informed that once their data has been anonymised and incorporated into themes it might not be possible for it to be withdrawn. In this case, every attempt will be made to extract their data, up to the point of publication.

Participants will not have to answer any questions that they do not want to. Participants will also receive a debrief sheet following the interview.

Service user/public involvement

During the proposal stage of the study, presentations were peer reviewed to gather feedback and to raise any potential problems. There was public involvement from service users from the Lancaster University Public Involvement Network (LUPIN) during the proposal stage.

The interview schedule was also put together with assistance from a person in the early stages of dementia.

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research

Instructions

1. Apply to the committee by submitting
 - ✓ The University's Stage 1 Self-Assessment Form (standard form or student form) **and** the Project Information & Ethics questionnaire. These are available on the Research Support Office website: [LU Ethics](#)
 - ✓ The completed FHMREC application form
 - ✓ Your full research proposal (background, literature review, methodology/methods, ethical considerations)
 - ✓ All accompanying research materials such as, but not limited to,
 - 1) Advertising materials (posters, e-mails)
 - 2) Letters of invitation to participate
 - 3) Participant information sheets
 - 4) Consent forms
 - 5) Questionnaires, surveys, demographic sheets
 - 6) Interview schedules, interview question guides, focus group scripts
 - 7) Debriefing sheets, resource lists
2. Submit all the materials electronically as a **SINGLE** email attachment in PDF format. Instructions for creating such a document are available on the FHMREC website (<http://www.lancs.ac.uk/shm/research/ethics/>).
3. Submit one collated and signed paper copy of the full application materials. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.
4. Committee meeting dates and application submission dates are listed on the research ethics committee website <http://www.lancs.ac.uk/shm/research/ethics>. Applications must be submitted by the deadline stated on the website, to:

Diane Hopkins
Faculty of Health & Medicine
B03, Furness College
Lancaster University, LA1 4YG
d.hopkins@lancaster.ac.uk

5. Attend the committee meeting on the day that the application is considered.

<p>1. Title of Project: The use of truth and deception in dementia care: Constructing the experiences of staff on general hospital wards.</p>
<p>2. If this is a student project, please indicate what type of project by ticking the relevant box:</p> <p> <input type="checkbox"/> PG Diploma <input type="checkbox"/> Masters dissertation <input type="checkbox"/> MRes <input type="checkbox"/> MSc <input type="checkbox"/> DClInPsy SRP <input type="checkbox"/> PhD Thesis <input type="checkbox"/> PhD Pall. Care/Pub. Hlth/Org. Hlth & Well Being <input type="checkbox"/> MD ✓ <input type="checkbox"/> DClInPsy Thesis <input type="checkbox"/> Special Study Module (3rd year medical student) </p>
<p>3. Type of study</p> <p>✓ <input type="checkbox"/> Involves direct involvement by human subjects</p>

Involves existing documents/data only. Contact the Chair of FHMREC before continuing.

Applicant information

4. Name of applicant/researcher:

Alex Turner

5. Appointment/position held by applicant and Division within FHM

Trainee Clinical Psychologist

6. Contact information for applicant:

[Redacted]

[Redacted]

7. Project supervisor(s), if different from applicant:

[Redacted]

[Redacted]

[Redacted]

8. Appointment held by supervisor(s) and institution(s) where based (if applicable):

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

9. Names and appointments of all members of the research team (including degree where applicable)

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

The Project

NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. Summary of research protocol in lay terms (maximum length 150 words).

The research aims to gather the views and experiences of general hospital staff on the use of deception when caring for patients with dementia. It has been suggested that 96% of residential and nursing home staff use lies in their work with people with dementia (James, Wood-Mitchell, Waterworth, Mackenzie, & Cunningham, 2006). It has been suggested that this is predominantly in the best interests of the person with dementia. Examples of situations where lying may occur include when a patient is asking for a loved who they cannot remember passed away years ago. There is currently much emphasis on the care of people with dementia in general hospitals (Department of Health, 2009) and research has suggested that hospital staff face similar dilemmas as residential staff when it comes to using deception in their care, with added medical pressures such as whether to share a medical diagnosis with a person with dementia (Elvish et al., in preparation). This research currently in preparation suggests this is an area that requires further elaboration. The aim is therefore to i) to develop a model using grounded theory methodology which identifies processes in decision-making around the use of deception by general hospital staff; ii) potentially inform the development of future guidelines to support general hospital staff in their care of people with dementia.

11. Anticipated project dates

Start date: Sept 2013 End date: May 2014

12. Please describe the sample of participants to be studied (including number, age, gender):

Participants will be staff working in general wards (that predominantly have a high population of older adults). Participants can be any staff member that has direct contact with patients, whether this be professional or ancillary staff. Participants will have had experience of working with patients that have dementia (as well as the illness that has brought them into hospital). There will be no restrictions on age or gender. I aim to recruit between 10 and 15 participants.

13. How will participants be recruited and from where? Be as specific as possible.

In order to gain approval for the study to proceed in the initial stages, contact has been made with senior dementia leads in both [REDACTED] [REDACTED]. The dementia leads will provide details of wards that have a high proportion of older adult patients and contact ward managers to inform them of the study. Once ethical approval has been obtained and the chief investigator has received confirmation that ward managers are happy for staff to be approached, information packs will be given for them to distribute amongst their staff. These information packs will include an information sheet (see additional documentation) and contact details form (see additional documentation). The signed contact details form can be returned by post to the chief investigator in the pre-paid envelope that will be provided, or the chief investigator can be contacted directly using the details provided.

Alternatively, if managers are happy for the chief investigator to enter the ward to present the study and to assist with recruitment, information packs could be distributed by the chief investigator in person e.g. during staff handover. This would also give staff members opportunity to ask any questions they might have and to sign up to take part if they wish to.

Information packs will have contact details for the chief investigator so that potential participants can contact them at a later time if more appropriate.

Posters will also be placed in staff rooms advertising the study and advising where further information can be sought.

14. What procedure is proposed for obtaining consent?

Once participants have stated an interest in taking part, times and locations for the interview will be arranged. If interviews are able to take place during work hours, this will need to be done in accordance with the ward manager so that participation can be authorised on the staff rota. Interviews can also take place out of working hours if participants would prefer. Prior to the interviewing starting, participants will have an opportunity to discuss any questions they may have. They will then be asked to sign a consent form stating that they are happy to proceed.

15. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

Staff may be concerned about discussing the use of deception when caring for their patients. However, the information sheet will highlight how research has found this to be a common issue for staff and will therefore acknowledge the difficulties associated with it. It will be highlighted in the information sheet that research has shown deception to be commonly used in dementia care in residential settings, generally in the best interests of the person with dementia. Participants will be informed that the purpose of the study is to gather the thoughts and experiences of general ward staff on the use of deception. This will enable staff to talk about the difficulties and think about their own practice. This may help to inform future policy and practice.

Participants may not want others to know that they are taking part. However, managers may need to allow access for participation of staff during work hours. Interviews will also need to take place on hospital premises and therefore staff may be seen to be taking part. However, participants will be informed that all identifiable information given in the interviews will be anonymised.

Staff may feel obliged to take part. It will be made clear within the information sheet and consent form that participation is voluntary and participants have the right to withdraw at any time, without their employment or legal rights being affected. However, they will be informed that once their data has been anonymised and incorporated into themes it might not be possible for it to be withdrawn. Participants will not have to answer any questions that they do not want to.

Staff may feel uncomfortable asking managers for time off from their shift to take part in the study. It will be made clear to staff (both by managers and the chief investigator) if managers have given their approval for staff to take part during work hours. Interviews will be arranged at a time and location that is convenient.

All participants will receive a debrief form following the interview.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).

There should be no risks to the researcher, as they will be interviewing staff members in a hospital location. Should the researcher have any worries or concerns, these can be discussed with either their academic or field supervisor.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There are no direct benefits to participants as a result of taking part in this study.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

If participants take part in the study out of work hours and this requires travelling to the trust specifically to take part, travel and parking expenses will be reimbursed up to the amount of £10.

19. Briefly describe your data collection and analysis methods, and the rationale for their use

Data will be gathered through the use of semi-structured interviews. A grounded theory method of analysis will be used on the transcribed data (Charmaz, 2006). Grounded theory methods of analysis are generally used when theory is not already available for the specific research area (Strauss & Corbin, 1998). Given that there is currently no in depth theoretical understanding of how staff in general ward settings conceptualise their experiences of using truth and deception in dementia care, a grounded theory method of analysis is deemed appropriate.

Each transcript will first be subjected to open coding. This involves a line by line analysis of the meaning of the individual accounts in order to generate initial codes. Once complete, axial coding will be adopted, where large amounts of data codes will be separated, sorted and synthesised into core categories or themes. At this stage, the understanding of the data moves from a descriptive level to understanding it in terms of conceptual analytic units. These core categories will then be built into a conceptual model and theory; synthesising them with one another and existing literature.

In line with grounded theory methods of analysis, recruitment will continue until the study has reached saturation. This means that further data or data analysis would not provide any further insights into the area of study. However, at this stage of the research design, it is difficult to predict when theoretical saturation of the data may be reached and therefore how many participants will be recruited into the study. However, based on previous research and the experience of the study supervisors and the study advisor, it is predicted that roughly 10-15 participants will enable theoretical saturation to be achieved.

20. Describe the involvement of users/service users in the design and conduct of your research. If you have not involved users/service users in developing your research protocol, please indicate this and provide a brief rationale/explanation.

During the proposal stage of the study, presentations were peer reviewed to gather feedback and to raise any potential problems. There was public involvement from service users from the Lancaster University Public Involvement Network (LUPIN) during the proposal stage. The interview schedule was also put together with assistance from a person in the early stages of dementia.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

During the study, personal data (including phone numbers and e-mail addresses that were provided by participants on contact details forms) will be transferred to a word document and stored on the secure university network. This will be accessible at the chief investigator's home so that interviews can be arranged. Hard copies of contact details forms will be destroyed. Personal data stored electronically will only be deleted once the study is complete and

summary reports have been written, so reports can be sent to participants (on email address provided). Consent forms will be kept securely at the University site, accessible only by the chief investigator, until completion of the study. They will then be stored securely by Lancaster University for ten years before being destroyed. The research director at Lancaster University will be responsible for data storage and deletion of data ([REDACTED]) once the chief investigator has completed the course.

All interviews will be recorded onto a portable audio device. As soon as possible following the interview, the audio recording will be removed from the portable device and encrypted and saved onto a password protected computer. In the meantime, the recorder will be stored securely. Once transferred, the audio recording will then be deleted from the portable device. Audio recordings will be transcribed within three months of the interview taking place. Transcriptions will be anonymised and all identifiable data will be removed. These anonymised transcripts will be stored on the secure university network. Access to transcription data will be restricted to the chief investigator and supervisors ([REDACTED]). Following completion of the study or publication, transcripts will be stored securely at Lancaster University for ten years before being destroyed (separate from consent forms). The research director at Lancaster University ([REDACTED]) will be responsible for data storage and deletion after the chief investigator has completed the course. Audio recordings will be deleted from the password protected computer following examination of the thesis report.

22. Will audio or video recording take place? no audio video

If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

All interviews will be recorded onto a portable audio device. As soon as possible following the interview, the audio recording will be removed from the portable device and encrypted and saved onto a password protected computer. In the meantime, the recorder will be stored securely. The audio recording will then be destroyed from the portable device as soon as it has been transferred onto the computer. Audio recordings will be transcribed within three months of the interview taking place. Audio recordings will be deleted from the password protected computer following examination of the thesis report. Following completion of the study or publication, transcripts will be stored securely at Lancaster University for ten years before being destroyed. The research director at Lancaster University ([REDACTED]) will be responsible for data storage and deletion of data after the chief investigator has completed the course.

23. What are the plans for dissemination of findings from the research?

The summary of the final report will be produced and distributed to the wards where staff have taken part. The chief investigator will also offer to present the findings to the ward staff. It will also be discussed with the dementia leads for the service if it would be beneficial for the findings to be presented elsewhere within the service. Each participant will have the opportunity to request the summary report be e-mailed to them.

The study will also be submitted for publication to a peer reviewed journal following completion.

It will also be presented at the Lancaster University thesis presentation day.

FHMREC Approval Letter

LANCASTER
UNIVERSITY



Applicant: [REDACTED]
Supervisor: [REDACTED]
Department: DHR

08 July 2013

Dear [REDACTED] and [REDACTED],

Re: The use of truth & deception in dementia care: Constructing the experiences of staff on general hospital wards

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, [REDACTED] if you have any queries or require further information.

Yours sincerely,

[REDACTED]
Secretary, University Research Ethics Committee

Cc [REDACTED] ([REDACTED]); Professor [REDACTED]

Research Support Office
Research and Enterprise Services

Lancaster University
Bowland Main
Lancaster LA7 4YT
United Kingdom

Tel: +44 (0) 1524 592812
Fax: +44 (0) 1524 593229
Web: <http://www.lancs.ac.uk>

Example of NHS R&D SSI Form (Trust 1)

Welcome to the Integrated Research Application System
IRAS Project Filter
<p>The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.</p>
<p>Please enter a short title for this project (maximum 70 characters) Dementia in dementia care: experiences of general ward staff</p>
<p>1. Is your project research?</p> <p><input checked="" type="radio"/> Yes <input type="radio"/> No</p>
<p>2. Select one category from the list below:</p> <p><input type="radio"/> Clinical trial of an investigational medicinal product</p> <p><input type="radio"/> Clinical investigation or other study of a medical device</p> <p><input type="radio"/> Combined trial of an investigational medicinal product and an investigational medical device</p> <p><input type="radio"/> Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice</p> <p><input type="radio"/> Basic science study involving procedures with human participants</p> <p><input type="radio"/> Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology</p> <p><input checked="" type="radio"/> Study involving qualitative methods only</p> <p><input type="radio"/> Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)</p> <p><input type="radio"/> Study limited to working with data (specific project only)</p> <p><input type="radio"/> Research tissue bank</p> <p><input type="radio"/> Research database</p> <p>If your work does not fit any of these categories, select the option below:</p> <p><input type="radio"/> Other study</p>
<p>2a. Please answer the following question(s):</p> <p>a) Does the study involve the use of any ionising radiation? <input type="radio"/> Yes <input checked="" type="radio"/> No</p> <p>b) Will you be taking new human tissue samples (or other human biological samples)? <input type="radio"/> Yes <input checked="" type="radio"/> No</p> <p>c) Will you be using existing human tissue samples (or other human biological samples)? <input type="radio"/> Yes <input checked="" type="radio"/> No</p>
<p>3. In which countries of the UK will the research sites be located?(Tick all that apply)</p> <p><input checked="" type="checkbox"/> England</p> <p><input type="checkbox"/> Scotland</p> <p><input type="checkbox"/> Wales</p> <p><input type="checkbox"/> Northern Ireland</p> <p>3a. In which country of the UK will the lead NHS R&D office be located:</p>

- England
 Scotland
 Wales
 Northern Ireland
 This study does not involve the NHS

4. Which review bodies are you applying to?

- NHS/HSC Research and Development offices
 Social Care Research Ethics Committee
 Research Ethics Committee
 National Information Governance Board for Health and Social Care (NIGB)
 National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

It looks like your project is research requiring NHS R&D approval but does not require review by a REC within the UK Health Departments Research Ethics Service – is that right?

- Yes No

4b. Please confirm the reason(s) why the project does not require review by a REC within the UK Health Departments Research Ethics Service:

- Projects limited to the use of samples/data samples provided by a Research Tissue Bank (RTB) with generic ethical approval from a REC, in accordance with the conditions of approval.
 Projects limited to the use of data provided by a Research Database with generic ethical approval from a REC, in accordance with the conditions of approval.
 Research limited to use of previously collected, non-identifiable information
 Research limited to use of previously collected, non-identifiable tissue samples within terms of donor consent
 Research limited to use of acellular material
 Research limited to use of the premises or facilities of care organisations (no involvement of patients/service users as participants)
 Research limited to involvement of staff as participants (no involvement of patients/service users as participants)

5. Will any research sites in this study be NHS organisations?

- Yes No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

- Yes No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

- Yes No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

Yes No

7. Do you plan at any stage of the project to undertake Invasive research involving adults lacking capacity to consent for themselves?

Yes No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Invasive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

Yes No

8. Is the study or any part of it being undertaken as an educational project?

Yes No

Please describe briefly the involvement of the student(s):

This is part of a doctoral thesis in clinical psychology - the chief investigator is a student.

8a. Is the project being undertaken in part fulfillment of a PhD or other doctorate?

Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

Yes No

Site-Specific Information Form (NHS sites)

Is the site hosting this research a NHS site or a non-NHS site? NHS sites include Health and Social Care organisations in Northern Ireland. The sites hosting the research are the sites in which or through which research procedures are conducted. For NHS sites, this includes sites where NHS staff are participants.

- NHS site
 Non-NHS site

This question must be completed before proceeding. The filter will customise the form, disabling questions which are not relevant to this application.

One Site-Specific Information Form should be completed for each research site and submitted to the relevant R&D office with the documents in the checklist. See guidance notes.

The data in this box is populated from Part A:

Title of research:
 The use of truth and deception in dementia care: Constructing the experiences of staff on general hospital wards.

Short title: Deception in dementia care: experiences of general ward staff

Chief Investigator: Title Forename/Initials Surname
██████████ ██████████

Name of NHS Research Ethics Committee to which application for ethical review is being made:

Project reference number from above REC:

1-1. Give the name of the NHS organisation responsible for this research site

██

1-3. In which country is the research site located?

- England
 Wales
 Scotland
 Northern Ireland

1-4. Is the research site a GP practice or other Primary Care Organisation?

- Yes No

2. Who is the Principal Investigator or Local Collaborator for this research at this site?

Select the appropriate title: Principal Investigator
 Local Collaborator

	Title	Forename/Initials	Surname
	[REDACTED]	[REDACTED]	[REDACTED]
Post	[REDACTED]		
Qualifications	[REDACTED]		
Organisation	[REDACTED]		
Work Address	[REDACTED]		
	[REDACTED]		
	[REDACTED]		
PostCode	[REDACTED]		
Work E-mail	[REDACTED]		
Work Telephone	[REDACTED]		
Mobile	[REDACTED]		
Fax	[REDACTED]		

a) Approximately how much time will this person allocate to conducting this research? Please provide your response in terms of Whole Time Equivalents (WTE).
 0.5

b) Does this person hold a current substantive employment contract, Honorary Clinical Contract or Honorary Research Contract with the NHS organisation or accepted by the NHS organisation? Yes No

A copy of a current CV for the Principal Investigator (maximum 2 pages of A4) must be submitted with this form.

3. Please give details of all locations, departments, groups or units at which or through which research procedures will be conducted at this site and describe the activity that will take place.

Please list all locations/departments etc where research procedures will be conducted within the NHS organisation, describing the involvement in a few words. Where access to specific facilities will be required these should also be listed for each location.

Name the main location/department first. Give details of any research procedures to be carried out off site, for example in participants' homes.

Location	Activity/facilities
1 L4 ward	Participants will be recruited from this ward, based on recommendations from the dementia lead that it has a high proportion of older adults admitted. Recruitment will be conducted with assistance from the ward manager who may distribute information packs to their staff. Alternatively, the chief investigator may go on to the ward to present the study to staff. Interviews are likely to be conducted off the ward, but in a private room close by.
2 L5 ward	Participants will be recruited from this ward, based on recommendations from the dementia lead that it has a high proportion of older adults admitted. Recruitment will be conducted with assistance from the ward manager who may distribute information packs to their staff. Alternatively, the chief investigator may go on to the ward to present the study to staff. Interviews are likely to be conducted off the ward, but in a private room close by.
3 L8 ward	Participants will be recruited from this ward, based on recommendations from the dementia lead that it has a high proportion of older adults admitted. Recruitment will be conducted with assistance from the ward manager who may distribute information packs to their staff. Alternatively, the chief investigator may go on to the ward to present the study to staff. Interviews are likely to be conducted off the ward, but in a private room close by.

4. B6 ward Participants will be recruited from this ward, based on recommendations from the dementia lead that it has a high proportion of older adults admitted. Recruitment will be conducted with assistance from the ward manager who may distribute information packs to their staff. Alternatively, the chief investigator may go on to the ward to present the study to staff. Interviews are likely to be conducted off the ward, but in a private room close by.

5. Please give details of all other members of the research team at this site.

8. Does the Principal Investigator or any other member of the site research team have any direct personal involvement (e.g. financial, share-holding, personal relationship etc) in the organisation sponsoring or funding the research that may give rise to a possible conflict of interest?

Yes No

7. What is the proposed local start and end date for the research at this site?

Start date: 31/07/2013
 End date: 29/08/2014
 Duration (Months): 13

8-1. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. (These include seeking consent, interviews, non-clinical observations and use of questionnaires.)

Columns 1-4 have been completed with information from A10 as below:

- Total number of interventions/procedures to be received by each participant as part of the research protocol.
- If this intervention would have been routinely given to participants as part of their care, how many of the total would have been routine?
- Average time taken per intervention (minutes, hours or days)
- Details of who will conduct the procedure, and where it will take place

Please complete Column 5 with details of the names of individuals or names of staff groups who will conduct the procedure at this site.

Intervention or procedure	1	2	3	4	5
Notification of research	1	0	15 minutes	Participants might be notified about the research either by the manager of the ward that they work on who will give out information sheets to their staff members, or if agreed by the manager, the chief investigator may come onto the ward to discuss the research in person with ward staff/potential participants	The ward manager/s of the wards identified [redacted] and [redacted] will inform staff of the study and distribute information packs. The chief investigator [redacted] may also present the study to staff members e.g. at staff handover, describing the study and answering any questions they may have.
Reading participant information sheet	1	0	20 minutes	Potential participants will read the information sheet by themselves before agreeing to take part in the study. The chief investigator can also go through the participant information sheet with potential participants if this would be of help to them.	Staff members from wards [redacted] and [redacted] will read the participant information sheet before agreeing to take part. The chief investigator [redacted] can also go through this with them.
Discussion about the research prior to	1	0	15 minutes	The chief investigator can discuss the research with potential participants if needed, prior to them agreeing to take	The chief investigator [redacted] will discuss the research with potential participants from [redacted] and [redacted]

agreeing to take part (optional)			part. This can be done over the phone or in person.	wards.	
Discussion to agree time and location of interview	1	0	10 minutes	The chief investigator will arrange a time and location for the interview with the participant. This can be done via telephone or in person.	Chief investigator [redacted] with potential participants (staff from [redacted] and [redacted] wards).
Seeking consent prior to starting the interview	1	0	15 minutes	The chief investigator will ask participants to read and sign the consent form immediately prior to commencing the interview. This will be in a private room at the hospital site.	Chief investigator [redacted] with participants (staff from [redacted] and [redacted] wards).
Semi-structured interview	1	0	1 hour	The chief investigator will facilitate the semi structured interview, in a private room at the hospital site.	Chief investigator [redacted] with participants (staff from [redacted] and [redacted] wards).
Debrief	1	0	5 minutes	The chief investigator will provide all participants with a debrief form and discuss any concerns they may have following the interview.	Chief investigator [redacted] with participants (staff from [redacted] and [redacted] wards).
Reading findings	1	0	30 minutes	Participants will have the option to receive a summary of the final report. If they request this, time will be taken for it to be read.	Chief investigator will send summary of report to participants (if requested). This will be read by participants in their own time.

8-2. Will any aspects of the research at this site be conducted in a different way to that described in Part A or the protocol?

Yes No

If Yes, please note any relevant changes to the information in the above table.

Are there any changes other than those noted in the table?

10. How many research participants/samples is it expected will be recruited/obtained from this site?

5-10

11. Give details of how potential participants will be identified locally and who will be making the first approach to them to take part in the study.

The dementia lead from the service [redacted] has assisted with identifying wards that regularly have a high proportion of older adult patients with dementia. When ethical approval has been given, the chief investigator will provide ward managers with information packs that will be distributed amongst the staff. Additionally, the chief investigator can go into wards and present the study to staff members e.g. during staff hand overs. If staff contact the chief investigator having received the information and decide that they would like to take part, the chief investigator will contact ward managers and discuss if there is a convenient time for the staff members to take time off the ward to take part. Alternatively, staff can take part in the study out of work hours.

12. Who will be responsible for obtaining informed consent at this site? What expertise and training do these persons have in obtaining consent for research purposes?

Name	Expertise/training
Alex Turner	The chief investigator has experience of prior research, undergraduate dissertation, master dissertation and doctoral level service related projects that have required consent to be obtained from participants. Also, within clinical training, it is often necessary to gain consent from clients within a therapeutic setting.

15-1. Is there an independent contact point where potential participants can seek general advice about taking part in research?

Participants will be told in the information sheets that if they wish to talk to someone outside of the Clinical Psychology Doctorate Programme, they may contact the Associate Dean for Research at Lancaster University. The contact details will be given on the participant information sheet.

16-2. Is there a contact point where potential participants can seek further details about this specific research project?

Potential participants will be given the contact details of the chief investigator if they want further details about this specific research project. They will also be given the contact details of the supervisors for the study and the research director of the clinical psychology programme at Lancaster University.

18. Are there any changes that should be made to the generic content of the information sheet to reflect site-specific issues in the conduct of the study? A substantial amendment may need to be discussed with the Chief Investigator and submitted to the main REC.

No changes should be needed to the generic content of the information sheet to reflect site specific issues.

Please provide a copy on headed paper of the participant information sheet and consent form that will be used locally. Unless indicated above, this must be the same generic version submitted to/ approved by the main REC for the study while including relevant local information about the site, investigator and contact points for participants (see guidance notes).

17. What local arrangements have been made for participants who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters etc.)

Due to not having the financial resources to pay for interpreters, participants must be English speaking. It is felt that as the study aims to interview staff members who work in an NHS setting, they are likely to have a good understanding and ability to speak English.

18. What local arrangements will be made to inform the GP or other health care professionals responsible for the care of the participants?

No arrangements will be made to inform the GP or other health care professionals responsible for the care of the participants, however, participants will be informed in the debrief sheet that if they have any concerns following taking part in the study, they should inform their manager or occupational health.

19. What arrangements (e.g. facilities, staffing, psychosocial support, emergency procedures) will be in place at the site, where appropriate, to minimise the risks to participants and staff and deal with the consequences of any harm?

Whilst it is not expected that staff will face any harm when taking part in the study, managers may be informed of their participation and therefore staff members will be able to discuss with them any concerns they may have following participation. It might also be suggested that they contact occupational health and contact details can be given. Given that ward managers will be informed of staff taking part (if during work hours), they will be able to ensure other staff members (not taking part) are suitably covered during the participants absence. Participants will be provided with a debrief form following the interview.

20. What are the arrangements for the supervision of the conduct of the research at this site? Please give the name and contact details of any supervisor not already listed in the application.

The chief investigator will receive supervision both from their academic and field supervisors. The chief investigator will meet at least monthly with both supervisors and this can be increased if felt necessary. Contact details for both supervisors are:

Address: [REDACTED]
 Phone: [REDACTED]
 Email: [REDACTED]

[Redacted]
 Address: [Redacted]
 [Redacted]
 [Redacted]
 [Redacted]
 [Redacted]
 Phone: [Redacted]
 Email: [Redacted]

21. What external funding will be provided for the research at this site?

Funded by commercial sponsor
 Other funding
 No external funding

How will the costs of the research be covered?
 There will be no costs to the research as it is part of a clinical psychology doctoral thesis. Expenses to participants and for additional expenses such as stationary will be covered by Lancaster University.

23. Authorisations required prior to R&D approval

The local research team are responsible for contacting the local NHS R&D office about the research project. Where the research project is proposed to be coordinated centrally and therefore there is no local research team, it is the responsibility of the central research team to instigate this contact with local R&D.

NHS R&D offices can offer advice and support on the set-up of a research project at their organisation, including information on local arrangements for support services relevant to the project. These support services may include clinical supervisors, line managers, service managers, support department managers, pharmacy, data protection officers or finance managers depending on the nature of the research.

Obtaining the necessary support service authorisations is not a pre-requisite to submission of an application for NHS research permission, but all appropriate authorisations must be in place before NHS research permission will be granted. Processes for obtaining authorisations will be subject to local arrangements, but the minimum expectation is that the local R&D office has been contacted to notify it of the proposed research project and to discuss the project's needs prior to submission of the application for NHS research permission via IRAS.

Failure to engage with local NHS R&D offices prior to submission may lead to unnecessary delays in the process of this application for NHS research permissions.

Declaration:
 I confirm that the relevant NHS organisation R&D office has been contacted to discuss the needs of the project and local arrangements for support services. I understand that failure to engage with the local NHS R&D office before submission of this application may result in unnecessary delays in obtaining NHS research permission for this project.

Please give the name and contact details for the NHS R&D office staff member you have discussed this application with:
 Please note that for some sites the NHS R&D office contact may not be physically based at the site. For contact details refer to the guidance for this question.

	Title	Forename/Initials	Surname
	[Redacted]	[Redacted]	[Redacted]
Work E-mail	[Redacted]		
Work Telephone	[Redacted]		

Declaration by Principal Investigator or Local Collaborator

1. The information in this form is accurate to the best of my knowledge and I take full responsibility for it.
2. I undertake to abide by the ethical principles underpinning the World Medical Association's Declaration of Helsinki and relevant good practice guidelines in the conduct of research.
3. If the research is approved by the main REC and NHS organisation, I undertake to adhere to the study protocol, the terms of the application of which the main REC has given a favourable opinion and the conditions requested by the NHS organisation, and to inform the NHS organisation within local timelines of any subsequent amendments to the protocol.
4. If the research is approved, I undertake to abide by the principles of the Research Governance Framework for Health and Social Care.
5. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to the conduct of research.
6. I undertake to disclose any conflicts of interest that may arise during the course of this research, and take responsibility for ensuring that all staff involved in the research are aware of their responsibilities to disclose conflicts of interest.
7. I understand and agree that study files, documents, research records and data may be subject to inspection by the NHS organisation, the sponsor or an independent body for monitoring, audit and inspection purposes.
8. I take responsibility for ensuring that staff involved in the research at this site hold appropriate contracts for the duration of the research, are familiar with the Research Governance Framework, the NHS organisation's Data Protection Policy and all other relevant policies and guidelines, and are appropriately trained and experienced.
9. I undertake to complete any progress and/or final reports as requested by the NHS organisation and understand that continuation of permission to conduct research within the NHS organisation is dependent on satisfactory completion of such reports.
10. I undertake to maintain a project file for this research in accordance with the NHS organisation's policy.
11. I take responsibility for ensuring that all serious adverse events are handled within the NHS organisation's policy for reporting and handling of adverse events.
12. I understand that information relating to this research, including the contact details on this application, will be held by the R&D office and may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
13. I understand that the information contained in this application, any supporting documentation and all correspondence with the R&D office and/or the REC system relating to the application will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.

Signature of Principal Investigator
or Local Collaborator:

Print Name: 

Date:

R&D Approval Letter (Trust 1)

[REDACTED]
Acute & Primary Care Research

[REDACTED]
[REDACTED] Associate Director: [REDACTED]
[REDACTED] Manager: [REDACTED]

30th July 2013

[REDACTED]
Trainee Clinical Psychology
Lancashire Care Foundation Trust
Division of Health Research, Faculty of Health & Medicine
Furness Building
Lancaster University
Lancaster LA1 4YT

Dear [REDACTED]

Study Title: The Use Of Truth and Deception In Dementia Care: Constructing
The Experiences Of Staff On General Hospital Wards
NHS REC Reference: N/A
EuDraCT Reference: N/A
R&D Reference: 2013/106neuro

Thank you for forwarding all the required documentation for your study as above. I am pleased to inform you that your study has been registered with [REDACTED] and has gained NHS R&D approval from the following NHS Trust:

[REDACTED]
All clinical research must comply with the Health and Safety at Work Act, www.hse.gov.uk and the Data Protection Act. <http://www.hmsc.gov.uk/facts>

It is a legal requirement for Principal Investigators involved in Clinical Trials to have completed accredited ICH GCP training within the last 2 years. Please ensure that you provide the R&D Department with evidence of this (certificate for completing the course). A list of GCP training courses can be obtained from the R&D Office.

All researchers who do not hold a substantive contract with the Trust must hold an honorary research contract before commencing any study activities related to this approval. The 'Research Passport Application Form'. This can be obtained from web addresses: <http://www.pmrctgroup.nhs.uk/researcherspassports.html> and <http://www.hopa.academic.org.uk/researcherspassports.html>. This form should be completed and returned, with a summary C.V and recent (within 6 months) CRB to the address shown above.

It is a condition of both NRES and NHS R&D approval that participant recruitment data should be forwarded on a regular basis. Therefore, progress reports must be submitted annually to the main REC and copied to the R&D office until the end of the study.
<http://www.nres.npsa.nhs.uk/applications/after-ethical-review/annual-progress-reports/>

Research & Development Department
[REDACTED]
[REDACTED]

Where clinical trials of investigational medicinal products are sponsored by [REDACTED] Foundation Trust or [REDACTED] Care Trust, it is a condition of Trust approval that Chief Investigators submit quarterly progress reports (to include Annual Safety Reports at the appropriate time) to R&D. For clinical trials of investigational medicinal products hosted within [REDACTED] NHS Foundation Trust and [REDACTED] Care Trust, the local PI will be expected to submit bi-annual progress reports to R&D. It is also a condition of approval that delegated duties (as agreed within clinical trial agreements and trial delegation logs) are fulfilled by only those delegated to undertake a specific duty. This will be monitored by the Sponsor's Representative during routine monitoring of the trial. Persistent non-compliance with these requirements may result in removal of Sponsorship or Trust R&D Approval.

Any amendments to the study should also be notified and approval sought by Ethics Committee and R&D Department. *Where [REDACTED] NHS Foundation Trust or [REDACTED] Care Trust is acting as Sponsor then amendments or changes MUST be discussed with the Sponsor prior to REC submission.*

On completion of the study you are required to submit a 'Declaration of End of Study' form to the main REC, which should also be copied and forwarded to the R&D office at the address shown above.

Any serious adverse events or governance issues related to the research must be notified to the R&D office.

Yours sincerely,

[REDACTED]

[REDACTED]
Associate R&D Manager

c.c. Sponsor
[REDACTED]

Research & Development Department
[REDACTED]
[REDACTED]

