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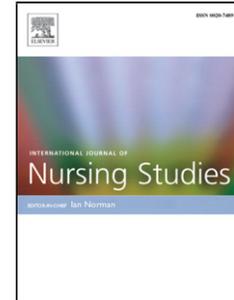
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## Accepted Manuscript

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**Healthcare Staffs' Experiences and Perceptions of Caring for People with  
Dementia in the Acute Setting: Qualitative Evidence Synthesis**

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# Healthcare Staffs' Experiences and Perceptions of Caring for People with Dementia in the Acute Setting: Qualitative Evidence Synthesis

## 1 Introduction and Background

Dementia is a term used to describe a group of disorders that have common symptoms (Cahill et al. 2012a). The most common conditions within this group are Alzheimer's disease and vascular dementia. It is estimated that one new case of dementia is added every three seconds Worldwide (Prince 2015) and, once diagnosed, median survival is 4.6 years (women) and 4.1 years (men) (Xie et al. 2008). The impact on the person and their families is extensive. The global cost of dementia, both financially and in terms of burden of disease, is rising and dementia has become a key health policy priority for many countries (OECD 2015). In Europe, dementia is estimated to cost €177 billion: approximately €22,000 per person, per year (Wimo & Prince 2010, Wino et al. 2011). Until preventive treatments become available, millions of people will live with dementia and efforts must focus on improving their lives and the management of their care (OECD 2015).

It is estimated that one quarter of people accessing acute hospital services are likely to experience dementia, in addition to the health problem that caused their admission to hospital (Alzheimer's Society 2009, Cahill et al. 2012b). A person with dementia is more likely to be hospitalised because of their complex needs and perceived risks to their wellbeing (Cunningham & Archibald 2006). A person with dementia also tends to stay in hospital for longer (King et al. 2006). However, admission to an acute hospital can exacerbate the effects of dementia because of disorientation and distress caused by separation from familiar people, environments and routine (Department of Health 2005). The longer people with dementia are in hospital, the effect on the symptoms of dementia worsens; discharge to a care home becomes more likely and antipsychotic drugs are more likely to be used (Alzheimer's Society 2009). The pace of activity in hospital places high demands on staff and, in these environments, their priority is monitoring and managing the acute needs of all the patients in the unit (Royal College of Nursing 2010). A survey by the Alzheimer's Society (2009) reported that 77% of carer respondents were dissatisfied with the overall quality of the care provided to people with dementia in acute settings.

Hospital design, staffing and processes should be adapted to better meet the needs of people with dementia and their carers (Travers et al. 2013). The Irish National Audit of Dementia Care in Acute Hospitals (2014) also identified key areas for improvement such as assessment, education, environmental design, liaison services, policy development and review of medication guidelines. Many initiatives are described in the literature that may help in the provision of better quality care. For example, the use of “dementia champions” has been identified as a means of promoting best practice and ensuring that staff are supported and educated in the care of people with dementia (Cunningham & McWilliam, 2006, Crabtree & Mack 2010, Royal College of Psychiatrists (RCP) 2011, 2013). A similar role is that of dementia nurse specialist (DNS), whose responsibilities include raising awareness of dementia among staff and ensuring the provision of good quality information to people with dementia and their carers (Elliot & Adams 2011). Further initiatives include resource packs, educational films and online learning packages for staff (McPhail et al. 2009, Dementia Services Development Centre 2010, Wesson & Chapman 2010, Howie 2012, Duffin 2013). More recently, the Royal College of Nursing (RCN) (2014) introduced the RCN Development Programme aimed at transforming dementia care in hospitals. Positive outcomes for staff included a boost to confidence and morale, and support in developing engagement with carers. In addition, carers of people with dementia felt their relatives were being cared for with more dignity and respect and carers felt more involved in the care activities.

While many exciting initiatives have been described, there is currently insufficient evidence to support their success in terms of outcomes and quality of care. Clarity is needed to establish how care can best be provided to people with dementia in the acute setting. This can be first achieved by synthesising existing knowledge on how healthcare staff perceive and experience the care that people with dementia receive in the acute setting. Qualitative evidence synthesis is a comprehensive approach to knowledge synthesis and can uncover current practices, elements of good care and challenges to appropriate care. Conclusions can then be drawn across studies to prompt further policy development and research.

## **2 Design**

The aim of this qualitative evidence synthesis was to explore the experiences and perceptions of healthcare staff in caring for people with dementia in the acute setting. Qualitative synthesis is appropriate for this purpose as it enables the interpretation of isolated, qualitative findings systematically and with rigour in order to inform healthcare policy and improve care of people with dementia in the acute setting (Finfgeld 2003, Thorne 2008). The specific approach used was framework synthesis, adapted from framework analysis as described by Ritchie and Spencer (1994). Framework synthesis provides a pragmatic approach to synthesis, whereby an existing conceptual framework is used to identify *a priori* themes (Carroll et al. 2011, Booth & Carroll 2015). It was deemed suitable for this review because a published framework existed that could be employed to structure the synthesis (Carroll et al. 2013). Framework synthesis is useful for describing and interpreting what is happening in a particular setting: in this case, the acute setting (Booth & Carroll 2015).

## 2.1 Conceptual Framework

A conceptual framework is an essential component for undertaking framework synthesis (Carroll et al. 2013). It helps to guide decisions regarding analysis and the interpretation of findings. In dementia care, the VIPS framework was developed to provide guidance on how the concept of person-centeredness can be applied to caring for people with dementia (Brooker 2007). The framework is based on four key elements: Values, Individualised, Perspective and Social (VIPS). These are described in Table 1. Person-centred care focuses on the individual needs of a person rather than on the efficiencies of the care provider; builds upon the strengths of a person; and honours their values, choices, and preferences (Brooker 2004, 2006, 2012, McCormack & McCance 2006, McCormack 2003, Kitwood 1992). In the context of dementia care, person-centeredness brings together ideas and ways of working with the lived experience of people with dementia that emphasises communication and relationships (Kitwood 1997). The VIPS framework has been adopted as a means of internally benchmarking the person-centeredness of practice within a number of service settings, particularly within the care home sector. It has been successfully used in the UK, Norway and USA (Røsvik et al. 2011, Passalacqua & Harwood 2012, Baker 2014). It is fitting that it can also be used to explore how people with dementia are cared for in the acute setting.

<b>THE VIPS FRAMEWORK (BROOKER 2006, 2016)</b>
<b>V:</b> A <b>value</b> base that asserts the absolute value of all human lives regardless of age or cognitive ability.
<b>I:</b> An <b>individualised</b> approach recognising uniqueness
<b>P:</b> Understanding the world from the <b>perspective</b> of the person identified as needing support.
<b>S:</b> Providing a <b>social</b> environment that supports psychological needs.

Table 1: The VIPS Framework

The “Value” element of the framework involves organisational elements such as management, vision, human resources, staff training and development. The “Individual” component requires an understanding of life history, valuing personal possessions, individual preferences and providing individualised support and care. “Perspective” refers to empathy, communication and advocacy, as well as a consideration of the physical environment and the physical health needs of the person. “Social” recognises the importance of being part of a community, the involvement of family and friends, demonstration of warmth, respect, validation and enabling the person’s social inclusion. The four elements of the VIPS framework provided the basis for exploring and synthesising primary qualitative data that focused on the care of people with dementia in acute settings. These core elements of the framework provided a structure that recognised the importance of the person with dementia as central to the entire process.

## 2.2 Review Team and Advisory group

The EPPI-Centre (2010) recommends both a review team and an advisory group for conducting qualitative evidence synthesis. The review team was responsible for the on-going conduct of the review. The team included individuals with expertise in qualitative research and subject area expertise: in this case, dementia care (Lloyd Jones 2004, EPPI-Centre 2010). The advisory team consisted of a researcher with extensive qualitative synthesis experience and an expert who understood the experiences of those caring for people with dementia and who had developed the VIPS framework.

## 2.3 Search Strategy

An extensive and exhaustive search technique was used (Lloyd Jones 2004, Sandelowski & Barroso 2007, Finfgeld-Connett 2010). A research assistant, with support from a librarian, conducted the search using the databases in Table 2. The search terms included all possible

combinations of: “dementia” or “Alzheimer”; “staff” or “health professional”; “qualitative” or “grounded theory” or “ethnography” “action research”; “hospital” or “acute care” or “clinical setting”; “perceptions” or “attitudes”; “interviews” or “focus groups”.

<b>Databases accessed:</b>
CINAHL
Embase
ETHoS
PsychINFO
Proquest
SCOPUS
Web of Science

Table 2: Search Strategy

Language and year parameters were not set, in order to capture as much relevant literature as possible. Two articles were translated from Finnish and Spanish into English for full text screening but were later excluded, based on the fact that they were not relevant. In addition, unpublished material, such as PhD theses, was included to avoid publication bias (Finfgeld 2003, EPPI-Centre 2010). Some studies focused on Alzheimer’s disease rather than overtly defining dementia. For comprehensiveness and inclusivity, “Alzheimer” was included in the search strategy. However, none of these articles met the inclusion criteria.

Qualitative research was defined as research conducted using widely accepted qualitative methods. Mixed methods studies were included if findings demonstrated that they were supported by raw data (Finfgeld 2003). The initial searches retrieved 692 references that were included for screening. From a management perspective, EndNote was used to manage all of the references that were deemed potentially relevant. The EndNote library was then imported into NVivo version 10. NVivo was used to manage all stages of the synthesis process: screening, quality appraisal, data extraction and synthesis. There is little published literature about using NVivo for all stages of framework synthesis and this is the focus of another paper (under review) focusing on the innovative methodological processes involved in this present review.

#### 2.4 Screening

Each report was screened independently by two members of the review team, who then met to discuss and resolve disagreements. In some instances, the third team member was consulted to confirm and agree decisions. The decision to screen for title and abstract

simultaneously was made because it was found that many titles did not describe the study clearly, making it difficult to determine applicability on title alone. Table 3 outlines the inclusion and exclusion criteria that were used for the screening process. Figure 1 illustrates the screening process.

<b>Included</b>	<b>Excluded</b>
Primary research studies	Literature Review and descriptive articles
Qualitative and mixed methods	
Acute setting should not be place of residence	Exclude community, long-term settings, and dementia specific settings.
All healthcare staff working in the defined acute setting	Exclude carers, relatives and People with dementia
Person with dementia as stated by the study author +/- formal diagnosis of dementia as described in the report	
Includes direct care +/- management of care	
Perceptions and experiences of healthcare staff	Exclude if focus is on knowledge, decision making, advanced care directives, detection, diagnosis

Table 3: Inclusion/Exclusion Criteria

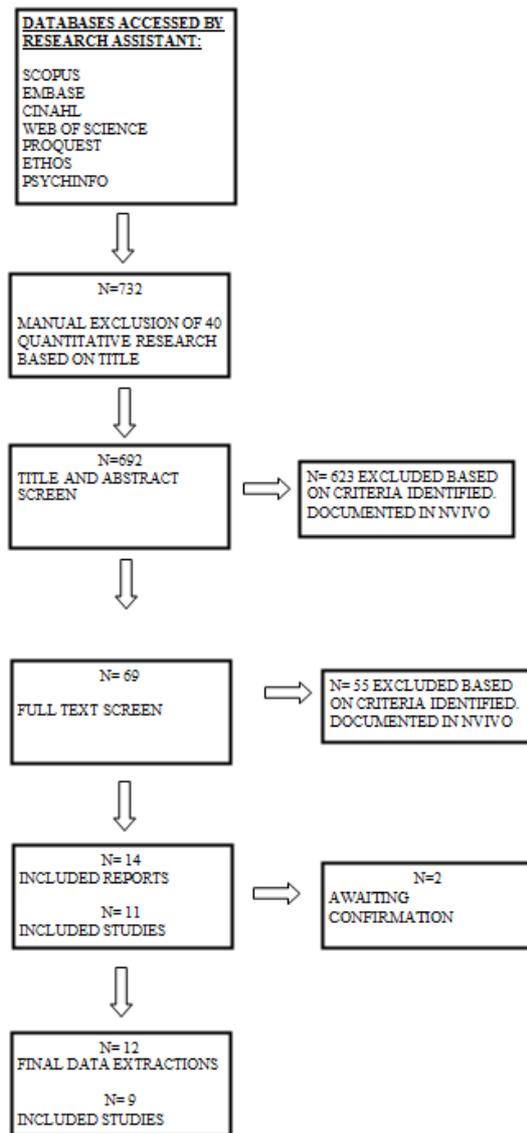


Figure 1: Screening and Selection Flow Chart

## 2.5 Data extraction and quality appraisal

Two members of the review team extracted the data and conducted the quality appraisal of each included report (n=12). A data extraction form was developed specifically for this review and included all the necessary information about the research design, setting and methods. It also allowed the review team to place the data into the conceptual framework. Data were defined as that which appeared in the results/findings section of the reports. Like previous framework synthesis conducted by Carroll et al. (2011), data included verbatim quotes from participants and findings that were reported by the study authors. Framework synthesis allows for the integration of primary and secondary data (Booth & Carroll 2015).

The discussion and conclusion sections were not included in the synthesis (Carroll et al. 2011).

If data emerged that did not translate to the existing VIPS themes, an additional section was included in the extraction form to capture these data for thematic synthesis. Thematic synthesis was then undertaken as an interpretive, inductive process (Carroll et al. 2011, Thomas et al. 2012). Quality appraisal was conducted simultaneously with extraction and the Critical Appraisal Skills Programme (CASP) tool was included in the extraction form. CASP is commonly used in qualitative evidence synthesis (Downe et al, 2007, Campbell et al. 2011, Valderas et al. 2012). It was recognised that studies of low methodological quality can still generate insights derived from the data (Dixon-Woods et al. 2005, Noyes et al. 2008). Therefore, the purpose of quality appraisal in this review was not to exclude studies but, rather, to distinguish between studies in terms of overall contribution and methodological rigour (CRD 2008). Carroll et al. (2011, 2013) describes sensitivity analysis, as a process of determining the effect of study quality on the synthesis findings. This helps to understand the impact of including studies that are deemed of a lesser quality (Thomas and Harden 2008). In this review, reports were classified using CASP, as of higher or lower quality. In NVivo, it was possible to query the findings and frequency of references under each theme and sub-themes using matrix query tools. Matrix query tools are useful for checking the integrity of qualitative findings (Houghton et al. 2013). A visual, colour-coded matrix query illustrated that the weighting of the findings was almost identical with or without the inclusion of lower quality reports. This process is described in more detail in another paper (under review).

## 2.6. Characteristics of included studies

Table 4 outlines the study characteristics included in the review. It is evident that the studies were conducted in 2002-2012, with many of them carried out in Australia. Some outlined specific qualitative methodologies, while others referred to generic qualitative approaches. No mixed-method studies were included in the final selection. Staff participants included medical staff, nursing staff, nurse managers, allied health professionals and nursing assistants. If the study included data from participants other than those identified in the inclusion criteria, or from a setting that was not identified as an acute setting, then those data were not included.

Author(s)/ Country	Date	Report Type	Design	Sample	Methods	Study Focus
Borbasi et al. Australia	2006	Journal	Interpretivist realism	23 multidisciplinary experts across the range of disciplines in 3 large teaching hospitals	Semi-structured interviews	To explore, understand, and interpret nurses' and healthcare professionals' experiences of managing patients who have dementia and have been admitted to hospital for treatment of a non-dementia-related illness. To provide a rich description of current practice and perceived better/best practice.
Cooper et al. Australia	2012	Report	Qualitative	51 carers, consultant physicians, nurses , pharmacists, occupational therapists, general practitioners and Alzheimer's Australia staff [Only data from acute care staff included in review]	Semi-structured interviews	This project aims to explore medication processes that occur during acute care episodes and in care transitions for people with a diagnosis of dementia and to make recommendations to improve practice.
Cowdell England	2008	PhD thesis	Critical interpretivist ethnography plus practice development and integrative review [only ethnography included in review]	12 interviews and observational data from 85 staff. Staff included registered and non- registered individuals from a range of disciplines including nursing, allied health professions, social work and medicine. [Patient and carer interviews not included in review]	Semi-structured interviews and non-participant observations	To explore the experiences of patients, lay carers and health and social care staff of care received by older people with dementia in the acute hospital setting.
	2010	Journal	Ethnography	Focused on nursing staff only, n=17	As above	The purpose of this study was to explore the experiences of patients and nursing staff of the care received by older people with dementia in an acute hospital setting.
	2010	Journal	Ethnography	11 people with dementia, 25 registered nurses and 33 nursing assistants [only staff data included in review]	As above	To investigate the experiences of patients and nursing staff in relation to the care delivered to, and received by, older people with dementia in an acute hospital setting.
Eriksson and Saveman Sweden	2002	Journal	Qualitative	12 nurses in five acute care wards and one accident and emergency department of an acute hospital	Semi-structured interviews	The aim of the study was to describe nurses' experiences of difficulties related to caring for patients with dementia in acute care settings.
Jones et al. Australia	2006	Journal	Qualitative descriptive exploratory	25 health professionals across three metropolitan hospitals including medical staff, nursing staff and managers, physiotherapist, occupational therapist and social worker	Semi-structured interviews	Generate a rich description of nurses' and healthcare professionals' experiences of caring for patients who have dementia and are being treated for non-dementia related illness in a hospital setting to provide a comprehensive picture of current practices

Author(s)/ Country	Date	Report Type	Design	Sample	Methods	Study Focus
Moyle et al. Australia	2010	Journal	A pragmatic, exploratory qualitative approach situated in the interpretive paradigm	N= 13 staff in acute medical and surgical wards. Senior staff included a medical doctor who specialised in gerontology, two acute care nursing directors and a clinical nurse consultant who was a specialist in the care of older adults in the acute care sector. Ward staff included three nursing unit managers, two clinical nurses, one registered nurse and three assistants in nursing.	Semi-structured interviews	The aim of this study was to describe the staff perspectives of current practice in the care of older people with dementia in the acute care and to critically evaluate the current care management in this setting in relation to the available literature
Nolan Ireland	2006	Journal	hermeneutic interpretation	7 nurses working in an acute hospital	In-depth, non-directive conversational interviews	The aim of this study was to illuminate nurses' experiences of caring for older persons with dementia in an acute hospital setting.
	2007	Journal	not explicit	As above	As above	The aim of this study was to explore nurses' experiences of caring for older people with dementia in an acute hospital setting
Rhynas Scotland	2010	PhD Thesis	A reflexive sociological approach using Bourdieu's Theory of Practice	38 nurses. 19 nurses participated in focus groups while a further 15 ward nurses and 4 Charge Nurses contributed through individual interviews. The majority of the contributing nurses were observed in practice.	Focus groups and interviews	The aim was to explore how nurses conceptualise dementia and how this conceptualisation relates to care and care planning?
Robinson et al. Canada	2012	Journal	Interpretive descriptive study	Sample included staff from Emergency medical Services: 1 Physician , 2 Leaders/managers, Paramedic/EMT and from the ED: 1Physician , 4 Leaders/managers and 4 RN [Only data from the ED were included]	Focus groups and semi-structured interviews	The aim was to identify key elements influencing the success of transitions in care for residents moving between NHs and EDs from multiple perspectives

Table 4: Characteristics of the 12 included studies

### 3 Synthesis Findings

VIPS provided the framework for synthesis. Initially, additional concepts were derived, but on further synthesis, they were integrated within the pre-identified themes. Eight sub-themes were also identified as outlined in Table 5.

<b>THEMES</b>	<b>SUB-THEMES</b>
<b>VALUING</b>	Pathways of care Culture of care
<b>INDIVIDUALISED</b>	“Pieces of the puzzle” Barriers to person-centred care
<b>PERSPECTIVE</b>	Interactions and impact on other patients The built environment
<b>SOCIAL AND PSYCHOLOGICAL</b>	“Forming relationships” Family involvement

Table 5: VIPS themes and sub-themes

### 3.1 Valuing

This theme focuses on infrastructure and management and how these support services in providing person-centred care for people with dementia. Within this theme, two sub-themes were identified: Pathways of care and culture of care.

#### 3.1.1 Pathways of care

This sub-theme examines some of the challenges around admission in the acute setting. Jones et al. (2006) identified that the number of patients with dementia in acute care settings is growing and that these patients are admitted across all sectors of the setting. It is difficult to provide the specialist care needed in the acute setting (Nolan 2007). A lack of clear reason for admission was challenging for nursing staff who felt that some people with dementia were being admitted and being cared for in acute medical wards whilst having no definitive medical diagnosis (Eriksson & Saveman 2002). Inadequate assessment could miss early onset dementia, which could prevent early treatment according to one geriatrician (Borbasi et al. 2006). If the person has a diagnosis of dementia, they are more likely to be assessed and cared for appropriately (Rhynas 2010).

Once in the acute setting, patients were often transferred between settings for investigations. This could be difficult for patients with dementia as it involves meeting with many different staff members (Eriksson & Saveman 2002). In the Emergency Department (ED), in particular, this could add the potential for delirium and it was considered important to transfer the person to a calmer environment as soon as possible (Robinson et al. 2012).

Planning for discharge could prove challenging, with delays in securing a place in residential care. These delays in transfer meant that the person with dementia might stay longer in the acute setting than was necessary and could be perceived to be "blocking beds" (Borbasi et al. 2006, Rhynas 2010). The need for an effective multidisciplinary approach to care and discharge planning was identified (Borbasi et al. 2006, Cowdell 2008). There was also a need for mutual respect and effective communication with staff working with people with dementia in the community to facilitate the "seamless transfer of care" (Cooper & Deeks 2012, Robinson et al. 2012). There is a requirement for management to examine how people with dementia are introduced and moved within the acute setting. Care pathways should focus on consistency and minimal disruption wherever possible.

### 3.1.2 Culture of Care

This sub-theme describes both the personal and organisational philosophies surrounding care of the person with dementia and how they impact on the culture of care. For some nurses, caring for people with dementia can be viewed as mundane and not particularly rewarding or prestigious (Cowdell 2010a). Many nursing staff articulated the view that they wished to care for people with dementia as they would members of their own family. However, in reality, they often provided care with kind intention but in a de-personalising way (Cowdell 2008, Cowdell 2010a). A focus on safety meant that attending to fundamental physical and psychosocial needs became less of a priority (Moyle et al. 2011, Rhynas 2010). It was identified that because of the acute environment, people with dementia may present with more challenging behaviours than they would in other settings and, therefore, restraint and "specialing" were more commonly used (Jones et al. 2006).

Restraint was defined in the studies as physical or chemical methods of demobilising a person with dementia (Borbasi et al. 2006). It was identified that restraint was sometimes inappropriately used because staff were too busy and did not have time to care for the person with dementia (Borbasi et al. 2006, Eriksson & Saveman 2002, Jones et al. 2006). Being "under pressure" due to limited time and resources was commonly referred to in the reports (Borbasi et al. 2006, Cowdell 2008, Cowdell 2010a, Cowdell 2010b, Eriksson and Saveman 2002). The use of restraint was also justified in terms of staff and patient safety (Moyle et al. 2011). It was ethically challenging for nurses who were caring for patients who had been

chemically sedated, which sometimes threatened the person's dignity (Eriksson and Saveman 2002). The use of "specialing" was considered challenging because the staff involved often did not participate in care and would sit and read rather than interact with the person with dementia (Moyle et al. 2011). There is a need to address the capacity of staff in acute settings to provide appropriate care to people with dementia in an often busy and stressful environment. Alternatives to restraint and "specialing" should be considered.

In addition to capacity, the attitudes and knowledge of the staff need to be examined. The studies showed that while staff members were often considered knowledgeable about dementia; some stereotyping was entrenched, which prevented nurses seeing beyond the person's confusion. This was more prevalent in surgical wards (Borbasi et al. 2006).

Uncertainty in caring for people with dementia meant that staff often focused on physical needs (Cowdell 2008). Nursing assistants tended to have had training only in managing aggressive behaviour (Cowdell 2008), whereas occupational therapy and social work staff believed their education had embraced dementia care from the outset (Cowdell 2008). Nurses could actively seek out education on dementia care but it was found to be not readily available (Cowdell 2008). It was noted in Rhynas (2010) that mental health nurses had greater knowledge of dementia care than general nurses. It was felt that a lack of understanding about care of the older person could also impact on care of people with dementia (Robinson et al. 2012). In care planning, understanding the disease of dementia would help staff to understand the associated pathologies, thus plan care more effectively (Rhynas 2010) and facilitate more effective care pathways (Robinson et al. 2012). It is necessary to provide education about appropriate care for the person with dementia but also there is a need to make education available and mandatory in areas where staff will meet and care for people with dementia.

### 3.2 Individualised

This theme focuses on evidence supporting individualised, person-centred approaches to care, or on the contrary, where this approach to care was not evident. The sub-themes were: "Pieces of the puzzle" and barriers to person-centred care.

#### 3.2.1 "Pieces of the puzzle"

This sub-theme explores how getting to know the person and their diagnosis could help in care planning and the provision of person-centred care. Senior staff seemed to use the

language of person-centred care more readily, whereas staff providing direct care alluded to it in a more abstract way or referred to it as individualised care (Cowdell 2008, Rhynas 2010). In one study, two physiotherapists were observed postponing a session with a person with dementia who was not responding, thus acknowledging the needs of the person were more important than adhering to routine (Cowdell 2008). Knowledge of the person with dementia was important in not assigning blame for their behaviour. Familiarity with the person facilitated an understanding of what might have triggered the behaviour (Nolan 2006). A thorough assessment promoted more appropriate care in terms of personal preferences and triggers (Robinson et al. 2012). Having all the “pieces of the puzzle” was viewed as particularly important (Cowdell 2008, Robinson et al. 2012).

Having the pieces of the puzzle and knowing the person with dementia allowed staff to make efforts to promote autonomy and independence in the acute setting. Signs, photographs and clocks gave people with dementia a "sense of place" and acted as visual prompts (Borbasi et al. 2006, Rhynas 2010). However, these opportunities might be limited in the acute setting due to infection control and the need for medical equipment (Rhynas 2010). Only one study identified nurses' efforts to maintain autonomy and promote independence (Nolan 2006). "Nurses wished to care for the older person with dementia as an autonomous being. Perceptions of the person with dementia as a person did not diminish with admission to the acute context or the degree to which the dementia had advanced" (Nolan 2006, p210).

### 3.2.2 Barriers to person-centred care

Routine approaches to care were often not person-centred but focused on physical care (Cowdell 2008, 2010a, 2010b). Nurses did "what needed to be done" (Cowdell 2010b, Rhynas 2010). This could be attributed to poor knowledge and resources (Eriksson & Saveman 2002, Jones et al. 2006). Staff could not "afford that luxury" of sitting down and spending time with the person with dementia (Jones et al. 2006).

Sometimes, person-centred care could be overlooked in the pursuit of safety. Moyle et al. (2011) illustrated an example where a nurse manager describes her advice to new nursing assistants. She outlines that she always prioritises safety over dignity, even if this means compromising privacy and propriety, such as leaving a bathroom door open. This conflict between safety and dignity needs to be explored from an infrastructural perspective. Re-examining the care environment could allow modifications to be made that would permit

increased levels of dignity without forfeiting safety. This relates back to the earlier findings outlining the need to explore alternatives to restraint.

### 3.3 Perspective

This theme refers to the perspective of the person with dementia and how they might interact with the acute setting and what staff can do/not do to affect this interaction. The sub-themes were: Interactions and impact on other patients, and the built environment.

#### 3.3.1 Interactions and impact on other patients

This sub-theme identified that people with dementia in the acute setting could exhibit behaviours that staff could find challenging (Borbasi et al. 2006). This caused frustration for nurses trying to carry out care when a person was hurting them physically or shouting at them (Eriksson & Saveman 2002, Jones et al. 2006). In cases where patients were being restrained, it seemed that the person was being blamed for their behaviour rather than the approach being used to manage the behaviour being questioned (Moyle et al. 2011).

In addition to aggressive behaviour, other interactions could pose problems in the acute setting. Sometimes the person might not be able to ring a bell or tell staff that they needed something, thus diminishing the quality of care that they received (Borbasi et al. 2006). Walking about in a disoriented way, as often demonstrated by the person with dementia in the acute setting, could impact on other patients, who might feel intrusion of their bed space and belongings (Eriksson and Saveman 2002, Jones et al. 2006). Advocacy was described in two studies (Borbasi et al. 2006, Nolan 2007), in terms of nurses acting as advocates for the person with dementia to prevent labelling, discrimination and stigmatisation in the acute setting.

It can be concluded that emphasis in these situations should be on finding the cause of the person's behaviour rather than attributing blame to the individual. Healthcare staff members need to advocate for the person with dementia and encourage understanding and compassion from other individuals. The situation can be difficult when other admitted patients may be dealing with their own ill health. Again, focusing on environment and infrastructure should include specialist areas that could appropriately care for people with dementia without impacting on the care of others.

### 3.3.2 The built environment

The acute environment is unfamiliar to the person with dementia, with noise and stimuli that could make their confusion worse and increase anxiety (Borbasi et al. 2006, Eriksson & Saveman 2002, Rhynas 2010). It could therefore be deemed unsafe, particularly at night-time (Borbasi et al. 2006, Jones et al. 2006). The layout was also described as unsuitable, with bathrooms often at a distance from the bedside (Borbasi et al. 2006). Doors sometimes needed to be locked; otherwise constant monitoring was required (Eriksson & Saveman 2002, Moyle et al. 2011, Nolan 2007). "Many nurses talked about the inappropriateness of the physical environment for dementia care. They highlighted the lack of privacy and use of communal facilities, repetitive décor" (Rhynas 2010, p264). Specialised environments are necessary to accommodate people with dementia.

### 3.4 Social and Psychological

This theme addresses the social and psychological needs of the person with dementia through communication, respect and bonding, and family involvement. The two sub-themes were: "Forming relationships" and family involvement.

#### 3.4.1 "Forming relationships"

Respect was articulated in terms of staff treating the person with dementia like a family member (Cowdell 2008). Bonding and building relationships with the person with dementia was viewed as a prerequisite to good care (Nolan 2006, Rhynas 2010). "The process was described as requiring persistence and authenticity on the part of the nurse...the requirement to treat the person with dementia as one would treat any person whom one was getting to know" (Nolan 2006, p211).

Interactions sometimes focused on physical care, because staff often experienced uncertainty regarding psychosocial care and communication (Cowdell 2008, 2010a, 2010b) Similarly, Jones et al. (2006) identified that communicating and negotiating care was seen as important but often hindered by lack of time. Communication can be difficult between staff and people with dementia (Eriksson & Saveman 2002). Staff caring for people with dementia needs to recognize that people with dementia, even those in the more advanced stages, can

communicate given sufficient time and support. Cowdell (2008, 2010b) recommends that staff need to listen to this client group and learn from their experiences.

### 3.4.2 Family involvement

The family's knowledge of the person with dementia was important in the delivery of individualised care and in helping people feel psychologically safe (Nolan 2006, Robinson et al. 2012). Family members can inform staff about particular triggers that exacerbate or soothe the manifestations of confusion in their relative. Their insight is crucial and members of staff need to maintain effective relationships with family members wherever possible (Nolan 2006). Family was a source of support for the person with dementia but there was also potential for conflict if families made decisions on behalf of the confused person that were not in their best interest (Cowdell 2008, Nolan 2006). While support can be beneficial, there is often no clear strategy for family involvement (Moyle et al. 2011).

## 4 Discussion

It is evident that the acute setting is not the ideal place for a person with dementia. This present synthesis identifies barriers to appropriate care for the person with dementia. These include ineffective pathways of care, unsuitable environments, inadequate resources and staffing levels and lack of emphasis on education and training for staff caring for people with dementia. Ultimately, the culture of the acute setting impacts on the care that is given and there needs to be "sweeping environmental and cultural changes" (Jones et al. 2006, p144). The reality remains that healthcare staff will care for people with dementia in the acute setting and efforts must be placed on improving welfare standards for this client group. Person-centred care requires improving standards across the whole healthcare organisation in a sustainable way and not just at the individual and ward level (Brooker & Latham 2016). This needs to be reflected in policies developed in acute setting to address the specific care needs of people with dementia and the strategies to be employed across the organisation.

Ultimately, there needs to be capacity, in ethos, organisation and structure, to care effectively for people with dementia in a person-centred way. Leadership is required at a senior level to instil the values needed for appropriate care and to ensure standards and procedures are in place within an organisation. In addition, leadership is also required for the day-to-day management and provision of care (Brooker & Latham 2016). Efforts should be placed on building organisational capacity and creating structured pathways of care to transition people

within the acute setting and to and from the community/residential settings (Borbasi et al. 2006, Cooper & Deeks 2012, Robinson et al. 2012). This requires effective multidisciplinary engagement across acute and community settings. The Royal College of Psychiatrists (2013) identified an increase in the number of hospitals in the UK that have care pathways in place for people with dementia but this may not be reflective of other countries. In addition, a discharge co-ordinator could improve the transfer of people with dementia from the acute setting (Cornell et al. 2012).

The environmental design of the traditional acute setting in the studies was shown to place people with dementia at risk of harm (Borbasi et al. 2006, Eriksson and Saveman 2002, Nolan 2007). There needs to be a focus on ways to enhance the environment. Borbasi et al. (2006) identifies that risk management should be an integral part of assessment and care. All new builds should incorporate dementia-friendly designs (Irish National Audit of Dementia Care in Acute Hospitals 2014). There are a number of tools available to audit existing environments and even minor changes can improve the experience for the person with dementia. One example of such an audit tool is the Enhancing the Healing Environment (EHE) dementia care tool for wards and hospitals (The King's Fund, no date). An appropriate environment will minimise the need to prioritise safety over dignity and ensure people are cared for in a safe and dignified manner. Regarding inappropriate use of restraint, Hughes (2008) emphasises that its use is a violation of human rights. Staff should explore more carefully the cause of the behaviour of concern in an effort to reduce the use of restraint. This requires education and training (De Bellis et al. 2011). It also necessitates the allocation of adequate resources as restraint may be more commonly used in instances where there are staff shortages (Hughes 2008).

It is evident that training and education are key areas for improvement. The synthesis revealed that staffs were not equipped with the right skills to provide appropriate dementia care in the acute setting and education is critical for the provision of meaningful care (Borbasi et al. 2006, Cowdell 2008, Eriksson & Saveman 2002, Nolan 2007, Rhynas 2010). Education and training should be easily accessible and organisation led (Cooper & Deeks 2012, Jones et al. 2006). However, other researchers have found that education alone will not sustain a change in a culture of care (Cowdell 2010a, Moyle et al. 2011). Staff education and training is of prime importance but must go beyond the education of individuals to facilitate positive organisational change (Moyle et al. 2011). Practice development initiatives need to

focus on staff at an emotional and intellectual level (Cowdell 2010a), with education endeavouring to rekindle empathy and focus more on person-centred approaches (Cowdell 2010b, Nolan 2006, Nolan 2007).

Recommendations arising from the synthesis include the requirement for "floating expertise" (Borbasi et al. 2006). Specialists, such as clinical nurse specialists and transitional care pharmacists could advocate and build capacity in an organisation to effectively care for people with dementia (Borbasi et al. 2006, Cooper & Deeks 2012). This emphasises the potential value in some of the initiatives described earlier, such as "dementia champions" (Cunningham and McWilliam, 2006, Crabtree & Mack 2010, RCP 2010, RCP 2013) and the dementia nurse specialist (DNS) (Elliot & Adams 2011).

Some of the studies in the synthesis identified a need to focus on best practice initiatives, championed by staff from the top of the organization (Borbasi et al. 2006, Jones et al. 2006). These initiatives could include development of clinical guidelines and models of best practice (Borbasi et al. 2006, Jones et al. 2006), focusing on empathy and person-centred care, and the elimination of the use of restraint (Cowdell 2008, Jones et al. 2006). Using the VIPS framework as a guide to examining practices in the acute setting would allow recognition of good practice and also identify areas for improvement (Brooker 2006, Brooker & Latham 2016). This review has shown that this framework is suitable for looking at the care of people with dementia in this context and could also be used as a framework for policy development.

Further, more extensive, research is needed to provide an evidence base for dementia care (Cowdell 2010a, Eriksson & Saveman 2002, Robinson et al. 2012). It should be noted that the studies identified for synthesis were conducted in 2002-2012. A number of audits and reports have been published since then and these provide more clear recommendations on what needs to be done to improve the care of people with dementia in acute settings. Consequently, more intervention research is warranted (Moyle et al. 2011), with a particular emphasis on measuring the effectiveness of some of the initiatives that have been introduced in the acute setting in recent years. The studies included in this synthesis were qualitative, exploring experiences and perceptions of care. However, little research has been undertaken to examine the effectiveness of interventions to improve care for people with dementia in the acute setting. There is also a need to examine the care of the people with dementia in non-dementia specialist facilities, such as ICU or surgical wards (Cowdell 2008, Nolan 2006).

This review employed framework synthesis as a pragmatic approach to exploring the care of people with dementia in acute settings using a previously published framework. It was deemed an appropriate approach, capturing a wide range of issues in a cohesive way. Having the developer of the VIPS framework as an advisor to the review was helpful for clarification purposes. The framework was found to be easy to interpret, very comprehensive and suitable for exploring the care needs of people with dementia. This is evident by the fact that no additional themes were needed to describe and interpret the data. The search strategy was comprehensive and screening conducted by at least two researchers added rigour to the process. In terms of critical appraisal, the majority of studies were deemed of high quality. Reports of lower quality were still included in the synthesis. Sensitivity analysis, using matrix queries within NVivo, confirmed that the findings from these studies did not influence the overall findings in terms of weighting or contribution. This review explored only the perspectives and experiences of staff but provides further scope for evidence synthesis focusing on care in the acute setting from the perspective of the person with dementia and their carers.

## 5 Conclusion

This review has identified key issues in the care of people with dementia in the acute setting. These include improving pathways of care, creating suitable environments, addressing resources and staffing levels and placing emphasis on the education and training for staff caring for people with dementia. Recommendations are made for practice consideration, policy development and future research. Through qualitative evidence synthesis, it has been possible to draw conclusions from a number of studies and this strengthens the findings and recommendations, which, in turn, provides better evidence for policy makers. This synthesis identified the usefulness of VIPS as a structured guide to exploring the care of people with dementia in acute settings. This paper recommends that this framework should be used to guide policy development also. The VIPS framework identifies issues at all levels of the acute hospital infrastructure, which can inform leaders at organisational and ward level. This, in turn, may inform the development of effective interventions to improve the quality of person-centred care for people with dementia in acute hospitals.

### **What is already known about the topic?**

- Dementia is a global issue that impacts greatly on health care delivery systems
- People with dementia have specific care needs when admitted to acute settings
- The acute environment is often unsuitable for the person with dementia

### What this paper adds

- There is a need to create capacity in the ethos, organisation and environment in which care is provided to people with dementia in acute settings
- This capacity can be created through education, leadership and structural design changes to the acute environment.
- The VIPS framework is suitable for guiding policy exploring ways to improve care for people with dementia in acute settings

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