



# The experiences and perceptions of care in acute settings for patients living with dementia: A qualitative evidence synthesis

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## ABSTRACT

**Background:** Increasing numbers of people with dementia are presenting to acute care facilities for management of medical conditions and co-morbidities. They require an individual approach to care due to the confusion and disorientation which may accompany their illness. Current evidence syntheses on this topic explore how staff, family and carers view their care. This review aims to complement previous work in the area by exploring care from the perspective of the patient living with dementia.

**Objectives:** The aim of this qualitative evidence synthesis was to explore the experiences and perceptions of patients living with dementia on the care they receive in acute settings.

**Design:** Qualitative evidence synthesis systematically draws the findings from individual studies together to create valid, reliable and meaningful evidence for healthcare policy development. Framework synthesis was utilised and guided by the VIPS framework; Values, Individualised, Perspective, and Social and psychological. The VIPS framework has previously been used for exploring staffs' views of care in the acute setting and provides guidance to caring for people with dementia.

**Review methods:** Following screening, data were extracted and appraised using Critical Appraisal Skills Programme. Framework synthesis, incorporating thematic synthesis, was conducted and the confidence in findings was assessed using GRADE CERQual.

**Data sources:** Seven qualitative studies that explored care in acute hospitals as experienced or perceived by the person living with dementia.

**Results:** The VIPS framework helped to capture views of care. Patients often experienced rushed and task-based approaches, poor communication, and exclusion in some cases. The environments were clearly unsuitable, sometimes exacerbating behaviours of concern, thus leading to unnecessary restraint due to an inability to protect this group.

**Conclusions:** Further research needs to be conducted in testing existing or developing new interventions to improve the physical environment, the systems of care and to provide more person-centred approaches to care. Organisational structures must ensure patients are cared for in a dementia friendly environment by a dementia trained workforce. At local level, involving support workers, eliminating unnecessary care practices, and facilitating individual choices of patients are recommended.

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## What is already known about the topic?

- Patients living with dementia often deteriorate in the acute hospital setting where falls, delirium and loss of function are frequently associated with increased length of stay and increased mortality.

- Family carers and staff struggle to adequately support to patients with dementia who are being cared for in acute settings.

## What this paper adds

- People living with dementia feel isolated and excluded from their care in acute settings.
- Staff training and systems of care must be adapted to incorporate person-centred approaches when treating persons with dementia.
- Further research is required to advise and remodel systems of care which will generate a more appropriate person-centred approach in acute setting.

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## 1. Introduction

Dementia is a global term for a number of conditions that cause a gradual decline in a person's personality and their ability to reason and remember. The various types of dementia cause damage to the brain cells, with Alzheimer's disease accounting for more than half of those affected (Alzheimer Society of Ireland, 2018). Current estimates suggest there are approximately 35.6 million people living with dementia worldwide (Briggs et al., 2016). People living with dementia often have co-morbidities requiring hospital admission, with increased pressure on health care services ill equipped to provide appropriate care (Timmons et al., 2016). The complexities of addressing the multi-dimensional needs of this cohort in hospital are broadly discussed in research (Houghton et al., 2016; Nilsson et al., 2012; Dewing and Dijk, 2016). Hospital costings show patients living with dementia (living with dementia) require three times more funding than caring for those without the condition (Briggs et al., 2015; Watkin et al., 2012). As inpatients, a higher incidence of reported adverse events such as falls, delirium, pressure sores, incontinence and fractures are associated with this group (Alzheimer's Society, 2009; Bridges and Wilkinson, 2011). Prioritisation of care for patients living with dementia is not always person-centered which focuses more on risk management and injury prevention. (Houghton et al., 2016; Dewing & Saskia, 2016).

## 2. Background

Despite the increasing numbers of patients living with dementia (living with dementia) presenting to acute settings, research demonstrates there is a lack of requisite knowledge on what constitutes person-centred care, proposing the focus rests on treating acute illness and co-morbidities (Gladman et al., 2012; Clissett et al., 2013; Digby and Bloomer., 2014). Patients living with dementia often struggle to express their needs, may communicate through actions and behaviours which are often challenging and difficult for others to comprehend (Borbasi et al., 2006; Clissett et al., 2013).

The concept of person-centred care has been present for many years and has long history in the philosophy of dementia care (Kitwood, 1997; Brooker, 2007). Previous research suggests the application of such values are not always realistic in the context of acute care, which is overshadowed by staffing constraints that directly impact on the workload of staff (Moyle et al., 2011; Eriksson and Saveman, 2002; Champion, 2014). Dewing and Saskia (2016) highlight the overall negative consequences of hospitalisation for patients living with dementia, with co-morbidities often overshadowing person-centred care. Deficits in mental health services, requisite knowledge and specialist care posts in nursing were identified shortfalls or barriers throughout the service. A qualitative evidence synthesis (qualitative evidence synthesis) by Houghton et al. (2016) explored the experiences and perceptions of healthcare professionals on care provided to patients living with dementia in the acute setting. This review captured an overall shortfall among the organisational, environmental and the general culture in which care is carried out. Key issues included poor staff training, a lack of care pathways and a lack of resources. A subsequent qualitative evidence synthesis by Burgstaller et al. (2018) explore the impact of acute care from the perspective of relatives of patients living with dementia. It found hospital systems and processes make family participation in patient care very difficult, especially because of environmental constraints, time and staffing pressures. This review suggests that opinions of relatives are strongly shaped by the attitudes, experience and communication that they encounter in the health setting. They propose health professionals have the potential to break through

this negativity and contribute more positively towards a patient's hospital stay.

To complete insights of this experience, it is also necessary to explore it from the perspective of the patient living with dementia. Consolidating these multiple perspectives will help to inform policy and guidance of how best to care for this group of individuals in the acute setting.

## 3. Methods

The aim of this qualitative evidence synthesis was to explore the experiences and perceptions of patients living with dementia who have been cared for in an acute setting. Knowledge syntheses are a vital component of evidence - based practice as they seek to source, summarize, and analyse pertinent studies on a specialized topic. They are a fast-developing area in nursing research and are often used to inform health policy and manage health related issues (Kastner et al., 2012; Barnett-Page and Thomas, 2009). The Framework Synthesis approach was selected as a suitable methodology for this study and is primarily based on the earlier framework analysis approach used in qualitative research (Spencer et al., 2003). In contrast to meta-ethnography, it uses a mostly deductive approach through which data from selected studies are mapped or coded against existing concepts (Carroll et al., 2011). However, this approach also acknowledges that not all findings fit in this way and inductive thematic synthesis is integrated in a "best fit" approach (Carroll et al., 2013) that The Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) was used as a checklist for reviewing the transparency of reporting in this qualitative evidence synthesis (Tong et al., 2012).

## 4. Search strategy

An experienced clinical librarian assisted in the development of a comprehensive search strategy using all conceivable variations and combinations of the following keywords "dementia", "Alzheimer's disease", "inpatients", "experience" and "qualitative". Experts advise the use of an experienced librarian alongside a multi-pronged search strategy to ensure a reliable, cogent, and meaningful qualitative evidence synthesis (Pearson et al., 2011; Booth, 2016). This search was undertaken during the month of October 2017 and was employed across six databases CINAHL, Medline, Embase, PsycInfo, ProQuest and Scopus. Year or language parameters were not set. The initial search yielded 4420 references (2606 following de-duplication), which were imported into an Endnote 8.0 file. The endnote file was subsequently uploaded to the Covidence Software Programme for Systematic Reviews ([www.covidence.org](http://www.covidence.org), 2017).

## 5. Screening

The title and abstract of 2606 studies were jointly screened by the author and EC who has expertise in dementia care nursing. Pre-specified characteristics including population, research topic, philosophical approach, and type of publication created an explicit basis for the screening process (see Table 1). A third reviewer, CH, with qualitative evidence synthesis expertise, oversaw the screening process and moderated any conflicts.

A total of 171 research reports were included for full text review. A further 151 of these were excluded. A total of twenty studies were selected for data extraction. It must be noted that at this stage, the review originally aimed to include families and informal carers as well as patients living with dementia. However, the Burgstaller et al. (2018) was identified during screening and it was considered more insightful to focus solely on the perspective of the person with dementia themselves. Thirteen studies focusing on the perspective

**Table 1**  
Original inclusion criteria.

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- o Patients living with dementia
  - o Families and informal carers
  - o Emergency or elective admission to an acute hospital setting
  - o Primary qualitative or mixed method studies that contained a distinct qualitative component
  - o Experiences or perceptions of care or management of care in the acute setting
  - o Persons with dementia as stated by the study author +/- formal diagnosis of dementia as described in the report.
- 

of families and carers only were excluded. The final seven studies that focused on patients' views were included for data extraction. This change was not reflected in the search strategy or initial screening process, see PRISMA chart (Appendix 1) (Table 2).

## 6. Data management and critical appraisal

The best fit framework approach was employed in synthesising data for this multi- study analysis (Carroll et al., 2013). The VIPS framework was identified as a suitable framework as it was previously used in a similar review (Houghton et al., 2016). It was developed to assist in translating the concept of person-centred care into practice and is widely used to guide standards within facilities which provide dementia care (Rosvik et al., 2011; Brooker & Latham, 2015). The VIPS acronym was developed by Dawn Brooker, representing: Values; Individualised; Perspective of the person; Social and Psychological (Brooker, 2006; Brooker & Latham, 2015). It provides a guide for how best to approach caring for people living with dementia from management ethos, direct care giving and care pathways (Table 3).

The included studies (n=7) underwent a quality appraisal process alongside data extraction via a data extraction form created by Houghton et al. (2016) which incorporated both the VIPS framework and the Critical Appraisal Skills Programme (CASP) appraisal tool (Appendix 2). Primary and secondary data were extracted via line-by-line coding and categorised into the four broad VIPS themes within the extraction form. The aim was to facilitate comparison with the Houghton et al. (2016) review. Data included verbatim quotes along with findings of all text labelled as 'results' or 'findings' in studies including abstract findings. In accordance with a "best fit" approach, inductive thematic synthesis was conducted within each of the four broad themes, resulting in eight subthemes, which reflected the data. It was anticipated that there may potentially be additional findings that would not fit within the VIPS framework, however, this was not an issue once synthesis began. Ultimately, while the use of VIPS had a deductive approach, conducting thematic synthesis within each of the four broad themes ensured that the synthesis had an inductive approach also ensuring perspectives were captured. All coding and synthesis were discussed and agreed upon by JW and CH.

## 7. Findings

The findings are presented using the VIPS framework, with inductive subthemes that were developed during synthesis. Table 4. outlines the themes and subthemes.

### 7.1. Values

This theme encapsulates the organisational ethos and environmental factors that facilitate or impede the multifaceted needs of

patients living with dementia in hospital. The subthemes are: Infrastructures and Systems of care.

#### 7.1.1. Infrastructures

The clinical settings presented many challenges in caring for patients living with dementia. Overall, the capacity of this patient group to function in the hospital environment was impeded by the physical environment and clinical structures. The physical surroundings were unfamiliar, busy, lacked privacy and were clearly unsuitable for some of the participants (Nilsson et al., 2012; Cowdell, 2008; Hung et al., 2013; Clissett et al., 2013; Hynninen et al., 2015). Nilsson et al. (2012), observed patients living with dementia on a busy acute unit, stating the place, pace and space was unsuitable, and care was described as "falling behind" (P.1685). The systems of care and multiple demands on staffing appeared to impact negatively on the physical needs of many patients who were in some cases unable to mobilize, use the toilet, eat or wash without assistance (Nilsson et al., 2012; Cowdell, 2008; 2010; Cowdell, 2008). In some settings being nursed in a context which failed to cater to their needs impacted psychologically on the patients manifesting in undue anxiety, fear and worry (Nilsson et al., 2012; Cowdell, 2008; Porock et al., 2015). Physical outcomes of this sub-optimal care included constipation, incontinence and sometimes delirium (Cowdell, 2008; Nilsson et al., 2012). Both observational and patient accounts described how the noisy climate and frantic pace of some settings worsened patients' disorientation. A patient in the study by Hynninen et al. (2015), "stated a peaceful environment stimulates recovery while the restlessness and noise from other patients is detrimental" (P.3694).

This perception was supported by Nilsson et al. (2012) and patient participants in the study by Hung et al. (2016) who felt confused and distracted by noise from co-patients, staff and multiple alarms ringing: "Chaotic clutter makes the brain feel overloaded by too many stimuli, overly charged if you know what I mean" (Hung et al., 2016. P6). This contrasted with narratives by researchers who described areas as silent, bare and lacking stimuli. They proposed the prolonged periods of inactivity encouraged withdrawn behaviour, and were deficient of anything which would offer comfort or identity (Cowdell, 2008; Clissett et al., 2013).

"In room three sat Clarence hunched over his table. His knuckles were in his mouth and he seemed to be intently chomping on them whilst staring out the window. There were no cards or personal effects in his room: it was Spartan and smelt of bleach" (Clissett et al., 2013. P.1500).

#### 7.1.2. Systems of care

Clinically, the study settings all appeared to function under a medical model where the philosophy of care was task-driven, and standards were based on safety and efficiency. Three of the studies depicted a culture which mitigated against holistic care and was managed by routines, offering little consultation with the patients (Cowdell, 2008; Norman, 2006; Nilsson et al., 2012). Researchers' accounts of distressing care involving hygiene, toileting and incontinence needs, exploited the vulnerabilities of this group, and overlooked patient centred rights to privacy and dignity (Hynninen et al., 2015; Cowdell, 2008; Nilsson et al., 2012; Porock et al., 2015).

"Walter has been incontinent. They tell him to sit in his chair and eat his lunch. He does not look comfortable or settled, they tell him they will 'clean him up afterwards'. To add to the humiliation the curtains are pulled back and the bed is stripped and remade in the middle of the bay" (Cowdell, 2008. P.150).

The practice of restraining problematic patients who wandered, climbed, or became aggressive was evident across some studies (Hung et al., 2016; Clissett et al., 2013; Nilsson et al., 2012).

**Table 2**  
Characteristics of included studies.

Study #	Author(s) Year	Country	Design	Sample	Subset population	Method	Study focus
1	<a href="#">Hynninen et al. (2015)</a>	Finland	Qualitative Descriptive	7 Patients with Dementia. 5 Women and 2 Men 74-85 Years of age.	All the interviewed patients had been diagnosed with mild or moderate Alzheimer's disease, and consisted of five women and two men aged 74-85 years (average age 81 years)..	Unstructured Interviews March-October 2012 There were four individual interviews, and three joint interviews (n = 2) with close relatives	To acquire a comprehensive picture of the treatment of older people with dementia in a surgical ward
2	<a href="#">Hung et al. (2016)</a>	Canada	Action research study underpinned by critical social theory and interpretive approach	5 participants, 3 men and 2 women. Age range of 65-84. All participants had a diagnosis of dementia.	All participants had a diagnosis of dementia, including Alzheimer's disease, vascular dementia or an unspecified subtype of dementia. They had a wide range of functional abilities and difficulties.	Patients with dementia shared stories, experiences and suggestions for making changes to the ward.	This study explores the perspectives of patients with dementia about the hospital environment
2	<a href="#">Norman (2006)</a>	UK	Observational study	8 patients were recruited for the observational phase of this study	Participants were recruited using a convenience sample of patients in the observation settings. Nursing staff were requested to identify potential participants and hand-over sessions were attended to identify further potential participants. No formal assessment was carried out to judge whether a participant had a positive diagnosis of dementia	Researcher moved from the position of observer to participant and back again.	The aim of the observations was to explore what happens to a person with dementia when admitted to a ward in a general hospital
4	<a href="#">Porock et al. (2013)</a>	UK	Descriptive exploratory	The study was attached to a cohort study which followed 250 older people.	Typically patients were admitted with a very wide range of medical diagnoses, often associated with a non-specific presentation such as falls, immobility or worsening confusion. All participants for the present study were identified by the researchers on the cohort study, and had some loss of cognitive function using the Mini-Mental State Examination (MMSE).	39 interviews plus 72 hours of non-participant observations of care on 45 occasions on 11 wards.	This qualitative study aimed to gain insight into the experience of hospitalisation from the perspectives of the older person with dementia
5	<a href="#">Clissett et al. (2012)</a>	UK	Observational study	As part of a cohort study of 250 patients, 34 participants were recruited into this in-depth qualitative study:	Participants were patients admitted to general medical, health care for older people and orthopaedic wards, aged over 70, who had been screened as having a possible mental health problems (using brief tests of cognition, depression, alcohol misuse and a question asking if there was any other reason to believe a mental health diagnosis might be present).	72 h of ward-based non-participant observation and 30 formal interviews concening 29 patients.	The aim of this paper was to explore the way in which current approaches to care in acute settings had the potential to enhance personhood in older adults with dementia.
6	<a href="#">Cowdell (2008)</a>	UK	Thesis document A critical interpretive ethnographic approach was used	A total of 11 patients were involved and their ages ranged from 80-94.	Eleven people with a pre-admission diagnosis of dementia participated: four male and seven female, aged 80-93 years. Mini Mental Test Examination Scores (Folstein et al., 1975) were 0-7 indicating severe dementia. It is acknowledged that these scores may have been influenced by superimposed physical illness. Two participants had been admitted from residential care, all others had come from their own homes where they had been receiving some level of support.	The data were collected through participant observation, informal conversations and interviews.	The purpose of this study was to explore the experiences of patients, lay carers and health and social care staff of the care received by older people with dementia in the acute hospital setting.
7	<a href="#">Nilsson et al. (2013)</a>	sweden	grounded theory approach inspired by Strauss and Corbin (1998) to develop a substantive theory on PCC of older people with cognitive impairment in acute care.	The substantive theory was grounded in a total of 110 hours of observation of 3 patients. One interview with 1 patient.	The study was conducted in a 20-bed cardiology ward at a university hospital in Sweden. total of 110 hours of ethnographic-style observations (Wolf, 2007) were completed over a period of six months in 2010-2011, mainly by the principal investigator (PI). The observations were initially unfocused and participatory in that the PI participated in activities at the unit to obtain an overall feel for the culture of the ward and to gain insight into the care provided to older people with cognitive impairment.	total of 110 hours of ethnographic-style observations	To develop a theoretical understanding of the processes hindering person-centred care of older people with cognitive impairment in acute care settings.



**Table 3**  
The VIPS framework.

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

**Table 4**  
Overview of themes.

Theme	Subtheme	Brief description
<b>Values</b>	Infrastructures	-The impact of physical environments, clinical structures, and the social climate on patient care.
	Systems of care	-Philosophy of care and its impact in the various settings.
<b>Individualised</b>	Not caring for the person	-Disregard for individual capacity, personality, or preferences.
	Caring for the person	-Preservation of identity, esteem and facilitating choice.
<b>Perspective</b>	Disruption and coping	-Patient coping mechanisms, behaviours and their impact on care.
	Perceived level of independence	-The perceived restrictions of hospitalization and its impact on physical and psychological wellbeing.
<b>Social</b>	Socializing with confidence and autonomy	-The impact of forming relationships, socialising, and seeking companionship on care in the confines of acute medical settings.
<b>Psychological</b>	External supports	-The contribution of external supports to patient wellbeing and their impacts on care.

## 7.2. Individualised

This theme offers an insight into care practises which facilitated or hindered the abilities, capacity, personality, and preferences of the patient living with dementia. The subthemes are: Not caring for the person; and caring for the person.

### 7.2.1. Not caring for the “person”

Many patients lacked a clear understanding of why they were on hospital and expected staff to spend more time with them (Hung et al., 2016; [Clissett et al., 2013](#)). Some “*felt ignored and insufficiently informed*” ([Hynninen et al., 2015. P.3695](#)). Indications from one study implied bedside rounds were rushed by doctors who offered limited opportunities for patients to converse or consult about their wishes ([Cowdell, 2008](#)). Patients in some studies spoke of their fears in relation to discharge planning, worried about having to go to a nursing home and most had a wish to return to their previous life (Hung et al., 2016; [Porock et al., 2015](#)). “*Hilda expressed some very real concerns about her future if she was admitted to residential care*” ([Cowdell, 2008. P86](#)). Some felt decisions were made, often against their wishes “*you don’t know where they’re going to put yer, you’re never sure, every day, it changes which is wrong*” ([Cowdell, 2008. P.120](#)). There was a paternalistic and prescriptive relationship between the staff and patients captured by the observed use of infantile language: “*The nursing assistant said in a baby voice ‘you’re going to have a nice bath Eileen’*” ([Cowdell, 2008. P.138](#)). A researcher noted that relatively independent and compliant patients were received more positively among staff as “*whole individuals*” whilst the more dependent patients were regarded as “*difficult*” and referred to by the needs associated with their care: “*We’ll do the heavies first*” (Norman et al., 2015. P.458.).

### 7.2.2. Caring for the “person”

In contrast to the lack of dignity experienced, there were accounts of person centred attitudes among some staff ([Clissett et al., 2013](#); [Cowdell, 2008](#); [Norman, 2006](#)). Care approaches were communicated to some of the patients and adapted or remodelled to cater for individual needs ([Porock et al., 2015](#); [Nilsson et al., 2012](#); [Cowdell, 2008](#)). Some staff used positive distractions, by giving patients a role or hobby for example, carrying linen or helping tidy bed-spaces as an alternative to being “*specialised*”. This also helped to alleviate potential boredom ([Porock et al., 2015](#); [Norman, 2006](#)). Esteem and preservation of identity was important

to patients and was promoted through warm and caring exchanges between the staff and patients ([Clissett et al., 2013](#)). Patients enjoyed talking to staff who spent time helping sort through their personal belongings. Pictures and personal items provided avenues for conversation, allowed patients to connect with other staff, and facilitated an expression of self ([Cowdell, 2008](#); [Clissett et al., 2013](#)).

Evidence from some settings depict task based approaches to care which were more centred on the physical aspects of care were prioritized ([Hynninen et al., 2015](#); [Cowdell, 2008](#)). Some interactions left the patient feeling insignificant ([Cowdell, 2008](#)), whilst others made them feel worthwhile ([Clissett et al., 2013](#)). Observational data suggested that promotion of the patient’s autonomy or capacity to function was hampered by time, staffing constraints and the how staff regarded them. The ability of some patients living with dementia to interact well with staff appeared to invoke an overall higher degree of positive regard. The individual personality traits of either the staff member or the patient appeared to influence the quality of care in some instances ([Cowdell, 2008](#); [Nilsson et al., 2012](#); [Clissett et al., 2013](#)).

## 7.3. Perspective

This theme explored the perspective of the patient living with dementia. It focuses on how patients engaged with the acute environment, what elements influenced their perspective or prevented them from “settling in”. The subthemes are: disruption and coping; and perceived level of independence.

### 7.3.1. Disruption and coping

Hospitalisation represented a disruption to the normal routine of patients living with dementia and many perceived it as a threat to their personhood ([Clissett et al., 2013](#); Hung et al., 2016; [Norman, 2006](#)). Work like activity, such as gathering belongings and interfering with other patients’ property appeared to occupy time however it sometimes created friction with co-patients ([Norman, 2006](#); Hung et al., 2016). Conversely, indications show displays of disengaged behaviours were also prevalent, and indications show some patients were unaware of the hospital surroundings. Many failed to interact with staff, refused medications and nursing care, and had an overall mistrust in the staff and setting (Hung et al., 2016; [Porock et al., 2015](#); [Cowdell, 2008](#)). Sensory stimulation in some busier environments exacerbated confusion for patients who could be heard calling out anxiously,

sometimes answering questions not directed at them (Cowell, 2010; Hynninen et al., 2012). Patients were seen to remove their clothing, cannulas, and catheters in a possible attempt to take control (Nilsson et al., 2012). Repeated displays of wandering were a common phenomenon, however, some staff were indifferent to signals of discomfort and returned patients to their bedsides (Cowell, 2008; Porock et al., 2015; Nilsson et al., 2012). Patients worried for the future: “Ben stated, *I don’t know what’s happening to me . . . do I stay here forever . . . people never look and they never speak*” (Cowell, 2008, P.120). Others expressed strong wishes to return to previous capacity and fretted for wellbeing of family members at home (Hynninen et al., 2015; Norman, 2006; Clissett et al., 2013).

#### 7.3.2. Perceived level of independence

Patients described feeling unsafe in hospital and complained about its restrictive impact on their independence (Cowell, 2008; Hung et al., 2016). Discomfort and lack of control was associated with shared toilet facilities; lack of space; and inability to control lighting or noise (Hung et al., 2016; Cowdell, 2008; Clissett et al., 2013). Being able to move about without restrictions was important to patients. It allowed them to feel socially confident (Hung et al., 2016; Norman, 2006) and be active in their own care (Hynninen et al., 2015). The pace of some wards caused anxiety and psychological distress (Hung et al., 2016; Hynninen et al., 2015). Walkways were cluttered with linen carts and equipment which made wayfinding difficult and unsafe for patients (Hung et al., 2016). Many were frightened by wandering co- patients who displayed challenging behaviour (Hung et al., 2016; Norman, 2006). The use of bright colours, handrails and signage were some suggested improvements by the patients (Hung et al., 2016). In the study by Hynninen et al. (2015), participants mistrusted medications “*preferring to deal with a bit of pain than taking painkillers*” (P.3697). In all but one study, boredom was a commonality and inextricably linked to the lack of stimulation and personal space. (Norman, 2006; Clissett et al., 2015; Porock et al., 2015).

“I guess one of the stressors involved with being in the hospital is you don’t have too much to do” The hospital is a very boring place to be because nobody does anything” (Hung et al., 2017, P.7).

#### 7.4. Social psychological

This theme explored if care and social ambiance enabled or prevented the patient to feel socially confident and know that they were not alone. The subthemes were socialising with confidence and autonomy and external supports.

##### 7.4.1. Socialising with confidence and autonomy

Some patients responded positively to being in hospital and attempted to gain control over the environment and themselves (Hung et al., 2016; Cowdell, 2008). Forming relationships, socialising, and seeking companionship were some of the constructive behaviours exhibited in an attempt to assert independence (Hung et al., 2017; Cowdell, 2008). Choices in care, meaningful relationships with staff, and social inclusion were some of the more positive psychological supports evident (Clissett et al., 2013; Cowdell, 2008; Porock et al., 2015). Conversely, participants expressed strong negative opinions about their care, some felt devalued and disempowered due to discriminatory labelling and the cultural attitudes towards patients living with dementia (Hynninen et al., 2015; Hung et al., 2016). In three of the studies, hospitalization was viewed as a significantly negative experience (Cowell, 2008; Norman, 2006) with some patients feeling disempowered, and socially excluded:

“I feel like being a loser! It’s a shame, you know you guys have your freedom and you know what I have none” (Hung et al., 2016, P.8).

Others felt their rights to autonomy were obstructed by the paternalistic climate and

despaired about constraints imposed by staff where there was a clear lack of freedom and choice. (Hung et al., 2016)

“I spend my day being tied up in this chair most of the time. I fell because I was not used to the kind of floor here in the hospital. The second time my head was a little dizzy. After that, they tied me up” (Hung et al., 2017, P.8).

Compelling evidence of the psychological impacts of hospitalization emerged mostly from observational narratives (Nilsson et al., 2012; Cowdell, 2008; Porock et al., 2013), however the first-person insight provided by Hung et al. (2015) augmented previous findings.

##### 7.4.2. External supports

The role of close relatives was important for mental and social wellbeing of patients. They valued visits from families who made a positive contribution to their care (Clissett et al., 2013; Cowdell, 2008; Porock et al., 2015). Family knowledge of the person with dementia helped ensure their needs or wishes were made clear, and ensured the patient was involved in decisions that affected them (Porock et al., 2015; Norman, 2006). These environments failed to keep patients in touch with outside life as there was a noted absence of televisions and radios in some of the wards (Cowell, 2008; Clissett et al., 2013). The value of research studies in supporting this cohort is highlighted through the views of Patients living with dementia in a study by Hung et al. (2016). Participants offered useful insights and practical solutions to guide future service development. This study highlighted the importance of involving the patients themselves as a knowledge source. This cohort of patients living with dementia appreciated being asked about their opinions of the hospital environment, suggesting it meant their views mattered and were being respected. They proposed a supportive environment would enable independence, provide activities to alleviate boredom, feel safe, and support social interactions.

##### 7.4.3. Assessment of confidence in findings

From the synthesis findings presented, a number of key summary statements were identified that comprehensively illustrated the main sights from the review. An overall assessment of the confidence in each of these summary statements was undertaken using the GRADE CERQual approach (Lewin et al., 2015) (see Appendix 3). The GRADE CERQual approach uses four key criteria to assess the researcher’s confidence in each of the developed findings. These four criteria are: Relevancy, Adequacy, Cohesion and Methodological Limitations. Confidence in the review findings are valued on a scale of high, moderate, low or very low. This review provides a reasonable representation of the phenomenon in question. The methodological limitations of a few studies were of moderate concern, however this was minimized by the high values placed on relevance of data to the findings. Assessment in relation to coherence found no contradictory or ambiguous issues amongst the data supporting the review findings. In relation to adequacy the review findings were enlightened by the rich body of knowledge in a proportion of studies which provided an acceptable interpretation of the meaning and context of what was being researched. These judgements on the confidence in each finding helped in the writing of the discussion and recommendations in this review.

## 8. Discussion

The VIPS framework enabled an exploration of the acute hospital experience for the patient living with dementia from four lenses: how they are valued within the hospital ethos and infrastructure, how they are treated as individuals by staff, how they perceive themselves in the acute setting, and how they socialise and feel supported in the acute environment. Core factors impacting on their experiences are represented across all four aspects of the frameworks. These core factors are: the environment, systems of care, and direct care. These core factors are discussed within the context of the other published qualitative evidence synthesis by Houghton et al. (2016) and Burgstaller et al. (2018). It is acknowledged that utilising the VIPS framework for this review is overly deductive and potentially limits the voice of the participants. On the other hand, it facilitates a comparison across the three reviews that enhances the ability to make robust conclusions.

The acute environment is clearly unsuitable for patients living with dementia. For the patient, the busyness, noise and chaos is challenging for them, makes them feel unsafe, and can exacerbate behaviours of concern. The use of bright colours, seated areas to rest, handrails and signage were some of the suggestions for improvement by patients (Hung et al., 2016; Cowdell, 2008; Clissett et al., 2013). Patients admitted to dementia friendly environments will have less falls, experience better health outcomes and have a shorter length of stay than similar populations who are admitted to traditional settings (Ulrich, 2001; Waller et al., 2016; Andrews, 2013). There is growing recognition of the need for dementia friendly wards which provide safe walking areas, signage, lighting, colour, and social spaces (Haus, 2018; Young et al., 2017). Involving the potential users of these environments can provide useful contributions in the design and remodelling of spaces and should be afforded the opportunity to provide input where appropriate (Topo et al., 2012; Digby and Bloomer, 2014).

Similarly, for staff working in acute care environments, care becomes more challenging and unfortunately in some instances, nursing staff resort to 'specialing' and using pharmacological or physical restraint (Houghton et al., 2016). Equally, relatives become overwhelmed and confused by the environment in which the patient living with dementia is being cared for (Burgstaller et al., 2018). The practice of restraining 'problematic' patients who wandered, climbed, or became aggressive was evident across some studies (Hung et al., 2016; Clissett et al., 2013; Nilsson et al., 2012). The ongoing and inappropriate use of restraint in hospitals demonstrates a lack of ability to protect, rehabilitate or support at risk patients (Moyle et al., 2010; Alzheimer Society of Ireland, 2018).

Systems of care are lacking in terms of care pathways, discharge planning and supports for staff in managing the specific needs of this client group; leading to symptom/task specific approaches to care. For the patient, this can mean a loss of independence, autonomy and dignity. Relatives feel excluded from decision making (Burgstaller et al., 2018); and staff experience frustration at caring for patient living with dementia in an inappropriate environments due to delays in transfer to more appropriate settings (Houghton et al., 2016).

Ultimately, the direct care given has the greatest impact on how the acute hospital experience is perceived. The need for individualised, person-centred care was emphasised across the three reviews. The involvement of family/carers as well as the person with dementia is critical for providing holistic care that places the person with dementia at its very core. Family members hold valuable resources which can help to support the patient in hospital, therefore greater efforts should be made to nurture

collaborate relationships and integrate relatives into care (Burgstaller et al., 2018; Simpson, 2016). Hospitalisation of a patient living with dementia is usually viewed as a negative event for their family (Jurgens et al., 2012; Moyle et al., 2010). The quality of dementia care in acute settings often fails to meet their expectations (Burgstaller et al., 2018), and can generate cycles of discontent throughout the patient journey (Jurgens et al., 2012). There is a need for more structured approaches to information sharing at the admission point of care to avoid discontent and facilitate better services (De Shun & O'Shea, 2014; Bauer et al., 2011).

While there were examples of good care across the three reviews, staffing levels and busyness could result in more paternalistic communication and task focused care. At worst, in this review, poor and inadequate care was observed. Patients should encounter care that enhances dignity, autonomy and independence where possible. Dementia specific training and education is essential and must be provided to front line staff to ensure they are equipped with the skills, knowledge and understanding required to provide holistic care to patients living with dementia (De Shun & O'Shea, 2014). Nurses must also be given opportunities to reflect on, and discuss the care provided as these settings do not always support their professional integrity or represent their personal ethos of care (Nilsson et al., 2012).

As evidenced in this discussion, this review has many commonalities with the other two reviews, and completes the exploration of how people living with dementia are cared for in acute settings, placing them at the centre of this experience. While the need for environmental and systems changes have been recommended and described previously, this review emphasises again the need for testing existing interventions that will create a safe space for nurses, in collaboration with empowered relatives/informal caregivers, to provide individualised care to a person living with dementia. This review, and that by Burgstaller et al. (2018), identifies loneliness and isolation of the patient living with dementia and their families, when they are in the acute environment. It is notable that this was not represented in the Houghton et al. (2016) review exploring staff perspectives. Strategies to improve the care experience must place the person and their relatives/informal caregivers as central to reduce this sense of exclusion. Assessment of function, cognition and mood should be compulsory alongside the various physical assessments where appropriate (De Siun & O'Shea, 2014). The findings in this review mirrors assertions that hospital managers must strive to foster a climate of care which provides cohesive and consistent multidisciplinary approaches to care and equips staff with skills that promote personhood (Houghton et al., 2016; Brooker and Lantham, 2016). Hospitals need to create a dementia friendly service through integrating support mechanisms such as dementia champions, volunteer personnel, and dementia specialist nurses (Banks et al., 2014; Williams, 2011). There is a lack of clear vision on what constitutes good care for this group, which is frequently overshadowed by prioritisation of physical care or needs relating to acute illness (Dewing and Dijk, 2016). It is also proposed the productivity and financial targets of hospital organisations mitigate against these standards by failing to provide the necessary staffing and support services in place (Clissett et al., 2015; Turner et al., 2017).

Efforts to address poor dementia care in hospitals is visible in the number of audits and reports which have emerged over the past decade (NHS, 2013; De Suin et al., 2014). The various charters and guidelines produced in their path are not reflected in the care, medical treatment, or outcomes of this group (Alzheimer Society, 2016; Improvement.nhs.uk, 2018). Deficits in service provision imply patients living with dementia are not valued at organisational or local levels and the care they receive is not based on trust,



respect or dignity. There is a need for healthcare systems to support the individual rights and entitlements of patients regardless of cognitive impairment to dispel discriminatory practice and promote person centred care.

## 9. Conclusion

It is fair to speculate that changes are forthcoming as dementia care now sits high on the political agenda of many developed countries (Wortmann, 2014; Haus, 2018). However, despite the many audits and initiatives a great deal more needs to be done to improve the diagnosis, treatment, and acute care of people with dementia (DoH, 2012; Hennelly and O'Shea, 2017). Organisational structures must ensure patients are treated in a dementia friendly environment by a dementia trained workforce. Ultimately practitioners need to understand the adversity these patients face in a strange place, recognise their rights to dignity and respect and strive to make their encounter with acute care more person-centred.

There is now evidence from three qualitative syntheses about the care of patients living with dementia in acute setting from the perspective of health care staff, family members, carers, and from the patients themselves. This provides sufficient in-depth insights for practitioners and researchers to address the deficiencies in care.

Further research needs to be conducted in to testing interventions which aim to improve the systems of care, person-centred approaches to care, and adaptations to the physical environment. Ultimately, the acute setting is challenging for the person with dementia, so interventions in community and long-term settings need to be developed to assist in keeping people living with dementia in more suitable environments.

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## Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.ijnurstu.2019.04.018>.

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