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The experiences of hospital staff who provide care for people living with dementia: A systematic review and synthesis of qualitative studies

Ruth Gwernan-Jones Senior Research Fellow Rebecca Abbott Senior Research Fellow Ilianna Lourida Research Fellow¹ Morwenna Rogers Information Specialist¹ Colin Green Professor of Health Economics² | Susan Ball Senior Research Fellow in Medical Statistics³ Anthony Hemsley Consultant Physician in Geriatric Medicine⁴ Debbie Cheeseman Consultant Nurse for Older People Linda Clare Professor of Clinical Psychology of Ageing and Dementia Darren A Moore Senior Lecturer Darren A Moore Senior Lecturer Chrissey Hussey Admiral Nurse | George Coxon Care Home Owner | David J. Llewellyn Associate Professor of Neuroepidemiology and Digital Health^{9,10} | Tina Naldrett Director of Clinical Services Jo Thompson Coon Professor of Evidence Synthesis and Health Policy Delicy

Abstract

Aims and objectives: To systematically review and synthesise qualitative data from studies exploring the experiences of hospital staff who care for people living with dementia (Plwd).

Background: In hospital, the number of Plwd continues to rise; however, their experiences of care remain problematic. Negative experiences of care are likely to contribute to poorer mental and physical health outcomes for Plwd while in hospital and after discharge. Experiences of the hospital staff who care for Plwd can also be poor or unrewarding. It is important to understand the experiences of staff in order to improve staff well-being and ultimately the experience of care for Plwd while in hospital. **Design:** Systematic review and evidence synthesis of qualitative research.

Data sources: We searched 16 electronic databases in March 2018 and completed forward and backward citation chasing.

Methods: Eligible studies explored the experiences of paid and unpaid staff providing care in hospital for Plwd. Study selection was undertaken independently by two reviewers, and quality appraisal was conducted. We prioritised included studies according to richness of text, methodological rigour and conceptual contribution. We adopted approaches of meta-ethnography to analyse study findings, creating a conceptual model to represent the line of argument.

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¹Evidence Synthesis Team, PenCLAHRC, University of Exeter Medical School, St Luke's Campus, University of Exeter, Exeter,

²Health Economics Group, University of Exeter Medical School, St Luke's Campus, University of Exeter, Exeter, UK

³Health Statistics Group, PenCLAHRC, College of Medicine and Health, University of Exeter Medical School, St Luke's Campus, University of Exeter, Exeter, UK

⁴Royal Devon and Exeter NHS Foundation Trust, Exeter, UK

⁵Centre for Research in Aging and Cognitive Health, University of Exeter Medical School, St Luke's Campus, University of Exeter, Exeter UK

⁶Graduate School of Education, College of Social Sciences and International Studies, St Luke's Campus, University of Exeter, Exeter,

⁷Hospiscare, Exeter, UK

⁸Devon Care Kitemark, Exminster, Exeter,

⁹Mental Health Research Group, University of Exeter Medical School, St Luke's Campus, University of Exeter, Exeter, UK

¹⁰The Alan Turing Institute, London, UK

Correspondence

Ruth Gwernan-Jones, University of Exeter Medical School, St Luke's Campus, University of Exeter, Exeter, EX1 2LU, UK. Email: R.C.Gwernan-Jones@Exeter.ac.uk

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Findings: Forty-five studies reported in 58 papers met the inclusion criteria, and of these, we prioritised 19 studies reported in 24 papers. The line of argument was that *Institutions can improve staff experiences of care for Plwd by fostering person-centred care (PCC)*. PCC aligned with staff perceptions of 'good care'; however, staff often felt prevented from providing PCC because of care cultures that prioritised tasks, routines and physical health. Staff experienced conflict over the care they wanted to give versus the care they were able to give, and this caused moral distress. When staff were able to provide PCC, this increased experiences of job satisfaction and emotional well-being.

Conclusions: Person-centred care not only has the potential to improve the experience of care for Plwd and their carers, but can also improve the experiences of hospital staff caring for Plwd. However, without institutional-level changes, hospital staff are often unable to provide PCC even when they have the experience and knowledge to do so.

Implications for practice: Institutional-level areas for change include the following: training; performance indicators and ward cultures that prioritise psychological needs alongside physical needs; adequate staffing levels; inclusive approaches to carers; physical environments that promote familiarisation, social interaction and occupation; systems of documentation about individual needs of Plwd; and cultures of sharing knowledge across hierarchies.

KEYWORDS

delivery of health care, dementia, patient care, personnel, hospital, qualitative research, systematic review

1 | INTRODUCTION

Demographic ageing is associated with increased rates of acute hospital admissions for older people with multiple comorbidities and complex care needs (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016), and currently, around 40% of patients over the age of 70 admitted to hospital have dementia (Sampson, Blanchard, Jones, Tookman, & King, 2009). Experiences of care in hospital for people living with dementia (Plwd) are often unsettling (Digby, Lee, & Williams, 2017; Reilly & Houghton, 2019), and understanding how to improve the experience of care in hospital for Plwd was the fifth highest priority for dementia research in the recent James Lind Alliance Priority Setting Partnership with the Alzheimer's Society (2013).

The experience of hospital care for Plwd can be characterised by feelings of fear and insecurity not only because of illness/injury, but also because of heightened disorientation, where in the unfamiliar setting of the hospital, Plwd are not sure where they are, why they are there or what is happening around them (Edvardsson & Nordvall, 2008). Many Plwd have difficulties with communication, and attempt to communicate their heightened distress through behaviour such as refusing medication, washing and toileting, repeated vocalisation and/or aggression (Porock, Clissett, Harwood, & Gladman, 2015). Care that is focused on tasks, routines and physical

health, and does not acknowledge the personhood of Plwd, can create a state of liminality for Plwd where they feel imprisoned and excluded (Digby, Lee, & Williams, 2018). This can increase existing levels of fear and insecurity (Kelley, 2017), and such behaviour can therefore escalate in hospital as Plwd become increasingly distressed.

Different explanatory discourses around the distressed behaviours of Plwd prompt different approaches for staff to address them. A common clinical discourse attributes these behaviours to 'behavioural and psychological symptoms of dementia' (BPSD) (van der Linde, Dening, Matthews, & Brayne, 2014), suggesting neuropathy resulting from cognitive impairment is responsible. Such attributions can lead hospital staff to dismiss these behaviours as untreatable symptoms, ignore them or address them using restraints or antipsychotic medications (Reilly & Houghton, 2019). An alternative attribution involves understanding distressed behaviours, sometimes termed 'behaviour that challenges' (British Psychological Society, 2018), as 'responsive' to unmet need. This attribution suggests that seeking to meet such needs will help resolve the 'responsive' behaviour (Handley, Bunn, & Goodman, 2017; Schindel Martin et al., 2016). Kitwood's (Brooker, 2019; Kitwood, 1997) seminal work on PCC for Plwd aligns with such attributions for the responsive behaviour of Plwd. Kitwood posits that deterioration during dementia results from a combination of neurological impairment,

personality, biography, health and social psychology, so, by meeting the psychological needs of Plwd, it is possible to optimise their quality of life in the face of neurological impairment. It has been suggested that PCC has the potential to reduce responsive behaviour in hospital by decreasing the physical and psychological discomfort that Plwd experience (Schindel Martin et al., 2016). PCC posits that the well-being of Plwd can be fostered in hospital (Brooker, 2019; Clissett, Porock, Harwood, & Gladman, 2013; Kitwood, 1997), through relationships with others such as staff and carers who seek to understand and meet five basic types of need (attachment, comfort, occupation, identity and inclusion). By exploring the experiences of hospital staff who care for Plwd, it is possible to understand better the issues that create difficulty, in order to inform interventions to address these issues. Moonga and Likupe (2016) reviewed the experiences of nurses and healthcare support workers who worked on orthopaedic wards, and Turner, Eccles, Elvish, Simpson, and Keady (2017) focused on the experiences of acute ward staff in order to inform training needs. Digby et al. (2017) reviewed experiences of care for hospital nurses and Plwd. These recent systematic reviews (Digby et al., 2017; Moonga & Likupe, 2016; Turner, Eccles, Elvish, et al., 2017) all found that staff agree that there is a need for care aligned with PCC, but face barriers to understanding the behaviour of Plwd, knowing how to provide care in the face of it, and perceived that they had insufficient time to give anything more than physical care. Moonga and Likupe (2016) focused on acute wards, and most of the included participants in the review by Turner, Eccles, Elvish, et al. (2017) and all of the staff participants in Digby et al. (2017) were nurses. It is important therefore to explore staff experiences of care for people living with dementia across all hospital settings and across all staff roles. In this paper, we aim to systematically review and synthesise qualitative data from studies exploring the experiences of hospital staff who care for Plwd. Our research question was: What is the experience of hospital staff caring for Plwd?

2 | METHODS

This systematic review is part of a larger series of systematic reviews (National Institute for Health Research (NIHR) Health Services and Delivery Research Programme 16/52/52; PROSPERO registration CRD42018086013) exploring approaches to improving the experience of care in hospital for Plwd, their family carers and the hospital staff who care for them (Gwernan-Jones et al., under review).

2.1 | Search strategy

The database search was designed by our information specialist (MR) for use in the larger study. The qualitative search strategy used medical subject headings combined with free-text terms for dementia (e.g. dementia, Alzheimer's disease, cognitive disorder), hospital settings (e.g. general hospital, acute hospital, acute care, acute setting, acute ward), interventions (e.g. patient care, patient-centred, dementia champions, dementia wards, training, activities, culture, communication) and terms

What does this research add to existing knowledge in gerontology?

- It is widely recognised that PCC improves experiences of care for Plwd and their carers; this review finds that PCC can also improve hospital staff experiences of caring for Plwd.
- PCC can reduce moral distress related to caring for Plwd and improve job satisfaction for hospital staff.

What are the implications of this new knowledge for nursing care with older people?

- Understanding that PCC is beneficial to hospital staff, as well as Plwd and their carers, provides additional impetus to engage with PCC practice.
- Understanding that PCC takes less time in the long run, because it reduces responsive behaviours (e.g. aggression, vocalisation) as much as it is possible to do so, encourages staff to provide, and support others to provide, PCC.

How could the findings be used to influence policy or practice or research or education?

- An important aspect of training involves attributing responsive behaviours to unmet needs. Time spent getting to know individual Plwd is valuable because it can prevent or resolve responsive behaviour.
- Simply providing staff training may be inadequate to effectively enable PCC; hospital cultures that prioritise psychological well-being of Plwd at the same level as physical health are needed to enable staff to spend time getting to know Plwd.

for qualitative research/experiences (interviews, experiences, questionnaires, perceptions). The search strategy was run on 4 March 2018 using MEDLINE, PsycINFO, Social Policy and Practice and HMIC (via OvidSp), CINAHL (via EBSCOhost), British Nursing Index and ASSIA (via ProQuest), Social Science Citation Index and Conference Proceedings Citation Index (via Web of Science) and ProQuest Dissertations & Theses Global. The full strategy as designed for MEDLINE and translated for the other databases is available in Appendix 1. The citation lists of included references were checked, and forwards citation chasing was carried out using Web of Science and Scopus.

2.2 | Inclusion/exclusion criteria for qualitative studies

Articles were included or excluded according to the following criteria:

2.2.1 | Population

This study included hospital staff delivering care to older adults with dementia. Where other types of participants were involved in the study (Plwd; carers), only findings about or from hospital staff were included. Studies that focused on staff who cared for older adults with delirium or acute confusion were excluded. Studies that focused on staff who cared for older adults with cognitive impairment or chronic confusion were included.

2.2.2 | Setting

This study focused on hospital settings that encompassed inpatients/ outpatients within a hospital, hospital day centres and rehabilitation wards. Non-hospital day care centres, care homes and hospices were excluded. Studies conducted outside OECD countries were excluded because societies and medical systems fundamentally different to the UK were likely to impact applicability in important ways.

2.2.3 | Outcomes/Aims

The aim of this study was to focus on the experience of providing care; studies that explored clinical aspects of dementia (e.g. prevalence, assessment, diagnosis) were excluded.

2.2.4 | Design

Primary studies collecting qualitative data (e.g. by conducting interviews, focus groups and observation using field notes) were analysed qualitatively. Open questions on surveys or questionnaires were excluded.

2.2.5 | Language

Only studies written in English were included.

2.3 | Study selection

The titles and abstracts of records returned in the search were screened by two reviewers independently (RGJ and RA). The records and reviewer decisions were organised in Endnote software v.X8 (Thomson Reuters). The records whose title and abstract met the inclusion criteria were obtained at full text wherever possible through the University of Exeter library, through general Web searching or from The British Library. Full texts were screened by two reviewers independently (RGJ and RA) according to the inclusion criteria. Two reviewers resolved disagreements, referring to a third reviewer where needed (RGJ, RA, JTC).

2.4 | Data extraction

We developed and piloted a data extraction template in Word v.2013 (Microsoft Corporation). Two reviewers (RGJ and RA) independently extracted data for three included studies, then compared and discussed the data extracted, refining the template in response. Data extracted included the following: study details and setting; population characteristics; methods; reviewer evaluation of the study; and findings (thematic structure). Finally, detailed findings from included studies were extracted by uploading PDFs into NVivo v.12 (QSR International) and coding study themes (see below, data analysis).

2.5 | Quality appraisal

We conducted quality appraisal in parallel with data extraction using an adapted form of the Wallace Checklist (Wallace, Croucher, Quilgars, & Baldwin, 2004). The purpose of the checklist was to draw reviewers' attention to a range of study aspects in order to consistently familiarise the reviewers with the methodological content of each study. Fourteen questions probed the reporting of research questions, explicitness and impact of the theoretical/ideological stance, study design, description of context, sample, data collection/robustness, analysis, relationship between data and findings, limitations, claims to generalisability, ethics and reflexivity (see Appendix 2). Each question was answered either 'yes', 'no' or 'can't tell'. Two reviewers (RGJ and RA) conducted quality appraisal independently. Disagreements were discussed with a third reviewer (JTC) where necessary.

2.6 | Prioritisation of studies

Because of the high number of papers that met the inclusion criteria, prioritisation of papers was conducted. Inclusion of too many studies in evidence synthesis of qualitative studies can make sufficient familiarity difficult to achieve (Campbell et al., 2011), and prevent anything more than superficial analysis (Bondas & Hall, 2007).

During data extraction and quality appraisal processes for all included papers, two reviewers independently evaluated the usefulness of each included paper according to three criteria: (a) richness of text, (b) methodological quality and (c) conceptual contribution. Richness of text was scored along a 4-point continuum of 'poor', 'some', 'good' or 'very good'. The criterion for scoring followed Geertz's concept of thick description (Geertz, 1973) and involved judgement of the extent to which participants and researchers provided background information necessary to understand and interpret experience. Methodological quality was assigned according to the number of 'yes' responses during quality appraisal, with a paper deemed good scoring \geq 10 'yes' responses. Conceptual contribution was scored along a 4-point continuum of 'poor', 'some', 'good' or 'very good'. The criterion for scoring involved judgement of the extent to which the study authors drew from or developed concepts

relevant to the questions of the review through use of existing theory, development of theory and/or conceptual models.

Papers that were judged to be 'good' and/or 'very good' in all three categories were given high priority, and contributed to the syntheses. Papers evaluated as 'good' or 'very good' in two of three categories were considered medium priority, to be used to check whether the synthesis represented the greater body of included papers. Papers evaluated as 'good' or 'very good' in none or one of three categories were judged to be least likely to contribute to the review. Following synthesis of high-priority studies, medium-priority study findings were compared to the concepts synthesised from prioritised studies in order to determine how similar the findings from each group were. It was considered unnecessary to compare the synthesis of high-priority papers to the studies judged as lowest priority since such studies tend not to impact syntheses because of their sparse or descriptive findings (Campbell et al., 2011).

2.7 | Data analysis and synthesis

Data analysis and synthesis broadly followed the approach of metaethnography (Noblit & Hare, 1988). Two reviewers (RGJ and RA) read and reread included papers during processes of familiarisation, coding, summarising and checking. During data extraction and the creation of tables summarising study characteristics, the same information about each study was documented in the same way, supporting the systematic identification of similarities and differences in study aims, location, design, interventions and findings. The initial process of coding also contributed to establishing relationships between studies. Translation and refutation of study themes within each review occurred throughout the review process. Relationships between study themes were discussed regularly between core reviewers (RGJ, RA, IL, JTC, MR). Noblit and Hare suggest using a pre-existing framework, for example by adopting the thematic structure from a key paper, to guide synthesis (Campbell et al., 2011; Noblit & Hare, 1988), However, we adopted an approach in line with Spicer, who posits the development of concepts through an inductive process of interpretation across studies (Spicer, 1976), RGJ, in consultation with RA, conducted translation of studies by further regrouping and refining concepts from the coded text to create a conceptual map. This conceptual map represents the concepts found by studies of staff experiences as a whole. In meta-ethnography (Noblit & Hare, 1988), the overall narrative linking the issues identified across studies is called a line of argument, and we explain these concepts below.

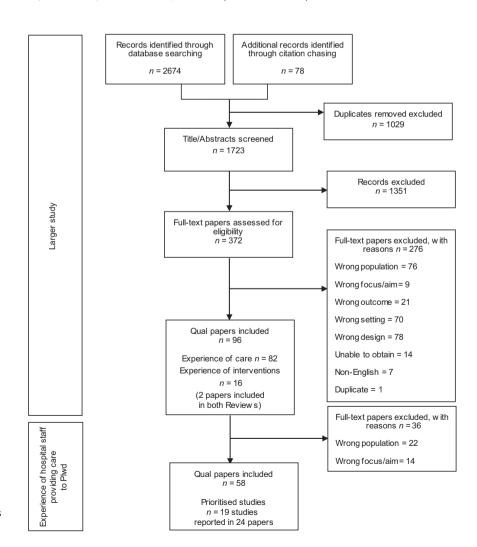


FIGURE 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram of the process of study selection

3 | FINDINGS

3.1 | Study selection

Figure 1 shows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram of the process of study selection. Of the 96 papers included in the larger study, 45 studies reported in 58 papers were included in this review of staff experiences of caring for Plwd in hospital. We prioritised 19 studies reported in 24 papers as most able to meet the questions of the review (see Appendix 3). Five studies were reported in multiple publications (Bryon, Dierckx de Casterle, Dierckx de Casterle, & Gastmans, 2012: Bryon, Gastmans, Gastmans, & De Casterlé, 2012; Bryon, Gastmans, & Dierckx de Casterle, 2010; Dowding et al., 2016; Emmett, Poole, Bond, & Hughes, 2013; Lichtner et al., 2016; Norman, 2003, 2006; Poole et al., 2014). To signify the singular nature of these studies, the journal article first published from each study will be cited when reporting number of studies with a particular finding (Bryon et al., 2010; Dowding et al., 2016; Emmett et al., 2013; Norman, 2006). When quoting an extract or reporting specific findings, the paper of origin will be cited.

Medium- and lowest priority studies were also identified (see Appendix 3). For comparison of the findings of medium-priority studies to the synthesis of high-priority papers, see Table 1. During this comparison, it was found that medium-priority studies supported the findings from prioritised studies. One study interpreted responsive behaviour as resistance, rather than unmet need as we have done in this synthesis (Featherstone et al., 2018). However, we considered these to be compatible interpretations.

3.2 | Study characteristics

Study characteristics are shown in Appendix 3. Prioritised studies were conducted in seven different countries: nine studies (47%) were conducted in the UK, and four (21%) were conducted in Sweden. All prioritised papers were published in peer-reviewed journals. Only one paper was published before 2000 (Berg, Hallberg, & Norberg, 1998), with 20 (83%) published since 2010.

Prioritised studies included participants with a range of staff roles including non-qualified and qualified nursing staff, ward managers, activity coordinators, hospital chaplains, senior and junior doctors and allied health professionals such as occupational therapists and physiotherapists. Although 13 studies involved hospital staff, Plwd and/or carer participants, only findings related to experiences of hospital staff caring for Plwd are reported in this review.

Studies were conducted in a range of hospital settings, including wards for older people (dementia; psychogeriatric; acute geriatric): 11 studies; rehabilitation wards: four studies; acute wards: ten studies; admission wards: one study; and palliative care wards: one study. Eight studies were conducted on more than one type of ward, and one study did not specify the type of ward.

3.3 | Quality appraisal

Because methodological rigour was one of the criteria used to prioritise studies, all prioritised studies scored 10 or more out of 14 sensitising prompts. The quality criteria against which studies most often scored 'yes' related to clear research questions, appropriate study design and the rigour of data collection. The quality criteria against which studies least often scored 'yes' related to reporting reflexivity.

4 | LINE OF ARGUMENT: HOSPITALS CAN IMPROVE STAFF EXPERIENCES OF CARING FOR PLWD BY FOSTERING PCC

The line of argument (main theme) representing the overall synthesis of the experiences of hospital staff of caring for Plwd was *Hospitals* can improve staff experiences of caring for Plwd by fostering PCC. Three subthemes represent the main aspects of the line of argument:

- PCC aligns with staff perceptions of 'good care';
- Hospital staff were often prevented from providing PCC; and.
- The ability of hospital staff to deliver PCC was linked to job satisfaction.

A conceptual map of the line of argument is shown in Figure 2. Table 1 shows the relationship between initial coding, subthemes and the line of argument, and how included studies contributed to these. Overall, hospital staff wanted to provide good care, which echoed the approaches of PCC by meeting the psychological and physical needs of Plwd. However, a range of issues involving institutional- and ward-level factors could prevent them from being able to do so. This discrepancy between their values and the care that they were able to give created moral conflict that could lead to burnout. However, the ability to deliver PCC was linked to increased job satisfaction. Therefore, by fostering the ability of hospital staff to provide PCC, institutions can improve staff experiences of caring for Plwd. This line of argument is explained in greater detail below.

4.1 | PCC aligned with staff perceptions of 'good care'

A number of prioritised studies (Berg et al., 1998; Bryon et al., 2010; Carr, Hicks-Moore, & Montgomery, 2011; Clissett, Porock, Harwood, & Gladman, 2014; Dowding et al., 2016; Edvardsson, Sandman, & Rasmussen, 2012; Goldberg, Whittamore, Pollock, Harwood, & Gladman, 2014; Jensen, Pedersen, Olsen, & Hounsgaard, 2017; Kelley, Godfrey, & Young, 2019; Nilsson, Rasmussen, & Edvardsson, 2016; Norman, 2006) provided descriptions of care that met the ideals described by nurses as 'good' care. Staff understood 'good' care to involve supporting the emotional needs and physical needs of Plwd, aligning with Kitwood's theory of PCC for Plwd (Brooker, 2019; Kitwood, 1997). For example, good care involved

TABLE 1 Associations between coding, subthemes and contributing studies

	Line of argument: Hospitals can impro	ve staff experiences of caring for Plwd by	fostering PCC
Initial coding	PCC aligned with staff perceptions of 'good care'	Staff were prevented from providing PCC	The ability of hospital staff to deliver PCC was linked to job satisfactio
Attitudes	✓	✓	✓
Experience of dementia	✓	✓	✓
Emotional impact	✓	✓	✓
Pride in work	✓	✓	✓
Providing emotional support	✓		✓
Role		✓	
Staff involvement in decision-making		/	✓
Values	✓	✓	✓
Ways of interacting with Plwd	✓	✓	✓
Continuity of care	✓	✓	✓
Staff:patient ratio		✓	✓
Interprofessional communication		✓	✓
Impact on time		✓	✓
Focus on physical needs		✓	✓
Hospital routine		✓	✓
Prioritised studies that contributed to subthemes	Bailey et al. (2015); Berg et al. (1998); Bryon et al. (2010); Byers & France (2008); Carr et al. (2011); Clissett et al. (2014); Digby et al. (2018); Dowding et al. (2016); Edvardsson et al. (2012); Goldberg et al. (2014); Jensen et al. (2017); Kelley et al. (2019); Nilsson et al. (2016); Norman (2006)	Bailey et al. (2015); Berg et al. (1998); Bryon et al. (2010); Byers & France (2008); Carr et al. (2011); Clissett et al. (2014); Digby et al. (2018); Dowding et al. (2016); Edvardsson et al. (2012); Emmett et al. (2013); Goldberg et al. (2014); Jensen et al. (2017); Kelley et al. (2019); Moyle et al. (2011); Nilsson et al. (2013, 2016); Norman (2006); Teodorczuk et al. (2015); Turner, Eccles, Keady, et al. (2017)	Bailey et al. (2015); Ber et al. (1998); Bryon et al. (2010); Byers & France (2008); Clisset et al. (2014); Jensen et al. (2017); Kelley et (2019); Nilsson et al. (2016); Norman (2006) Teodorczuk et al. (2017) Turner, Eccles, Keady, et al. (2017)
Medium-priority studies that supported the findings of prioritised studies by subtheme	Allwood et al. (2017); Ashton & Manthorpe (2017); Borbasi, Jones, Lockwood, & Emden (2006); Bower (2017); Cowdell (2010a); Crowther, Brennan, & Bennett (2018); Eriksson & Saveman (2002); Featherstone et al. (2018); Fry, Chenoweth, MacGregor, & Arendts (2015); Griffiths, Knight, Harwood, & Gladman (2014); Kelley (2017); Krupic, Eisler, Sköldenberg, & Fatahi (2016); Pinkert et al. (2018); Scerri, Innes, & Scerri (2015)	Allwood et al. (2017); Ashton & Manthorpe (2017); Borbasi et al. (2006); Bower (2017); Cowdell (2010a); Crowther et al. (2018); Eriksson & Saveman (2002); Featherstone et al. (2018); Griffiths et al. (2014); Hayward (2009); Hayward, Robertson, & Knight (2012); Kable, Chenoweth, Pond, & Hullick (2015); Kelley (2017); Nolan (2006); Pinkert et al. (2018); Scerri et al. (2015); St John & Koffman (2017); Thuné-Boyle et al. (2010); Watts & Davies (2014)	Ashton & Manthorpe (2017); Bower (2017); Brooke & Stiell (2017) Eriksson & Saveman (2002); Featherstone et al. (2018); Griffiths et al. (2014); Hayward et al. (2012); Kelley (2017); Pinkert et al. (2018); Thuné-Boyle et al. (2010); Watts & Davies (2014)
Medium-priority papers that refuted the prioritised study findings	None	,,	

staff who sought personal information in order to be able to better interpret the behaviour and meet the needs of Plwd including their psychological need for explanation, reassurance, occupation, connection, inclusion, personal acknowledgement and physical care,

descriptions that echo the five subcategories of PCC: attachment, inclusion, identity, occupation and comfort. Here, an end of life nurse working with Plwd equates her role as doing good to patients, and clarifies that doing good is holistic,

... through our nursing experience we detect things very quickly.... We see the patient literally, figuratively naked. We simply notice things more quickly. It is the nature of every nurse to do good to the patients... and a holistic view fits in with that....".

[Nurse, p1109, reviewer and author edits] (Bryon et al., 2010)

Carr et al. (2011), in a study of spiritual care for Plwd, found that spiritual care did not have to be linked to religious needs, but 'is rooted in the promotion of personhood through intentional caring attitudes and actions' (p409), and many nurses in included studies showed this kind of care. Despite some studies suggesting staff perceived that Plwd were unable to 'give back' (Byers & France, 2008; Norman, 2006), other staff described times when, in response to good care, Plwd were able to connect and respond in kind (Berg et al., 1998; Carr et al., 2011),

I had a patient who ... gave up, didn't want to live any more ... [I] asked if he was afraid to die but he wasn't afraid at all and asked – Are you afraid? – that surprised me ... it made me think and I was strengthened by his conviction.

[Nurse, p274, reviewer edits] (Berg et al., 1998)

This extract provides an example of how PCC, as Kitwood suggests, can enable Plwd to be at their best, and that such connections can be in turn beneficial to staff.

Despite many examples of good care, prioritised papers predominantly reported that the care provided was seen as being in opposition to good care, because of priorities imposed by wards or institutions, insufficient time or knowledge about dementia and/or limited personal knowledge of a Plwd (Berg et al., 1998; Bryon et al., 2010; Byers & France, 2008; Carr et al., 2011; Clissett et al., 2014; Digby et al., 2018; Dowding et al., 2016; Edvardsson et al., 2012; Goldberg et al., 2014; Jensen et al., 2017; Nilsson et al., 2016; Norman, 2006). However, one study (Bailey, Scales, Lloyd, Schneider, & Jones, 2015) demonstrated the complexities of characterising care, arguing against the use of dichotomised concepts, and another study suggested that connections between staff and Plwd occurred along a continuum (Kelley et al., 2019). We therefore characterise care as occurring along a continuum from care focused on tasks/routines and physical needs, to care that involves personal interaction that supports the personhood of Plwd alongside physical care. The latter can be described as 'good' care.

4.2 | Staff were often prevented from providing PCC

Studies described a number of issues that staff perceived to be barriers to providing good care. These included the following:

- Inadequate levels of training;
- Performance indicators and ward cultures that prioritised physical needs;

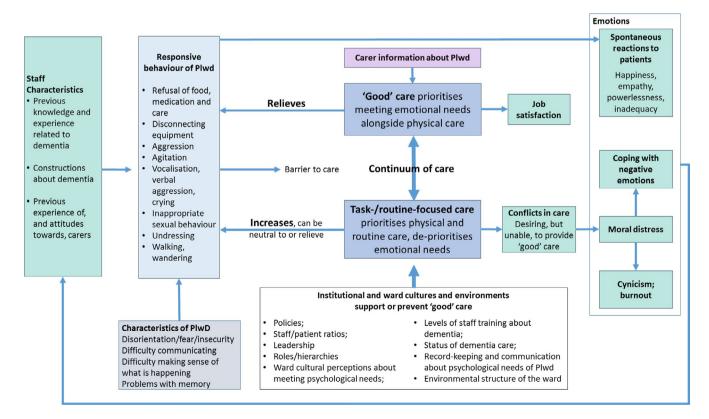


FIGURE 2 Concept map depicting the line of argument representing staff experiences of caring for Plwd in hospital. Main theme: Hospitals can improve staff experiences of caring for Plwd by fostering PCC

- Ward and institutional cultures that inhibited the sharing of knowledge across roles and hierarchies, including lack of documentation about personal aspects of Plwd; and
- Physical environments that prevented familiarisation, social interaction and occupation.

4.2.1 | Inadequate levels of training

Hospital staff who had past experience of caring for Plwd were more able to draw on their skills to interpret non-verbal cues (Berg et al., 1998; Lichtner et al., 2016) and recognised the importance of 'building a picture' of the Plwd to inform their understanding of how to best care for that person (Berg et al., 1998; Bryon et al., 2010; Carr et al., 2011; Clissett et al., 2013; Norman, 2006). This included recognising that responsive behaviours often signified an unmet need (Berg et al., 1998; Bryon et al., 2010; Carr et al., 2011). However, many staff lacked experience or knowledge of dementia and this could prevent good care, ...they try to fit [Plwd] into the 'medical' or 'nursing' model which is...the perfect patient who doesn't complain, who stays by the bed and does everything they are told to do. My impression is that they're annoying to the nursing staff or an inconvenience or more trouble than the person next to them. So there's often shifting that goes on to try and get them off their unit. [Doctor, p423, author and reviewer edits] (Moyle, Borbasi, Wallis, Olorenshaw, & Gracia, 2011).

In further examples, hearing impairment was mistaken for difficulties with cognition by a staff member with limited experience (Nilsson, Rasmussen, & Edvardsson, 2013). A lack of knowledge could mean the use of inappropriate assessment tools (Dowding et al., 2016; Nilsson et al., 2013), or the use of force to complete routine tasks (Nilsson et al., 2016), and left staff feeling unsure about how to respond to individual behaviours of Plwd (Turner, Eccles, Keady, Eccles, Keady, Simpson, & Elvish, 2017). Teodorczuk, Mukaetova-Ladinska, Corbett, and Welfare (2015) found that knowledge and skills gaps underpinned poor practice, which was compounded further if colleagues modelled suboptimal practice.

Staff held different concepts about dementia, which could affect the way in which they provided care. Some staff understood that Plwd might have unmet needs, which were expressed through responsive behaviours (Berg et al., 1998; Bryon et al., 2010; Carr et al., 2011), while other staff thought that such behaviours were solely the result of neurological impairment (Moyle et al., 2011) or interpreted them as Plwd being awkward or disruptive (Edvardsson et al., 2012; Porock et al., 2015).

4.2.2 | Performance indicators and ward cultures that prioritised physical needs

Staff who were well trained and experienced in caring for Plwd, and who understood the responsive behaviour of Plwd as reflecting unmet need, could still be prevented from providing PCC. Workplaces often prioritised structures and routines that supported efficient completion of physical caregiving tasks (Bailey et al., 2015; Berg et al., 1998; Byers & France, 2008; Clissett et al., 2013; Goldberg et al., 2014; Jensen et al., 2017; Nilsson et al., 2013; Norman, 2006; Teodorczuk et al., 2015). While an understandable approach, this could act as a barrier to the kind of interactions between Plwd and staff required by PCC because of insufficient staffing numbers (Byers & France, 2008; Goldberg et al., 2014; Lichtner et al., 2016). Frequent rotation of staff led to brief encounters between Plwd and individual staff, in particular, senior staff (Nilsson et al., 2013). This not only prevented staff from getting to know Plwd due to a lack of time, but also meant that staff could feel reluctant to engage with Plwd,

We rarely have the same patients for very long, instead we are moved between different units ... sometimes you tend to think that I'm only to have this patient for one day, and then you don't get so involved.

[Nurse, p1686] (Nilsson et al., 2013)

Staff perceived that caring for Plwd required more time and that a lack of time was a key reason why good care did not always happen (Byers & France, 2008; Goldberg et al., 2014; Lichtner et al., 2016; Moyle et al., 2011; Nilsson et al., 2013, 2016; Turner, Eccles, Keady, et al., 2017). Some studies found that staff perceived they should prioritise the needs of patients other than Plwd because of the ward culture that focused on physical health (Clissett et al., 2014; Moyle et al., 2011; Nilsson et al., 2013). For example, from observations on a cardiology ward Nilsson et al. (2013) concluded that disease was the organising care principle, which meant Plwd did not fit within the system of care within the unit,

I don't think that older people with cognitive impairments fit in here with us ... it's difficult to combine cognitive impairments with acute care. And we should ask ourselves to what extent we should treat people with dementia.

[Nurse, p1686, reviewer edits] (Nilsson et al., 2013)

It was also suggested that ward policy had a key role to play in fostering provision of PCC. In order to give good care, staff highlighted the need to understand preferred routines and personal information about Plwd (Berg et al., 1998; Bryon et al., 2010; Dowding et al., 2016; Nilsson et al., 2016). Some talked about the importance of involving family carers, either by providing information or tips that helped staff understand certain behaviours (Kelley et al., 2019; Lichtner et al., 2016), or by their presence alongside the Plwd and their ability to physically help when staff time was limited (Kelley et al., 2019; Porock et al., 2015). However, despite often recognising that carer involvement could help inform good care, it was rare for there to be a clear strategy or ward policies for involving them (Moyle et al., 2011), and staff could differ in their approach to carer involvement within wards and across wards

(Kelley et al., 2019). In a study about the use of deception to manage the emotions of Plwd, Turner, Eccles, Elvish, et al. (2017) noted a lack of policy to guide staff on this difficult issue.

4.2.3 | Ward cultures that inhibited the sharing of knowledge across roles and hierarchies, including lack of documentation about personal aspects of Plwd

Another issue that affected whether staff were able to provide PCC involved roles and hierarchies (Bailey et al., 2015; Berg et al., 1998; Bryon et al., 2010; Moyle et al., 2011; Teodorczuk et al., 2015). Role in this sense referred to both the type of professional field (domestic, healthcare assistant (HCA), nurse, physician, allied health professional) and the perceived hierarchies within and across these roles. Due to the importance of psychological well-being for Plwd in hospital, those who knew personal information about patients were particularly helpful in guiding decisions about their care. These could often be the people perceived as lower in the ward hierarchy-cleaners, porters, healthcare assistants-but also allied health workers (occupational therapists, physiotherapists, social workers), nurses and volunteers. A number of studies suggested that the valuable information they held could be ignored or that they did not think it appropriate or feel empowered to speak up, despite their expertise in 'knowing' the Plwd (Bailey et al., 2015; Berg et al., 1998; Bryon et al., 2010; Teodorczuk et al., 2015; Turner, Eccles, Keady, et al., 2017). Teodorczuk et al. (2015) suggested this could result in a feeling of powerlessness, which could then stifle practice. Some roles with the capacity to meet the psychological needs of Plwd did not facilitate PCC. Nurses who were 'specials', whose role it was to keep the Plwd safe, were not expected to interact with the Plwd despite spending hours next to them,

> We don't even take them routinely for walks...it is only if the nurse wants to go for a walk they will be taken...Often these specials will sit and read 'women's' magazines the entire shift.

> > [Clinical Nurse Consultant, p421, author edits]
> > (Moyle et al., 2011)

A number of studies found that systems for sharing information that fostered PCC such as personal preferences and backgrounds of Plwd, and individual approaches to managing responsive behaviour, were non-existent, were not consistently maintained (Dowding et al., 2016; Jensen et al., 2017; Nilsson et al., 2013, 2016; Turner, Eccles, Keady, et al., 2017) or were difficult to access,

I don't think we have a set heading that we document beneath. Instead you have to search in the text if you want to get information about the patient's cognition. [Nurse, p1686] (Nilsson et al., 2013)

Hospital staff who did find the time to get to know a Plwd could not record the useful information they discovered, so each member of staff was required to re-establish the same information 'from scratch at every shift' (Jensen et al., 2017, p10).

4.2.4 | Physical environments that prevented familiarisation, social interaction and occupation

Staff participants from a number of studies perceived that the atmosphere in an acute care environment was not suitable for Plwd. The busy environment, the noise and the rapid pace were perceived by many to be less than ideal in relation to what these patients needed (Berg et al., 1998; Nilsson et al., 2016; Porock et al., 2015; Teodorczuk et al., 2015). Staff participants also described the unsuitability of wards for fostering good care for Plwd because of design that prevented interaction with others, for example because Plwd were alone in a room, sat alone or were kept in bed (Clissett et al., 2014; Kelley et al., 2019; Nilsson et al., 2013).

She [the deputy ward manager]...says that whilst she doesn't like putting dementia patients in side rooms she can't have wandering patients with sick patients who are recovering from surgery.

[Researcher field notes, p1824] (Clissett et al., 2014)

The physical structure of wards communicated their purpose and focus: resources (e.g. provision of social space), equipment and furnishings were often there to promote physical care with little provision for systems to support the sharing of knowledge about personal information of Plwd, or facilitate communication and interactions between staff, carers and Plwd (Clissett et al., 2014; Kelley et al., 2019; Moyle et al., 2011; Teodorczuk et al., 2015). One study offered a slightly different emphasis by finding that a 'home-like' environment alone was inadequate to create the experience of being at home, but rather, such an experience required personal interaction that created feelings of safety, connection and welcome (Edvardsson et al., 2012).

This section has described barriers to the ability of hospital staff to provide PCC; in the next section, we will discuss the emotions such barriers created for staff, and how these affected job satisfaction.

4.3 | The ability of hospital staff to deliver good care was linked to job satisfaction

The values of individual staff were closely connected to job satisfaction: where they were able to meet their self-expectations for providing care, job satisfaction was high. When hospital staff were prevented from providing good care, they experienced 'conflicts in care', and this could result in negative emotion and moral distress. Hospital staff described coping with such emotions by setting up barriers between themselves and Plwd, continuing to experience and express the emotions at home, and/or seeking support from other staff. Where they were unable to cope with negative emotions,

they were at risk of cynicism and burnout. Where they were able to provide good care, they reported job satisfaction.

We describe in more detail below the emotions staff associated with conflicts in care, how they attempted to cope with these emotions and the resulting impact on job satisfaction.

4.3.1 | Conflicts in care

Staff described conflicts in care, where they were unable to provide the care they wanted to give; this left them feeling inadequate and frustrated, as though they were not doing a good job. A lack of knowledge left staff and nursing students feeling unsure about how to fulfil their nursing role (Berg et al., 1998; Nilsson et al., 2013, 2016; Turner, Eccles, Keady, et al., 2017).

You simply feel inadequate, I cannot, and I don't have the knowledge. You try everything and anything and nothing seems to work. It's like you improvise, make random long-shots, trying one thing after the other.

[Nurse, p50] (Nilsson et al., 2013)

Even with greater levels of experience of dementia, and understanding that responsive behaviour likely represented an unmet need, such behaviours could be quite challenging for staff and impacted their ability to deliver the care they wanted to give (Nilsson et al., 2016; Porock et al., 2015).

You become so frustrated that you have to leave the room, it feels like you cannot cope with this, it is too difficult when you are pinched, hit or have your hair pulled. I have certainly walked out of showers and felt 'no way, someone else needs to take over.'

[Nurse, p52] (Nilsson et al., 2016)

Staff:patient ratios and ward expectations of staff often underestimated the complex care Plwd needed, and meant that staff sometimes experienced conflicting priorities (Bailey et al., 2015; Bryon et al., 2010; Jensen et al., 2017) and/or did not have enough time to provide good care (Byers & France, 2008; Clissett et al., 2014; Nilsson et al., 2016). This could cause frustration and distress,

I'm starting to take care of my patients the way the hospital is dictating to me to take care of them because that is the way it is. Inside that doesn't feel good, it angers me and I can't change it.

[Nurse, p45] (Byers & France, 2008)

Nurses and HCAs in particular were seen to experience conflict in relation to providing 'physical care' (cure) as opposed to 'emotional care' (care) (Bailey et al., 2015; Porock et al., 2015). One nurse who had previously worked in a nursing home said,

Juggling responsibilities is a challenge - hospitals are about cure rather than care. Here we cure, in the nursing home we cared.

[Nurse, p45] (Porock et al., 2015)

Bailey et al. (2015) characterised this experience as an implicit and often unacknowledged conflict between opposing discourses, one around the nature of medical care, and the other around the nature of PCC. Another study found that the personal and professional integrity of nurses was often compromised in caring for Plwd as, despite having a greater need for time and attention, staff faced being unable to meet the needs of Plwd because they had very limited possibilities to do so,

It is eating me away not getting the time and peace to be present; you know you are not doing a good job. [Nurse, p51] (Nilsson et al., 2016)

Finally, two studies highlighted the conflict staff experienced in deciding whether to tell the truth or not, and the impact that could have on them and on Plwd (Jensen et al., 2017; Turner, Eccles, Keady, et al., 2017). In the study by Turner, Eccles, Elvish, et al. (2017), in response to difficult questions, to manage behaviour, provide personal care or share medical information, staff either told the truth, passed the buck, distracted or lied to Plwd. Although most said that telling the truth was their preferred option, they also said they thought telling the truth was inappropriate because it undermined their relationship with the Plwd, because of their responsibilities on the ward or because of their ethical beliefs (Turner, Eccles, Keady, et al., 2017). Distracting was considered to be the best option across participants, as it also allowed staff to avoid giving upsetting information or to avoid lying. When it did not work, staff considered lying. When relatives were present, staff were more likely to tell the truth; when patients with dementia were significantly agitated, staff were more likely to lie based on previous experiences of patients who had become physically aggressive.

In another study observing delivery of oral medicines for Plwd on an orthopaedic ward, concealment of medicine, in the sense of giving it to the patient while assisting with eating, was observed to be prevalent (Jensen et al., 2017). This often followed previous unsuccessful attempts to give medication, and was compounded by a lack of information shared between staff and shifts. It was observed to be a contentious issue for staff and one in which the autonomy of the Plwd could be ignored because staff focused on the necessity of the task at hand (Jensen et al., 2017).

4.3.2 | Coping with emotions

Staff dealt with the emotional burden of caring for Plwd in different ways. Staff described creating a barrier, by either physically withdrawing from the Plwd if the situation got too challenging, for example by leaving the room, or by disengaging (Bailey et al., 2015; Berg et al., 1998; Clissett et al., 2014; Nilsson et al., 2016). Nurses described being forced to 'deaden one's conscience', for example by

ignoring screams and disregarding confused patients' constant calls for attention (Nilsson et al., 2016). Disengagement could also be achieved through focusing on tasks and routine care,

...and I think if you're used to dealing with central lines and drug rounds and things, to be dealing with some-body who is screaming for their mum all the time, it is distressing and you are going to say I'll do that job thank you rather than that one.

[Consultant Psychiatrist, p752] (Teodorczuk et al., 2015)

Most studies characterised disengagement in negative terms; however, Bailey et al. (2015) noted that hospital staff do not have inexhaustible emotional resources, and sometimes, staff needed to care for themselves in order to engage again. Another study also observed that staff needed to protect themselves emotionally. The authors found that staff responded in three ways to the perceived challenges of caring for Plwd: by embracing the personhood of Plwd, protecting themselves without jeopardising personhood or suspending the personhood of Plwd (Clissett et al., 2014). Bailey et al. (2015) also made the qualification that constructive disengagement, when staff withdrew only to the extent necessary to care for themselves, was different to disinterest or uncaring behaviour towards Plwd.

Other staff coped by seeking support through talking or venting to colleagues (Berg et al., 1998; Bryon, Dierckx de Casterle, et al., 2012; Nilsson et al., 2016). However, some nurses said that sometimes they took the problems home to their family, which could create further negative impacts (Bailey et al., 2015; Berg et al., 1998; Byers & France, 2008). Both Berg et al. (1998) and Bryon, Gastmans, et al. (2012) found that staff described coping as a learnt process, with skills that developed over time.

4.3.3 | Job satisfaction

Along the continuum of care, it seemed the more the staff were able to deliver good care, the better their well-being and the better they felt about both their personal and professional integrity (Nilsson et al., 2016). However, caring for Plwd is complex,

You can go home and think I've done a good shift, I've done a good job, but you don't actually get any satisfaction, do you know what I mean? All you can do is as I've just said, you've done a good job, you've done your job right, but I just love it 100 per cent.

[Nurse, pp257] (Bailey et al., 2015)

This nurse referred to the fact that, as Plwd do not get better, 'you don't actually get any satisfaction'. Nonetheless, when she felt she had done a good job, she loved work '100 per cent'. PCC supported job satisfaction because staff perceived the care they were giving was of high quality despite the emotional work of caring for Plwd (Clissett

et al., 2014). Unfortunately, the more common experience described by staff was that they were made to focus on routine or task focused care at the expense of supporting the psychological well-being and autonomy of the Plwd. A nurse in the study by Byers et al. summarised this experience,

You finally get off from work and you don't really feel like you have accomplished anything ... when you have run all day and you didn't get done what you think you needed to get done to care for your patients.... There is not any accomplishment. You can't say, I really helped this person today.

[Nurse, p47, author and reviewer edits] (Byers & France, 2008)

5 | DISCUSSION

This is the first comprehensive systematic review of hospital staff experiences of caring for Plwd across a wide range of hospital settings and type of role. Our line of argument, representing the overall message of the synthesis, is that hospitals can improve staff experiences of caring for Plwd by fostering PCC. Hospital staff understood 'good' care as care that met the psychological needs of Plwd alongside their physical needs, in accordance with concepts of PCC. Hospital staff spoke of emotional distress due to witnessing the realities of dementia including responsive behaviour by Plwd, particularly when staff did not have adequate experience and/or training to use constructive strategies for interacting with Plwd. However, when staff understood how to provide good care to Plwd, they were often prevented from providing it by institutional and ward cultures that prioritised physical, task- and routine-focused care. Hospital atmospheres and environments also created barriers to familiarisation, social interaction and occupation for Plwd. Staff could experience moral distress in such situations, when their desire to provide good care was in conflict with the type of care they had the resources to provide. When staff were able to provide PCC, they reported that this supported their sense of job satisfaction.

Without action taken to change hospital cultures that prioritise physical care over the psychological needs of Plwd, staff will remain unable to routinely provide PCC. Our review is new in showing this to be detrimental to hospital staff experiences of caring for Plwd, and this knowledge compounds previous calls for PCC to be delivered in hospital settings because of findings that PCC supports improved experiences of care in hospital for Plwd (Digby et al., 2017; Reilly & Houghton, 2019; Turner, Eccles, Elvish, et al., 2017) and their carers (Beardon, Patel, Davies, & Ward, 2018; Burgstaller, Mayer, Schiess, & Saxer, 2018). Concepts of PCC for dementia have been around for 20 years (Kitwood, 1997) and are already adopted by policymakers and advocates of Plwd internationally as best practice (Department of Health, 2009; Gerontologist, 2013; Laver et al., 2016; World Health Organisation, 2017). Studies included in this review are predominantly published within the past 10 years; however, they

demonstrate that despite agreement over the potential value in hospital of PCC to Plwd, it is still not being consistently implemented. In the UK, a recent audit of dementia care in general hospitals confirmed this finding (Royal College of Psychiatrists, 2019).

The barrier to providing PCC in hospital that was most often mentioned by staff in this review was a lack of time, in common with other systematic reviews that focused on hospital staff as participants (Digby et al., 2017; Moonga & Likupe, 2016; Turner, Eccles, Elvish, et al., 2017). We consider perceptions of a lack of time to follow from a number of the other issues highlighted by this review, including inadequate staffing levels, ward priorities around routine tasks and physical care that occlude PCC, and a lack of structures that support staff to share information about the individual needs of Plwd, which wastes time. Inadequate time also can lead to the conflicts in care that staff described facing, which contributed to emotional distress and burnout, and acted as a barrier to work satisfaction. Ultimately, PCC can only come with structural changes on wards that address such issues. However, there is some suggestion that PCC can free up time.

Staff commonly perceived that PCC took more time because it involved establishing relationships with Plwd. Conceptually, PCC could have the potential to take less time in the long run, because an important barrier to staff providing care is the responsive behaviour of Plwd. The more established relationships with staff are, the more secure Plwd are likely to feel, and the less likely they are to exhibit responsive behaviour. When Plwd do show responsive behaviour, staff who have established relationships with Plwd will be most able to resolve distress. By contrast, studies have shown that care that is focused on tasks, routines and physical care while ignoring the personhood of Plwd can exacerbate responsive behaviour (Handley et al., 2017; Schindel Martin et al., 2016).

Studies exploring staff experiences of interventions to improve the experience of care in hospital for Plwd also found that staff commonly spoke of issues related to time. Wilkinson, Coates, Merrick, and Lee (2016) explored the experiences of junior doctors who became dementia champions, and found that changing practice to PCC involved a 'threshold': initially, the doctors thought that PCC would take longer, but over time came to believe it took less time in the long run. Some hospital staff in other studies perceived that the addition of volunteers to interact with Plwd (McDonnell, McKeown, Keen, Palfreyman, & Bennett, 2014; Wong Shee, Phillips, Hill, & Dodd, 2014), carer support strategies (Durepos, Kaasalainen, Carroll, & Papaioannou, 2017; Woods & Tadros, 2014) and access technology (Margot-Cattin & Nygård, 2006) saved them time. However, other staff thought that, despite changes introduced by interventions, there was still not time to provide PCC (Brooke & Semlyen, 2017; Horner, Watson, Hill, & Etherton-Beer, 2013; McDonnell et al., 2014; Naughton et al., 2018; Spencer, Foster, Whittamore, Goldberg, & Harwood, 2013; St John & Koffman, 2017). Studies that report promising approaches to supporting PCC in hospital include the following: carer support groups (Durepos et al., 2017), family videos to address responsive behaviour (Hung, Au-Yeung, et al., 2018), video reflexivity when training staff in PCC (Hung, Phinney, Chaudhury,

& Rodney, 2018), technology to create privacy and safety (Margot-Cattin & Nygård, 2006), volunteers to offer companionship and activities (McDonnell et al., 2014) and training up junior doctors as Dementia Champions (Wilkinson et al., 2016). However, further studies are needed to explore what resources it is necessary to add in order for psychological care and usual task-/routine-focused care to be provided together, and whether PCC does in fact take less time in the long run.

5.1 | Strengths and limitations

The strengths of this review include a large number of studies (58) representing 1,135 hospital staff, and the richness, methodological and conceptual quality of the 19 prioritised studies contributing data to this systematic review and synthesis. We extend the findings of other systematic reviews of staff experience by synthesising information about a range of hospital staff including domestic staff and porters, doctors and allied health professionals and nurses. A limitation is that we were unable to conduct synthesis with all included studies because of their large number; however, the findings were interrogated by comparison with medium-priority papers, which were in accordance. Another limitation is the focus on experiences of hospital staff without recourse to experiences of those making decisions about hospital care, such as healthcare commissioners. The quality, number and commensurate themes of included studies support the potential for analytic generalisability (Polit & Beck, 2010). Transferability to similar contexts in qualitative research needs to be confirmed by the reader (Lincoln & Guba, 1985).

6 | CONCLUSION

This systematic review adds weight to previous reviews, which suggested that PCC will improve experiences of care for Plwd in hospital. It finds that supporting staff to provide PCC to Plwd improves staff experiences of caring for Plwd. However, there is a need for further exploration of ways in which the barriers to PCC in hospital settings can be overcome.

Implications for practice

Institutional-level areas for change include the following: training; performance indicators and ward cultures that prioritise psychological needs alongside physical needs; adequate staffing levels; inclusive approaches to carers; physical environments that promote familiarisation, social interaction and occupation; systems of documentation about individual needs of Plwd; and cultures of sharing knowledge across hierarchies.

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CONFLICT OF INTEREST

None.

AUTHOR CONTRIBUTIONS

Study design: RA, MR, CG, SB, AH, DC, LC, DAM, GC, DJL, TN, JTC; Data analysis: RG-J, RA, IL, MR, CG, SB, AH, DC, LC, DAM, CH, GC, DJL, TN, JTC and Manuscript preparation: RG-J, RA, IL, MR, CG, SB, AH, DC, LC, DAM, CH, GC, DJL, TN, JTC.

ORCID

Ruth Gwernan-Jones https://orcid.org/0000-0002-0223-6581
Rebecca Abbott https://orcid.org/0000-0003-4165-4484
Ilianna Lourida https://orcid.org/0000-0003-4439-2192
Morwenna Rogers https://orcid.org/0000-0002-6039-238X
Colin Green https://orcid.org/0000-0001-6140-1287
Susan Ball https://orcid.org/0000-0002-9937-4832
Darren A Moore https://orcid.org/0000-0003-0628-3323
David J. Llewellyn https://orcid.org/0000-0002-2441-4246
Jo Thompson Coon https://orcid.org/0000-0002-5161-0234

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APPENDIX 1

MEDLINE search strategy

Database: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

- exp Dementia/nu, px, rh, th [Nursing, Psychology, Rehabilitation, Therapy]
- 2. exp Delirium/nu [Nursing]

- 3. exp Confusion/nu [Nursing]
- 4. dementia.ti,ab.
- 5. alzheimer*.ti,ab.
- 6. (cognitive adj2 (disorder* or dysfunction or impair*)).ti,ab.
- 7. delirium.ti,ab.
- 8. or/1-7
- 9. Hospitals, General/ma, mt, og, st, ut [Manpower, Methods, Organization & Administration, Standards, Utilization]
- 10. general hospital*.ti,ab.

- 11. acute hospital*.ti,ab.
- 12. (acute adj2 care).ti,ab.
- 13. (hospital* adj3 (experience or care or setting)).ti,ab.
- 14. (general adj3 ward*).ti,ab.
- 15. (acute adj3 ward*).ti,ab.
- 16. (acute adj3 setting*).ti,ab.
- 17. (admission adj3 hospital*).ti,ab.
- 18. ((ambulance or paramedic) adj5 care).ti,ab.
- 19. (discharge adj2 hospital).ti,ab.
- 20. or/9-19
- 21. Patient Care Management/
- 22. Nursing Staff, Hospital/ed, og, px, st, ut [Education, Organization & Administration, Psychology, Standards, Utilization]
- 23. Medical Staff, Hospital/ed, px, st, ut [Education, Psychology, Standards, Utilization]
- 24. Nurses/ed, og, px, st, ut [Education, Organization & Administration, Psychology, Standards, Utilization]
- 25. care.ti,ab.
- 26. healthcare.ti,ab.
- 27. (patient centered or patient centred).ti,ab.
- 28. (person centered or person centred).ti,ab.
- 29. (nurse or nurses).ti,ab.
- 30. staff.ti,ab.
- 31. champion*.ti,ab.
- 32. dementia ward*.ti,ab.
- 33. training.ti,ab.
- 34. education.ti,ab.
- 35. dementia specialist*.ti,ab.
- 36. ((hospital or ward) adj staff).ti,ab.
- 37. health professional*.ti,ab.
- 38. befriend*.ti,ab.
- 39. (visitor* adj5 (hospital* or ward*)).ti,ab.
- 40. communication.ti,ab.
- 41. (dementia adj2 friend*).ti,ab.
- 42. activities.ti,ab.
- 43. (ward adj3 (design or ambience or decor*)).ti,ab.
- 44. (garden* or outdoor* or outside).ti,ab.
- 45. culture.ti,ab.
- 46. or/21-45

- 47. qualitative research/
- 48. (experience or experiences).ti,ab.
- 49. interview*.ti,ab.
- 50. questionnaire*.ti.ab.
- 51. focus group*.ti,ab.
- 52. qualitative.ti,ab.
- 53. feelings.ti,ab.
- 54. perception*.ti,ab.
- 55. 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54
- 56. 8 and 20 and 46 and 55

APPENDIX 2

Fourteen sensitising prompts to appraise quality of included studies, adapted from the Wallace checklist ()

- 1. Is the research question clear?
- 2. Is the theoretical or ideological perspective of the author explicit?
- 3. Has the theoretical or ideological perspective influenced the study design, methods or research findings?
- 4. Is the study design appropriate to answer the question?
- 5. Is the context or setting adequately described?
- 6. Is the sample adequate to explore the range of subjects and settings, and has it been drawn from an appropriate population?
- 7. Was the data collection adequately described?
- 8. Was data collection rigorously conducted to ensure confidence in the findings?
- 9. Was there evidence that the data analysis was rigorously conducted to ensure confidence in the findings?
- 10. Are the findings substantiated by the data?
- 11. Has consideration been given to any limitations of the methods or data that may have affected the results?
- 12. Do any claims to generalisability follow logically and theoretically from the data?
- 13. Have ethical issues been addressed and confidentiality respected?
- 14. Is-are the authors reflexive?

APPENDIX 3

Summary of included study characteristics

Studies (n = 45)					
First author, date (n = 58)	Country	Hospital (n)	Type of ward (n)	Information about dementia of patients cared for	Data collection Participant role (n)
Allwood et al. (2017)	UK	Large teaching hospital (1)	Health care of the older person ward (NR)	Staff cared for patient participants who had a diagnosis of dementia documented in their medical notes	Videoed Interactions (41) Total staff (26) (Nurses: 11; allied health professionals: 6; Doctors: 9) Plwd (26)
Ashton & Manthorpe (2017)	UK	Acute hospital (1)	Inpatient wards (NR)	Staff had regular contact with Plwd	Interviews (12) Total staff (12) (Domestic staff and porters: 12)
Bailey et al. (2015)	UK	2 urban, 1 rural hospital from 1 NHS Trust (3)	Dementia wards (3)	Staff caring for Plwd on a dementia ward	Interviews (30) Total staff (30) (Healthcare assistants: 15; nurses: 11; ward managers: 3; activity coordinator: 1) Observation (NR)* Staff, Plwd and carers Focus groups (3)* Staff (NR)*
Baillie, Cox, & Merritt (2012); Baillie, Merritt, & Cox (2012)	UK	NHS Trust hospitals ('several')	Varied (NR)	Students had cared for older people with dementia while on placement in hospital	Focus groups (4) Nursing students (20)
Bartlett & Clarke (2012)	UK	Acute hospital (1)	Varied (NR)	Staff cared for people dying from cancer with a coincidental dementia	Interviews (5) Total staff (5) (Nurses: 2; senior nurse manager: 1; chaplain: 1; senior healthcare assistant: 1)
Berg et al. (1998)	Sweden	NR (1)	Psychogeriatric ward (1)	Staff cared for Plwd rated as suffering from severe dementia	Interviews (24) Nurses (13)
Borbasi et al. (2006); Jones, Borbasi, Nankivell, & Lockwood (2006)	Australia	Large metropolitan teaching hospitals (3)	Varied (NR)	Staff provided care to people with dementia on a regular basis	Interviews (25) Total staff (25) (Senior medical officers: 4; clinical nurse consultants: 5; clinical nurses: 3; nurse unit managers: 3; Registered Nurses: 1; occupational therapists: 2; social workers: 3; assistant director of nursing: 1; physiotherapist: 1; other: 2)
Bower (2017)	UK	Hospitals in 2 NHS Trusts (2)	Acute medical units (NR)	Staff were recruited due to their close contact with Plwd with dementia	Interviews (21) Total staff (21) (Nurses: 12; healthcare assistants: 9)

APPENDIX 3 (Con	unuea)				
Studies (n = 45) First author, date (n = 58)	Country	Hospital (n)	Type of ward (n)	Information about dementia of patients cared for	Data collection Participant role (n)
Brooke & Stiell (2017)	UK	Ambulance service providers (2)	N/A	Paramedic students transported people with dementia to hospital while on clinical placement with ambulance service providers	Focus groups (6) Paramedic students (57)
Bryon, Dierckx de Casterle et al. (2012); Bryon, Gastmans et al. (2012); Bryon et al. (2010)	Belgium	4 general, 2 university, 3 psychiatric hospitals (9)	Geriatric, psychogeriatric, internal medicine and palliative support wards (NR)	Staff involved with Plwd at end of life	Interviews (21) Nurses (21)
Byers & France (2008)	USA	NR (NR)	Medical surgical units (NR)	Staff cared for people with dementia in acute settings	Interviews (9) Registered Nurses (9)
Carr et al. (2011)	Canada	Tertiary care centre (1)	Specialised and secure unit designed for the care of elderly persons admitted with moderate-to-severe dementias (1)	Staff and carers cared for Plwd with dementia admitted to a dementia unit	Interviews (30) Total staff (16) (Registered Nurses: 5; licensed practical nurse/ recreational therapists: 6; hospital chaplains: 5) Carers (5) Plwd (8) Observation* (25 hr)
Clissett et al. (2014)	UK	Large teaching hospitals located in one NHS Trust (2)	General medical health care for older people (6) or trauma orthopaedic wards (6)	Plwd were identified through hospital staff perceptions of problems with mental health; the studies focused on 29 of 34 of these Plwd with cognitive impairment Family were considered to be carers when they had at least weekly contact with the Plwd	Interviews (39) Carers (35) Observation (72 hr) 29 PlwD Staff* Carers*
Cowdell (2008); Cowdell (2010a, b)	UK	Acute hospital (1)	Acute wards providing specialist care for older people (2), rehabilitation ward providing specialist care for older people (1)	Preadmission diagnosis of dementia	Interviews (18) Staff (NR)* Carers (NR) PwD (1) Observation (125 hr) Total staff (58) (Registered Nurses: 25; nursing assistants: 33) Carers (7) Plwd (11)
Crowther (2017); Crowther et al. (2018)	UK	Large teaching hospital (1)	Elderly medicine acute ward (1), general medicine acute ward (1), elderly medicine long stay ward (1), orthopaedic surgery longer stay ward	Staff cared for people with dementia in hospital settings	Interviews (25) Staff (25)



APPENDIX 3 (CON	tillueu)				
Studies (n = 45) First author, date (n = 58)	Country	Hospital (n)	Type of ward (n)	Information about dementia of patients cared for	Data collection Participant role (n)
Digby et al. (2018)	Australia	Large general teaching hospitals in different health services (2)	Subacute geriatric rehabilitation wards (5)	Diagnosed with dementia	Interviews (30) Plwd (30) Observation (120 hr) Plwd (30) Staff (NR)* Carers (NR)
Dowding et al. (2016); Lichtner et al. (2016)	UK	Hospitals (4)	Vascular (1); elderly medicine (3); continuing care (1); stroke rehabilitation (1); surgical (2); acute admission unit (1)	Diagnosis of dementia was recorded in Plwd' notes	Interviews (56) Total staff (52) (Healthcare assistants, nurses, doctors, other members of the multidisciplinary team)* Carers (4) Observation (480 hr) Focused on 31 Plwd and their interactions with HCP*
Edvardsson et al. (2012)	Sweden	University hospital (1)	Psychogeriatric ward (1)	Diagnosis of dementia	Observation (36 hr) Plwd, staff,* carers (NR)
Emmett et al. (2013); Poole et al. (2014)	UK	Hospitals (2) in 2 separate NHS Trusts	Orthogeriatric ward (1); Care of the elderly ward (1); rehabilitation ward (1)	20 formally diagnosed with dementia; all with cognitive impairment (MMSE mean 17 range 7-28); those with a diagnosis of delirium were excluded	Observation (111 days) Health and social care professionals (NR)* PwD (NR) Carers (NR) Interviews (92) Total staff (35) Senior and junior doctors, general practitioners, qualified and non- qualified, senior and junior nursing staff, occupational therapists, social workers, psychologists, a care home manager, a chaplain, a physiotherapist and a independent mental capacity advocate Carers (28) Plwd (29) Focus groups (4) Total staff (22) Carers (3)
Eriksson & Saveman (2002)	Sweden	Medium-sized hospital (1)	Acute wards (5), accident and emergency department (1)	Staff had experience caring for people with dementia	Interviews (12) Nurses (12)

APPENDIX 3 (Con	tillucuj				
Studies (n = 45) First author, date (n = 58)	Country	Hospital (n)	Type of ward (n)	Information about dementia of patients cared for	Data collection Participant role (n)
Featherstone et al. (2018)	UK	Hospitals (5-range of types, geographies and socio-economic catchments)	Trauma, orthopaedic wards and medical assessment units (10)	Staff were known to care for a large number of people with cognitive impairment	Observation* (155 days) Ethnographic interviews (414) Nurses, healthcare assistants and clinical staff (108) Ethnographic interviews with Plwd and carers (71) Plwd (10) Carers (37)
Fry et al. (2015)	Australia	District hospitals (2), Tertiary referral hospitals (2)	Emergency departments (4)	Staff had experience caring for people with cognitive impairment	Focus group interviews (16) Emergency nurses (80)
Fukuda, Shimizu, & Seto (2015)	Japan	Hospitals (6)	Internal medicine (17), surgical ward (8), mixed internal medicine and surgical (16), other (9)	Staff had experience caring for people with dementia	Focus group interviews (8) Nurses (50)
Goldberg et al. (2014)	UK	Large hospital (1)	Medical and mental health unit (1); standard care wards (11)	Identified by staff as 'confused'; most had dementia or delirium	Observation (360 hr) Plwd (60) Staff (NR)* Carers (NR)
Griffiths et al. (2014)	UK	Large general teaching hospital (1)	Wards that admitted Plwd for acute care (11), including respiratory medicine (3), rheumatology (1), trauma orthopaedics (2), acute geriatric medicine (2) and diabetes and endocrinology (3)	Staff who worked with confused older Plwd whether due to dementia or delirium	Interviews (60) Total staff (60) (Senior consultant: 5; middle-grade doctor: 5; junior doctor: 5; senior nurse: 10; nurses: 15; healthcare assistant: 10; occupational therapist: 5; physiotherapist: 5)
Hayward (2009); Hayward et al. (2012)	UK	Hospital (1)	Range of wards (NR)	Staff who had at least one memorable incident of inappropriate sexual behaviour with an older adult with dementia	Interviews (14) Staff (14)
Hung et al. (2017)	Canada	Large hospital (1)	Medical unit (1)	Diagnosis of dementia	Go-along videoed interviews (9) Plwd (5) Observation (20 hr) Staff (NR)* Plwd (NR) Carers (NR)
Jensen et al. (2017)	Denmark	General hospital (1)	Hip fracture unit on an orthopaedic surgery ward (1)	Diagnosis of Alzheimer's disease	Observation (257 hr) Plwd (3) Staff who cared for them (NR)*



TENDIX 5 (COII	itiiiacaj				
Studies (n = 45) First author, date (n = 58)	Country	Hospital (n)	Type of ward (n)	Information about dementia of patients cared for	Data collection Participant
Kable et al. (2015)	Australia	NR (1)	Acute tertiary facility (1)	Staff who were involved with supporting PwD in acute hospital settings, or caring for them in the community after discharge	Focus groups (4) Total staff (33) (Junior medical officers: 5 Nurses: 16; Allied health professionals: 12)
Kelley (2017); Kelley et al. (2019)	UK	General hospitals (2) in separate NHS Trusts	Elderly care rehabilitation ward (1), acute elderly care ward (1)	Plwd had a suspected or confirmed diagnosis of dementia	Observation* (400 hr) Interviews (47) Staff (23) Plwd (4) Carers (11) In-depth case studies (12 carer-patient dyads) Document analysis
Krupic et al. (2016)	Sweden	University hospital (1)	Department of orthopaedic surgery	Staff who had opportunity to meet Plwd with dementia	Interviews (10) Nurses (10)
LaMantia et al. (2016)	USA	University-affiliated public safety-net hospital (1)	Teams providing care to older adults within the Indiana University Geriatrics Programs (NR)	Staff who cared for older adults affected by cognitive impairment	Focus groups (3) Total staff (22) (Nurses: 8; social workers: 7; medical assistants: 4; physicians: 2; other: 1)
Moyle et al. (2011)	Australia	Large hospital (1)	Acute medical or surgical wards (NR)	Staff who cared for or treated people with dementia	Interviews (13) Total staff (13) (Gerontologist: 1; nursing directors: 2; clinical nurse consultant: 1; nursing unit managers: 3; clinical nurses: 2; Registered Nurse: 1; nursing assistants: 3)
Ng (2009)	UK	Hospital (1)	Organic disease ward for Plwd with dementia (1)	Observations on a ward for people with dementia	Observation (NR) Plwd and staff (NR)*
Nilsson et al. (2013)	Sweden	University hospital (1)	Cardiology ward (1)	Observations of older Plwd with cognitive impairment	Observation (110 hr) including about 100 informal interviews with staff,* Plwd and carers Interviews (11) Total staff (9) (Registered Nurses: 4; doctors: 2; licensed practising nurses: 3) Carers (1) Plwd (1) Document analysis
Nilsson et al. (2016)	Sweden	University teaching hospital (1)	general medical, oncology and neurological clinics (3)	Staff worked on wards chosen because of high prevalence of older cognitively impaired Plwd	Interviews (13) Total staff (13) (Registered Nurses: 8; assistant nurses: 5)
Nolan (2006, 2007)	Ireland	Large acute hospital (1)	Specialist unit for acutely ill older persons	Staff worked on wards on which older persons with dementia were cared for	Interviews (7) Nurses (7)

Studies (n = 45)				Information about	Data collection Doublein at
First author, date (n = 58)	Country	Hospital (n)	Type of ward (n)	dementia of patients cared for	Data collection Participant role (n)
Norman (2003, 2006)	UK	Large general hospital (1)	Surgical and medical ward (1); admissions (1); longer stay units (NR)	Plwd whom nurses perceived had dementia	Observation (100 + hours) Plwd (8) and the staff* and carers caring for them Focus groups (4) Total staff (26) (healthcare assistants, nursing students and qualified nursing staff) Interviews (7) Plwd (4, also observed) Carers (3)
Pinkert et al. (2018)	Germany and Austria	Hospitals in Germany (5) and Austria (4)	Acute wards (NR)	Hospital staff with experience of caring for people with cognitive impairment (Austria); hospital staff involved with dementia-specific care concepts and who had experience treating Plwd	Focus groups (Austria: 7; Germany: 5) Nurses (Austria: 46; Germany: 22)
Scerri et al. (2015)	Spain	Geriatric rehabilitative care ancillary hospital service (1)	Geriatric rehabilitation wards (2)	Hospital staff working on a geriatric rehabilitation ward	Interviews (43) Total staff (33) (Qualified nursing staff: 16; nursing aids and clerks: 9; occupational therapists, pharmacists, physiotherapists, speech language pathologists, physiotherapy aides, occupational therapy aides: 8) Carers (10)
St John & Koffman (2017)	UK	Large teaching hospital (1)	Elderly care wards (3)	Staff worked on elderly care wards	Interviews (8) Total staff (8) (Staff nurse: 1; healthcare support worker: 2; activity worker: 2; dignity manager: 1; occupational therapist: 1; student nurse: 1)

Studies (n = 45) First author, date (n = 58)	Country	Hospital (n)	Type of ward (n)	Information about dementia of patients cared for	Data collection Participant role (n)
Teodorczuk et al. (2015)	UK	District General Hospital (1)	NR	Hospital staff from diverse disciplines with different perspectives on dementia and delirium	Interviews (15) Total staff (15) (1 each of: Liaison nurse; junior doctor; physiotherapist; ward sister; care facilitator; operational manager; social worker; executive director; healthcare assistant; consultant geriatrician; occupational therapist; hospital cleaner (domestic); pharmacist; porter; nutritionist/ nurse) Focus groups (5) Total staff (12) (Specialists in liaison old age psychiatry including 7 nurses and 3 doctors) Carers (15) Plwd (2)
Thuné-Boyle et al. (2010)	UK	Inner city general hospital (1)	Acute wards (NR)	Carers responsible for the decision-making of Plwd with advanced dementia	Interviews (41) Carers (20) Total staff (21) (Nurses: 5; doctors: 4; general practitioners: 2; speech therapist: 1; social worker: 1; nursing home manager: 2; nursing home nurses: 2; nursing home carers: 4)
Turner, Eccles, Keady, et al. (2017)	UK	NHS Trust (2) Hospitals (NR)	General hospital wards (8)	Staff with direct experience of working with Plwd with dementia	Interviews (12) Staff (12)
Watts & Davies (2014)	UK	General hospital (NR)	Medicine/surgery/ older people/ rehabilitation wards (NR)	Nursing students caring for people with advanced dementia	Interviews (11) Nursing students (11)

Note: Prioritised studies are in bold font; medium-priority studies in plain font; *lowest priority studies in italics*. Abbreviations. NR: not reported; Plwd: people living with dementia; UK: United Kingdom; USA: United States of America. Data were collected (observation, interview or focus group) about hospital staff without reporting number of participants.