

Older people's experiences in acute care settings: systematic review and synthesis of qualitative studies

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Abstract

Background

There is no recent synthesis of primary research studies into older people's experiences of hospital care.

Objective

To synthesise qualitative research findings into older people's experiences of acute health care.

Design

Systematic procedures for study selection and data extraction and analysis.
Comparative thematic approach with meta-ethnographic features for synthesis.

Data sources

Worldwide grey and published literature written in English between January 1999 and December 2018 identified from databases: CINAHL, Medline, British Nursing Index, EMBASE Psychiatry, International Bibliography of the Social Sciences, PsychINFO, and AgeInfo.

Review methods

Systematic review and synthesis of 61 qualitative studies and two systematic reviews describing older patients' experiences of care in acute hospital settings.

Results

The physical and social environment of the hospital positioned many older patients as insignificant and powerless to influence the care they received. Patients subjugated their needs to those of staff and other patients, holding back information and requests for help. Patient knowledge of the time-based schedules for care, and experiences of waiting for care and of staff limiting their time with them served to reinforce patients' feelings of insignificance and powerlessness, reflecting the perceived primacy of bureaucratic organisation of care over individual needs and preferences. Highly negative experiences would result if these aspects of context were not mediated by individualised relational work by staff, nursing staff in particular. Some groups of patients were at particular risk of negative experiences: people with dementia and/or delirium; people with difficulty communicating, hearing or understanding; people from ethnic minority groups, especially where there was a language difference; people with low functional/physical ability; people with low literacy; and people without regular visitors and/or family support. Three key features of care consistently mediated negative feelings and were linked to more positive experiences were: "maintaining identity: see who I am", "building relationships: connect with me", and "partnering in care: involve me".

Conclusion

Older people's care experiences in hospital may be negative in the absence of relational work by nurses to maintain people's identity, establish caring connections and ensure that individual patient needs, preferences and values are

honoured in the care that is delivered. Relational care by nurses can mediate powerful institutional drivers that may otherwise result in negative experiences and poor care. Organisational and service-wide commitment are needed to create the culture and context in which relational care can flourish.

Tweetable abstract

Synthesis of qualitative research on older ppl's hospital experiences: hospital's physical and social environment positions older ppl as insignificant and powerless. Highly negative experiences result if impact of context not mediated by individualised relational work by nurses.

What is already known

- Acute hospital admission can be a significant event for older people, and can threaten older people's sense of identity and involvement.
- Enriched environments for care are associated with all those involved (that is, staff, students, older patients and relatives) experiencing a sense of security, belonging, continuity, purpose, achievement and significance.
- Relationship-centred approaches to care can enhance the wellbeing of older people, staff and relatives.

What this paper adds

- The physical and social environment of the acute hospital setting has a direct impact on the experiences of older people in the patient role.

- Bureaucratic approaches to care management and delivery can result in highly negative and dehumanising experiences of care, worsening as patient complexity increases.
- Relational work by frontline staff, nursing staff in particular can mediate the impact of the hospital environment for patients through “maintaining identity: see who I am”, “building relationships: connect with me”, and “partnering in care: involve me”.

Key words

Aged

Aged, 80 and over

Hospitals

Human dignity

Professional-patient relations

Qualitative research

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Background

In many developed countries, ageing populations and drivers of shorter length of hospital stay have resulted in an in-patient population with more complex needs (World Health Organization, 2015). In addition to more general wards, people aged over 65 years now make up most of the patient population on general and specialist adult acute hospital wards (National Audit Office, 2016). It is now widely acknowledged that health services need to develop to better meet older people's needs (Bridges et al., 2019, Oliver et al., 2014). In the UK, acute care developments for older people have been significant, and resulting initiatives include the National Health Service Acute Frailty Network, reducing avoidable admissions, early supported discharge schemes, "end PJ paralysis" (to encourage hospital inpatients to get out of bed and be active on the ward) and increasing use of comprehensive geriatric assessment outside of specialist care for older people services (for example, in surgery and oncology) (Acute Frailty Network, undated, Ewbank et al., 2017, Oliver, 2017, Partridge et al., 2014, Whittle et al., 2017).

In spite of this focus on improving services for older people, their personal experiences of care when they are admitted to an acute hospital do not feature highly in developments of policy and practice, with improving outcomes, reducing

risk and financial efficiencies acting as more overt drivers of care. Insights into care experiences may improve our understanding of the mechanisms that lead to patient deterioration and poor outcomes, while also highlighting other service improvements that may be needed. As patient complexity grows, more responsive health services are needed, with understanding patient experiences essential to developing responsiveness (Bridges et al., 2019). This paper presents the findings from a systematic review of qualitative research focused on older peoples' experiences of acute in-patient care in general hospital settings. The review was originally reported in 2010 (Bridges et al., 2010), and has been updated as reflected in the methods set out below. There is an increasing number of qualitative studies providing such insight, and so an up-to-date overview of this work is merited.

Methods

This review and synthesis aimed to understand older people's experiences of acute inpatient care in general hospital settings. We focused on qualitative research studies as the primary data source for the review. Older people tend to evaluate care differently to younger people, often more positively, and these relatively positive evaluations may be because older people's expectations of care are lower than those of younger adults (Batbaatar et al., 2017, Bridges et al., 2019, Victor et al., 2018). There is also a psychological threat in asking people to evaluate their care, especially while they are still in receipt of it (Bridges et al., 2018, La Monica et al., 1987). In addition, written survey methods may exclude participation by people at highest risk of a poor experience (for instance,

low literacy or cognitive impairment) (Gould et al., 2018). Focusing on people's experiences of care in their own words may be less threatening than direct evaluations, and may enable accounts and perspectives to emerge that use of more structured instruments may exclude, and so a focus on qualitative research was merited for this review (Goldberg and Harwood, 2013, Gould et al., 2018).

Systematic procedures were used for study selection and data extraction and analysis. A comparative thematic approach to synthesis was taken with a number of features adopted from the literature on meta-ethnography (Britten et al., 2002, Marston and King, 2006, Thomas and Harden, 2008). This approach of induction and interpretation mirrored the qualitative methods of the studies within the synthesis (Britten et al., 2002). Organisation of the original review and synthesis was managed through EPPI-Reviewer, an on-line software tool (Thomas and Brunton, 2006). The updated review was organised using on-line tools Rayyan and Trello (Qatar Computing Research Institute, undated, Trello, 2019). PRISMA guidelines were used here to guide reporting (Moher et al., 2009). A review protocol is available from the authors on request.

Searching

We identified papers for possible inclusion by combining searches of electronic databases, hand searches of reference lists of papers and contact with experts in the field. Databases searched included CINAHL, Medline, British Nursing Index, EMBASE Psychiatry, International Bibliography of the Social Sciences, PsycINFO, and AgeInfo. We used medical subject headings and freetext searches related to older people, acute health services and qualitative research

(see example in Figure 1). Searches were limited to papers published in English between January 1999 and December 2018.

Figure 1: Search strategy for PsycINFO

1	m	elder* OR aged OR geriatric* OR geront* OR senior*
2		frail* OR dementia*
3		hospital* OR "acute care" OR emergenc* OR inpatient*
4	DE	"Qualitative Research" OR DE "Grounded Theory"
5		qualitative
6		S4 OR S5
7		S1 OR S2
8		S3 AND S6 AND S7
9	DE	"Client Satisfaction"
10		patient satisfaction OR experience* OR view* OR opinion* OR perception* OR attitude*
11		S9 OR S10
12		S8 AND S11

Selection

Studies were included that used qualitative methods through face-to-face contact and a semi-structured or open-ended questioning approach to explore older patients' self-reported experiences of care in an acute hospital setting. We also included studies that used other approaches to understanding patient experiences, including in-depth observation, structured questionnaires based on prior qualitative research or devised in such a way to enable respondents to relate their experiences in an open-ended way. These studies were not sought

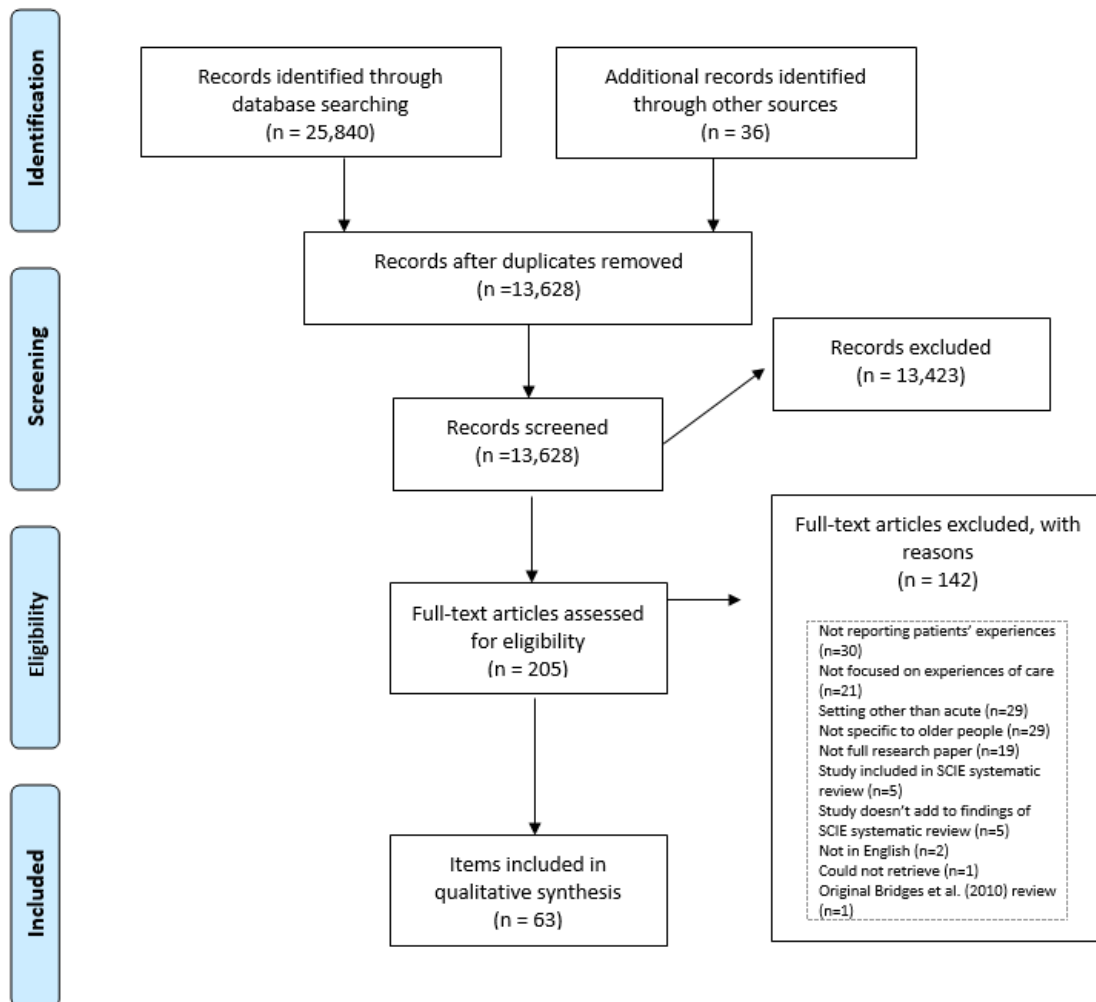
out deliberately but were not excluded if they emerged during the search (Social Care Institute for Excellence, 2006).

Initial database searching resulted in 25,840 hits (Figure 2). These results were added to eight items already known to the reviewers. Scanning the bibliographies of all retrieved items (including those subsequently excluded) led to 28 further relevant items being identified. Review of titles and abstracts, and removal of duplicates led to the retrieval of a total of 205 items for more detailed evaluation. Abstracts, methods sections and, where necessary findings sections (where methods provided insufficient detail as to the nature of data collected) of all 205 items were then read and the inclusion and exclusion criteria applied.

One hundred and forty-two items were excluded at this stage, including ten items related to a review by the Social Care Institute for Excellence (SCIE). This SCIE review (SCIE 2006) reported older people's experiences of hospital discharge and was included in the synthesis reported below. Other items identified were not included if they had already been included in the SCIE review (n=5) or if two reviewers independently concluded that their findings did not add to the findings of the SCIE review (n=5). Other reasons for exclusion are shown in Figure 2.

A final sample of 63 items was obtained for synthesis, between them reporting on 61 primary studies and two systematic reviews.

Figure 2: PRISMA flow diagram



Quality assessment

Each primary study was appraised using the Critical Appraisal Skills Programme criteria for evaluating qualitative research (Critical Appraisal Skills Programme, 2006) in addition to an evaluation of the degree to which they represented participants' views (Thomas and Harden, 2008). The findings from these appraisals were not used to inform the inclusion or exclusion of studies, as there are no accepted methods to guide these decisions (Thomas and Harden, 2008),

and it was felt that even low quality studies may be able to contribute to the findings. Study quality informed relative weightings in the analysis, with higher quality studies assigned greater weight.

Data extraction

Single researchers (JB, PC, MF, AY) undertook title/abstract screening of subsets of studies. Full papers were reviewed in the same way with decisions then made about inclusion/exclusion through research team discussion. Other research team members cross-checked samples of screening and preliminary selection decisions, with disagreements resolved through research team discussion. JB, PC, MF and AY extracted data for analysis.

Data synthesis

The nature of qualitative data means that approaches to synthesis are needed that seek to “understand and transfer ideas, concepts and metaphors across different studies” (Britten et al. 2002, p. 210) with a view to generating novel understandings of the phenomenon (Britten et al., 2002, Strike and Posner, 1983, Thomas and Harden, 2008). We used a comparative thematic approach to synthesis (Marston and King, 2006, Thomas and Harden, 2008) with a number of features adopted from the literature on meta-ethnography (Britten et al., 2002, Noblit and Hare, 1988). This consisted of three stages: all text in primary studies labelled as ‘results’ or ‘findings’ was inductively coded line-by-line; descriptive themes were developed; and analytic themes were generated (Thomas and Harden, 2008).

During coding in the first stage, original text in each code was repeatedly re-examined in its original context, compared against other data and discussed to ensure consistency of interpretation and the adequacy of the emerging coding framework. Existing codes were refined and new codes were developed accordingly. Data on key aspects of study context, especially patient characteristics, were also extracted, re-visited and used to inform coding decisions. The second stage consisted of grouping related codes together to generate descriptive themes. In the third stage, visual mapping was used to visualize and explore the relationship of individual codes and groups of codes to one another, and the degree of each in being central or peripheral to understanding patient experiences. Analytic themes were hypothesized and then tested using the descriptive coding framework. 'Checking back' to the original data and its context continued throughout this final stage.

'Results' or 'findings' text from studies added from the updated searches was not treated entirely inductively. Inductively derived codes were instead mapped, where there was a fit, against the three core relational care themes generated in the original review ("creating communities: connect with me", "maintaining identity: see who I am" and "sharing decision-making: include me") (Bridges et al., 2010). Newly generated codes in each of these themes were then grouped and visually mapped against each other, while comparing across, adding to and further refining the analytic themes generated during the original review. We actively sought out data that did not fit the original themes with the intention of developing new analytic themes as necessary.

Results

This review was aimed at understanding older people's experiences of acute in-patient care in general hospital settings. Most of the primary studies included were single-site (n=38 studies), interview (n=54) studies conducted on older people's experiences of acute hospital care. The countries where studies were carried out are shown in Table 1. Other study and sample characteristics are shown in [web-based] Tables 2 and 3. To improve readability of the findings below, we have not cited all the relevant studies for each knowledge claim. Instead, we cite illustrative examples of more recent contributing studies.

Table 1: Countries in which primary studies were conducted

Country	Number
UK	19
USA	7
Sweden	9
Australia	4
Denmark	2
Norway	2
Finland	1
Greece	1
Switzerland	1
The Netherlands	1
Brazil	1
New Zealand	1
Taiwan	1
Not specified	11

The findings provide an in-depth understanding of older people's experiences of care in acute hospital settings. As illustrated below, a great deal about the hospital setting and the organisation of care positioned people in a patient role as powerless to influence the care they received. Highly negative experiences would result if these aspects of context were not mediated by individualised relational work by staff, and by nursing staff in particular.

The quality of technical medical care appeared to be taken for granted by people in receipt of care and rarely attracted comment (Lyons and Paterson, 2009, Nyborg et al., 2016). People commented more often on aspects of experiences and care mediated through interpersonal relationships with staff, usually nursing staff, referred to hereafter as relational care. People expressed concerns about the delivery of fundamental nursing care, perceiving their personal needs as in tension with ward routines and the busyness of nursing staff (Cheah and Presnell, 2011, Nyborg et al., 2016). Findings suggest that admission to hospital often engendered overwhelming feelings of fear, vulnerability, worthlessness, powerlessness and alienation (Bridges and Nugus, 2010, Cheah and Presnell, 2011, Cowdell, 2010, Koskenniemi et al., 2013). Some groups were at particular risk of negative experiences. These were people with dementia and/or delirium; people with difficulty communicating, hearing or understanding; people from ethnic minority groups, especially where there was a language difference; people with low functional/physical ability; people with low literacy; and people without regular visitors and/or family support (Chang et al., 2012, Cowdell, 2010, Ekdahl et al., 2010, Funk et al., 2018, Porock et al., 2015, Stenwall et al., 2008). Old age

appeared to heighten the risk of a negative experience (Bridges and Nugus, 2010, Koskenniemi et al., 2013).

People consistently reflected that the relationships they had with staff, often nursing staff, mediated negative experiences with three features of relational care linked to more positive experiences: “maintaining identity: see who I am”, “building relationships: connect with me”, and “partnering in care: involve me”.

Table 4 illustrates how individual review items contributed to the development of these three relational care themes.

Table 4: Contribution of individual review items to final themes

	See who I am	Connect with me	Involve me		See who I am	Connect with me	Involve me
Study				Study			
(Andersson et al., 2002)	X	X	√	(Li, 2005, Li, 2005, Li et al., 2000)	√	√	√
(Andersson et al., 2011)	√	√	√	(Littlechild and Glasby, 2001)	X	√	√
(Archibald, 2003)	X	X	√	(Lyons and Paterson, 2009)	X	√	√
(Berg et al., 2006)	√	√	√	(Lyytinen et al., 2002)	√	√	√
(Bergh et al., 2005)	X	X	X	(Maben et al., 2012)	√	X	X
(Boltz et al., 2010)	√	√	√	(McCurren and Cronin, 2003)	√	√	√
(Bridges, 2008, Bridges et al., 2010)	√	√	√	(Neville, 2006)	√	√	√
(Brooks Carthon et al., 2017)	√	√	√	(Norman, 2006, Norman, 2003)	√	√	√
(Brown et al., 2007)	√	X	√	(Nyborg et al., 2016)	√	X	√
(Carretta et al., 2013)	√	X	√	(Nyden et al., 2003)	√	√	√
(Chang et al., 2012)	√	√	√	(Pennbrant et al., 2013)	√	√	√
(Cheah and Presnell, 2011)	√	√	√	(Persson and Määttä, 2012)	√	√	√
(Costello, 2001)	X	X	√	(Petry et al., 2019)	√	√	√
(Cowdell, 2010)	√	√	√	(Policy Research Institute on and Ethnicity, 2001)	√	√	√
(Coyle and Williams, 2001)	√	√	√	(Porock et al., 2015)	√	√	X
(Davies et al., 1999)	√	√	√	(Raftopoulos, 2005)	√	√	√
(Digby and Bloomer, 2014)	√	√	X	(Randers and Mattiasson, 2000)	√	√	√
(Douglas and Douglas, 2004)	√	√	√	(Richardson et al., 2007)	X	√	√
(Duppils and Wikblad, 2007)	X	√	√	(Satterly et al., 2000)	√	X	√
(Ek Dahl et al., 2010)	X	√	√	(Shankar et al., 2014)	√	√	√
(Eckhardt et al., 2005)	√	√	√	(Spilsbury et al., 1999)	√	√	√
(Ekman et al., 1999)	X	√	√	(Stenwall et al., 2008)	√	√	X
(Fagerberg and Jonhagen, 2002)	√	√	√	(Strandberg et al., 2002)	√	√	√
(Funk et al., 2018)	X	√	√	(Tadd et al., 2012)	√	√	√
(Gallagher and Seedhouse, 2002)	√	√	X	(Tauber-Gilmore et al., 2018)	√	√	X
(Hancock et al., 2003)	√	√	√	(Tolson et al., 1999)	√	√	√
(Hines, 2000)	√	√	√	(Uhrenfeldt and Høybye, 2014)	X	√	X
(Huckstadt, 2002)	√	√	√	(Uhrenfeldt and Høybye, 2015)	√	√	X
(Jacelon, 2003, Jacelon, 2004, Jacelon, 2004)	√	√	√	(van der Meide et al., 2015)	√	X	√
(Koskenniemi et al., 2013)	√	√	√	(Watson et al., 1999)	√	√	√
(Latimer, 1999)	√	√	√	(Willman, 1999)	X	√	√

Maintaining identity: see who I am

The process of becoming an in-patient led to loss of identity for many people. Negative experiences were linked to being treated solely as a patient, rather than as a unique person with individual perceptions, experiences and expectations. Older people reported processes that depersonalised them, their transformation into the patient role marked by a lack of attention paid to who they were as individual people. Some people felt that this lack of attention was exacerbated by their lower societal status due to their age, in addition to other threats to their personhood such as a dementia diagnosis (Bridges and Nugus, 2010, Koskenniemi et al., 2013, Porock et al., 2015).

“They seemed awfully rushed and so they didn’t really have time to I don’t think to look at you, and to take the time to see if you was okay” (Tadd et al. 2012 p.35)

“They (the nurses) have to consider that not all older people are forgetful . . . Older people need also information and they understand it!” (Koskennieme et al. 2012, p.10)

“[Anna] talked about how this made her feel like an object that the staff pushed forward following their own professional aims rather than accepting her present feelings of being unable to increase her mobility” (Uhrenfeldt & Høybye 2015, p.4)

The most negative experiences were associated with people being “done to” rather than “cared for”, painting a powerful picture of patients being processed on

a production line, feeling as if staff viewed them as objects of work with no active agency of their own.

“Sometimes people talk to you; and some just don’t, they’ll go ahead and do what they’re supposed to do and go on back to business”. (Brooks Carthon et al. 2017, p.568)

“In the end, I feel like I’m being moved around like a parcel, I’m being moved like a parcel from chair to commode to bed. I feel like a parcel and not a person anymore” (Maben et al. 2012, p.90).

People also highlighted that individual needs related to personal routines, or preferences for timing of care, often differed from the set schedules of ward work meaning that these needs could not be accommodated (Cheah and Presnell, 2011, Koskenniemi et al., 2013, Nyborg et al., 2016).

“No, I haven’t said anything. I was never asked. They don’t ask me that much about how I want things – they’ve got their schedule, after all. You know, they have their meal times and their routines and that, and we just have to go with it” (Nyborg et al. 2016, p.6).

In addition to the stress of resulting care delays or care being available before it was needed, this lack of responsiveness also meant that daily activities did not have the same meaning as at home, potentially leading to further erosion of identity (Brooks Carthon et al., 2017, Cheah and Presnell, 2011).

“When you’re home...you’re able to do more. I go walking in a lovely environment which I get a lot of enjoyment from. Whereas

walking here, you're just walking to get the exercise and build up your fitness" (Cheah & Presnell, 2011, p.123).

Depersonalised care was a significant threat to people's identity. People in receipt of care felt alienation and a diminished sense of personal significance, and felt that they did not matter to the staff (Bridges and Nugus, 2010, Brooks Carthon et al., 2017).

"At the hospital, they do to us whatever they want, our life is nothing. We have to accept, because we depend on others and still more in this moment of weakness and frailty because of the illness" (Carretta et al. 2013, p.335).

This meant that they held back from sharing their concerns because they did not think they would be listened to (Brooks Carthon et al., 2017, Nyborg et al., 2016, Pennbrant et al., 2013). Helpful interventions identified included staff getting to know individuals and what was important to them; as well as protecting people's privacy, personal space and belongings. It helped when staff showed that they understood people's experiences in the context of who they were, their life and roles outside of hospital and how that interacted with what was happening to them in the hospital (Cheah and Presnell, 2011, Pennbrant et al., 2013).

People's accounts reflected that nursing staff had a core role in maintaining identity, more significant than other staff groups.

"They recognized me immediately (from a previous hospitalization) and were very kind, they did what they could for me" (Petry et al. 2018, p.48)

“It feels good when a nurse’s gestures and expressions are friendly. Words are not so important . . . what is seen in a human being is more important” (Koskenniemi et al. 2012, p.8).

Building relationships: connect with me

For people in receipt of care, a ‘connected’ relationship with nursing staff in particular provided reassurance that staff recognised and would meet all their needs for treatment and care, and that they were safe, legitimate as a patient in receipt of acute care and significant as a human being that matters to others.

Nursing attention to fundamental care needs was of key importance to people in hospital. Negative experiences related to a fear that it would be delayed or not delivered at all, and this fear could be ameliorated through relational care by nurses. Pain relief, being helped to use the toilet, exercise, bathing, eating and drinking all featured in people’s accounts of their experiences (Brooks Carthon et al., 2017, Chang et al., 2012, Koskenniemi et al., 2013, Maben et al., 2012, Porock et al., 2015, Shankar et al., 2014).

“I was having a problem with constipation and they give me something like to help me go to the bathroom, and I had asked for a commode. And they took their time about giving me that” (Brooks Carthon et al. 2017, p.566)

“You know it boils down to strong basic nursing care, nurses who care about the patient. I felt stronger, better when someone helped me get comfortable, get rest and get food that I could eat and enjoy somewhat” (Boltz et al. 2010, p.384)

People wanted to retain their independence in daily living activities when possible, concerned to return to their homes as independent as they were before admission and this desire underlay some of the concerns about the delivery of fundamental care (Boltz et al., 2010, Cheah and Presnell, 2011).

“I didn’t realize this until now, but there should be more attention paid by nurses to help people walk and take care of themselves. The doctors don’t focus on this. The physical therapist is only with you a short time. The nurses are with the patient and can see how the patient is progressing. I did have a nurse who would say, ‘I’ll help you walk to the bathroom. You won’t use a urinal at home.’ It was an inconvenience but he (the nurse) was doing the right thing” (Boltz et al. 2010, p.385).

People worried that the lack of attention to their personal routine and to maintaining their personal skills in activities would lead to a greater dependence on others after discharge.

Maintaining connections with family and social networks helped people feel supported and connected, especially where dementia, delirium and/or communication difficulties were present.

“My son came to visit as soon as he got the message . . . I felt really good about it” (Koskenniemi et al. 2012, p.11)

“Patient: - Some [encounters with a relative] are so nice I forgot about it, for a while. It is always so nice with kindness.

Interviewer: What do you forget: - What do you forget?

Patient: - That I am acute confused. I think my thoughts are so clear then...” (Stenwall et al. 2008, p.1582).

Negative experiences were linked to fears of care not being delivered or to staff not showing empathy for the individual situation, or missing opportunities for meaningful communication (Brooks Carthon et al., 2017, Shankar et al., 2014, Uhrenfeldt and Høybye, 2015, Uhrenfeldt and Høybye, 2014). Fearfulness and frustration were commonly reported emotions in these situations.

People valued attentiveness from staff, finding it helpful when staff showed that they accepted their needs as legitimate and offered timely, personalised help (Brooks Carthon et al., 2017, Koskenniemi et al., 2013, Petry et al., 2019).

Helpful interventions by staff were words, expressions and actions that promoted people feeling listened to and cared for, respected and welcome, and feeling that help would be given when it was needed (Koskenniemi et al., 2013, Petry et al., 2019). Kindness, approachability, attentiveness, responsiveness and warmth were all cited as being of importance (Bridges and Nugus, 2010, Brooks Carthon et al., 2017, Koskenniemi et al., 2013, Pennbrant et al., 2013).

“She came and gave me my medication. When I asked for medication for pain, about ten minutes she came right back to the room with it. And she talked to me and joked around with me, stuff like that, you know, tried to make me feel better”. (Brooks Carthon et al. 2017, p.566).

Partnering in care: involve me

While preferences for formal involvement in treatment and care decisions varied (Cheah and Presnell, 2011, Social Care Institute for Excellence, 2006), findings across the individual studies reflected a consistent desire to understand what

was happening and what was planned (Brooks Carthon et al., 2017, Cheah and Presnell, 2011, Nyborg et al., 2016). This understanding served to lessen anxiety.

“Older people need also information and they understand it! I need information and I want to know!” (Koskenniemi et al. 2012, p.10).

It was clear from many studies that this minimal expectation was not met in many cases. Many people in a patient role reflected that they held very little power compared to staff and it was therefore impossible for them to get the information that they needed without staff allowing this to happen (Cheah and Presnell, 2011, Nyborg et al., 2016, Pennbrant et al., 2013). Staff groups commonly mentioned in relation to this theme were medical and nursing staff, although people often referred to the “staff” or “caregivers” without specifying which professional group they were referring to.

“One cannot talk with the doctor because the doctors seem to be short on time ... they steer the discussion and one feels one shouldn't ask questions” (Pennbrant et al. 2012, p.172)

People with cognitive impairment, hearing difficulties or language differences were at particular risk of not understanding what was happening:

“It's disturbing, because needless to say I want to know what's being discussed...I just lose interest after a while if I don't follow what's going on” (Funk et al. 2018, p.31)

Findings reflected that older people experienced an overwhelming sense of powerlessness when in hospital and this strongly influenced decisions about

asking for information or for help outside of scheduled care opportunities.

Particular influencing factors were the fast pace at which staff were perceived to go about their work, and the time-based scheduling of care activities, but in many accounts, everything that happened to them on the ward served to undermine their sense of significance, and thus their ability to control what happened. This included the attitudes of individual staff members.

“I asked the nurse to help me to the toilet (for defecation), but she said, ‘You were there just yesterday’...” (Koskenniemi et al. 2012, p.10)

“I asked “How many tests are you taking?” “I’ll take as many as I want,” [the doctor] said.” (Pennbrant et al. 2012, p.172)

People reported staff moving swiftly about the ward and limiting the time they spent with individual patients. Some staff appeared to deliberately avoid interaction with people in a patient role.

“They [doctors] often sweep in with a little entourage and then they – they pontificate and then they sweep out again (laughs)...before you can ask a question” (Cheah & Presnell 2011, p.125)

“I asked for the bed pan, because I was so exhausted ... A girl [health care assistant] came in, turned off the buzzer and said ‘We are doing handover; no one can help you now” (Tauber-Gilmore et al. 2018, p.227)

“When you call them (nurses), they come, handle the task quickly and go away again very soon afterwards...I wonder why

*they do not look more carefully for the reason for the call”
(Koskenniemi et al. 2012, p.9)*

“People never look and they never speak” (Cowdell 2010, p.87).

These reports were often underpinned by a sense that there were not enough nursing staff for the amount of work that needed to be done (Persson and Määttä, 2012, Porock et al., 2015).

*“I suppose I’d really like to be more involved, but I can see how [the nurses] run from one bed to the next, and after all, I’m not the only person here! There are hundreds of other people”
(Nyborg et al. 2016, p.5)*

As mentioned earlier, people in receipt of care highlighted that individual needs related to personal routines, or preferences for timing of care, often differed from the set schedules of ward work and this meant that these needs could not be accommodated in a timely way (Cheah and Presnell, 2011, Koskenniemi et al., 2013, Nyborg et al., 2016, Porock et al., 2015).

*“I have medicines which I have to take at different times of day.
At first it was very difficult to make the nurses understand that
the timing of these medicines is very important. The hospital has
its own rules” (Koskenniemi et al. 2012, p.10)*

Because of the mismatch between individual needs and ward schedules, waiting for care was a commonly reported phenomenon that served to intensify feelings of powerlessness (Cheah and Presnell, 2011, Koskenniemi et al., 2013, Shankar et al., 2014). People rationalised their waits with reference to how busy the staff were and subjugated their needs to those of other patients.

“When I asked for a painkiller, the nurse said, ‘You’ll get it when it’s your turn’.” (Koskennieme et al. 2012, p.10)

People felt unable to ask for what they want or to be seen as criticising care. They perceived themselves as of lowest significance in the hierarchy of the ward. They did not wish to be seen as difficult or demanding, some fearing this would impact negatively on their care. They felt that they had to work to be liked by staff because that would improve their chances of better care (Maben et al., 2012, Nyborg et al., 2016, Persson and Määttä, 2012, Petry et al., 2019).

“I don’t dare criticize. It might result in worse care” (Persson and Määttä 2012, p.666)

“It’s not to ingratiate myself, but it’s really important that the people who work here have a good working environment. Really important. And then we strike up a relationship. For of course, that makes them notice me in return” (Nyborg et al. 2016, p.7)

In response to their observations, experiences and diminished sense of personal significance, people in a patient role subjugated their personal needs, judging that the nurses and other staff had enough to do, and that their personal needs were not as important as those of other patients (Brooks Carthon et al., 2017, Nyborg et al., 2016).

“But they must be with someone who is more ill or that they have to treat” (Andersson et al. 2011, p.648)

People in a patient role were highly vigilant, paying close attention to staff workload, behaviour and mood (Maben et al., 2012, Nyborg et al., 2016, Persson and Määttä, 2012, Petry et al., 2019). They actively prioritised which needs to

bring to staff's attention and used their observations of staff capacity to inform decisions about whether to ask for help or not.

“Before Patient K (female, 71) started a conversation with the nurses and the staff, she would need to make sure that the person she was talking to was receptive. She sensed and tested the ground and “wait until they’re not feeling stressed”” (Nyborg et al. 2016, pp.6-7)

It also seemed common for people in receipt of care to actively choose to withhold information from staff.

“I usually don’t tell staff that I have hearing loss unless they ask me about it. Sometimes I do, and other times I just figure – why bother? They don’t really care” (Funk et al. 2018, p.31)

“No, I haven’t said anything. I was never asked. They don’t ask me that much about how I want things – they’ve got their schedule, after all. You know, they have their meal times and their routines and that, and we just have to go with it” (Nyborg et al. 2016, p.6)

“He [doctor] didn’t listen ... I didn’t tell him everything because he wouldn’t listen to me anyway ... What is the point when they do not care about me anyway ... about my knowledge about my own body.” (Pennbrant et al. 2012, p.171)

People accepted the imposition of powerlessness, deferring to the need for hospitalisation and recovery (Cheah and Presnell, 2011, Ekdahl et al., 2010).

“Int: When you were in hospital, did you participate in your care and treatment?”

Pat: My treatment? No, they do what they think they have to do. What they think is the best for me at just that time” (Ekdahl et al. 2010, p.237)

Some accounts reflected that some people preferred, because of their advanced age and feeling very ill, to share or delegate decision-making to their relatives (Ekdahl et al., 2010, Nyborg et al., 2016, Pennbrant et al., 2013).

“Then my daughter phoned the doctor and said that she didn’t want to lose her mother...(voice wavers) and then she said that if you are not going to operate on my mum tonight, she will be moved to my home town and operated on there! You see, when a person, an old person, falls ill, they can’t express those feelings themselves; they just stay quiet. And they can’t actively participate or ask questions about what they are going to do, how they will do it and who will do it. It is a simple fact that people, when we’re old, we just can’t do it” (Koskenniemi et al. 2012, p. 11)

A sense of powerlessness over what was happening and feelings of not being significant were prevalent in the studies reviewed, suggesting they are common experiences for older people in hospital. As a result, people did not ask for the help that they needed or share relevant information with staff, thus reinforcing their lack of control. However, the data also reflect that if individual members of staff act to make people feel significant (“see who I am”) and sufficiently secure (“connect with me”) to voice the help that they need, then participation could improve.

““If you are worried [and] people chat to you quite matter of factly and normally, it makes you relax. Even just wee remarks as they

go past make you feel a bit better, a bit calmer” (Lyons & Paterson 2009, p.27).

““They are very communicative and very //Older person: yes open// and empathetic – that surprised me positively. They certainly have enough patients and it is an acute care hospital. I was surprised //Older person: Yes, not just a number// No, no, and they explained things, if you received a new medication, the physician first talked to you, very much on eye-level (family member / older person)”. (Petry et al. 2018, p.47)

These findings reflect that participation in decision-making needs to be individually and carefully negotiated with people. This included staff understanding each person’s expectations and wishes about their health and what will happen to them, and valuing what expertise they and their family have. Helpful interventions included providing information in a way that responds to individual needs such as cognitive impairment or communication difficulties. However, findings also point to the role that staff have in using relational care to mediate the organisational signals that position patients as not significant. Findings reflect that feelings of powerlessness and insignificance can be lessened if individual staff can act to build and maintain connections with individual people in receipt of care, providing a medium through which people feel able to participate.

Discussion

This review and synthesis aimed to understand older people’s experiences of acute in-patient care in general hospital settings. Much of the research reviewed suggests that care experiences are often negative with people feeling unable to

ask for the help that they need or to share information that could shape their care and treatment plan. These constraints on patient participation may explain, in part, poor outcomes resulting from unrecognised and unmet fundamental care needs. The review findings highlight the importance of relationships with staff, particularly nursing staff, in shaping individual experiences of acute care, and the role that staff have in reinforcing or lessening the impact of powerful institutional drivers on care and experiences.

Many people painted a picture of being a patient as being a passive observer, waiting for depersonalised care to be delivered by the clock of the ward routine. Care preferences or individual requirements were felt to be disregarded.

Fundamental care was delayed or missing. People felt that they were losing their personal skills and ability to manage independently. They perceived that their personal needs were in tension with ward routines and the busyness of nursing staff.

When staff did not use relational care to maintain patient identity, people felt alienated, unimportant, and dehumanised. They felt like objects of work at the hands of staff. When staff did not establish a human connection with them, people felt insignificant and fearful that their care needs would not be met.

However if staff helped people to feel significant and secure, experiences improved markedly and improved the capacity of individuals to voice their needs and ask for help. These findings throw important light on the mechanisms behind poor outcomes for older people of a hospital stay (Fogg et al., 2017, Gill et al.,

2011, Gill et al., 2015), and illustrate the importance of relational care to delivering the individualised care needed to promote and maintain health.

Our findings suggest that older people in a patient role may be subject to stigmatisation or discrimination, perhaps because of their role as patients, but perhaps also because of their old age and other stigmatizing characteristics such as cognitive impairment or frailty. This discrimination may not be conscious or overt on the part of staff, although the findings suggest that some people felt that they were treated differently because of their old age, and the accounts of being ignored or spoken to sharply reflect treatment of the patient as if they were of lower social standing. These perceptions by staff, and the self-subjugating behaviours of patients may be rooted (consciously or unconsciously) in perceptions about the attributes of old age.

Goffman's classic work on stigma (Goffman, 1963), draws attention to the human tendency to accord a lesser social status to people with undesirable attributes that signal a difference from others. In societies that assign primacy to human youth, vitality and bodies and minds that are not impaired, people who are of older age and living with multimorbidity including cognitive impairment may be seen as "not quite human" (Goffman, 1963, p.15), because they possess multiple, visible attributes that may discredit them in the eyes of others.

Assigning them the status of patient may discredit them further because of the dependency on others that patient-hood implies in a world that values autonomous living (Durocher et al., 2015, Mackenzie and Stoljar, 2000, Sherwin and Winsby, 2011). Goffman also draws attention to the concerns that the

stigmatized individual may have about the way they will be treated by others. If when they come into hospital, older people think that they might be discredited, they may feel the need to employ strategies to minimise the effect of this on their care. Goffman's work suggests that people in this situation work hard to present themselves in an acceptable way, to minimise the possibility that their words and actions will be misinterpreted by others. He notes that, in anticipation of the way they will be treated because of their discrediting attributes, people may respond by "defensive cowering" (Goffman, 1963, p. 28). Our findings about patients subjugating their own needs and not asking for help resonate strongly with Goffman's theory and point towards the active role that frontline staff need to play, through relational care, to overcome the shame and fear that may arise from being a hospital patient. "See who I am", "connect with me" and "involve me" are messages that guide practitioners in working in this way.

Our findings reveal other factors beyond the control of frontline staff that can impact on people's capacity to be partners in their care. Current health policy, for instance in the UK, promotes person-centred health care, the importance of shared decision-making between professionals and patients, and the value of care that is designed around what matters to that individual, particularly in older age (NHS England, 2019, World Health Organization, 2015). In contrast, these findings reflect that the characteristics of the hospital setting and the organisation of care commonly position people in a patient role as utterly powerless to influence the care that they receive, and sometimes frightened at the prospect of doing so. Disempowerment and feelings of insignificance were triggered by

unhelpful staff responses to expressed need but also by other signals including the visible spectacle of staff moving about swiftly, the knowledge of time-based scheduling of staff-patient interactions, the impression that staff were limiting their time with individual people, and the experience of waiting for care. Our findings that staff can mediate these institutional signals through their relational work are important, but attention also needs to be paid to other elements of hospital context that may need to change to alter the unintended signals sent to patients.

Turning again to the work of Erving Goffman, our findings resonate with the characteristics of total institutions (Goffman, 1961):

“First, all aspects of life are conducted in the same place and under the same single authority. Second, each phase of the member’s daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, all phases of the day’s activities are tightly scheduled, with one activity leading at a prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials” (Goffman, 1961, p.17).

Our findings on the perceived precedence of the routine over the actual needs and preferences of individual patients indicate that the “bureaucratic organization of whole blocks of people” (Goffman, 1961, p.18) is how older people may be experiencing their care in hospital. The more complex their needs by way of, for instance frailty, multimorbidity or dementia, the less likely it is that a routinised approach to care will meet their needs and the more likely it is that poor

experiences and health outcomes will result. The findings throw light on the social processes that may exclude people in a patient role from participating in decisions about their care, the effect of which could only be mitigated by the involvement of an advocate who demonstrates care and attention, either a family member or a member of nursing staff who demonstrates responsiveness to that individual's needs and concerns. Professional discourse and health policy need to develop to better reflect the complexities of participation of older people in health care decisions, as the default assumption is of the active, empowered patient, able and willing to challenge poor care (Entwistle et al., 2012, Mol, 2008). Such discourse does not account for the experiences of people with cognitive impairment, or people experiencing direct or indirect discrimination, suggesting there may be relational challenges specific to these groups, which undermine the quality of their care and which require addressing directly. As suggested by the findings here, a focus on improving relational aspects of care with groups most likely to receive poor care would be a worthwhile endeavour, particularly focusing on challenging discrimination, carrying out meaningful mental capacity assessments and making adaptations to care to enable greater patient participation.

While the findings of this review indicate that people's experiences were often negative, there were also many examples of the positive impact that individual nurses had in helping people to feel significant, safe, connected and listened to. Importantly, however, while nurses and nursing undoubtedly have a key role in shaping experiences of acute care, these messages are not just for nurses,

grounded as they are in the experiences of older people in the social and physical environment of an acute hospital and shaped through interactions with a range of acute care staff.

It is clear is that an organisational and service-wide commitment is required to create the culture and context in which relational care can flourish. Health care practice of the kind indicated here as helpful involves engaging more explicitly with the emotional and often difficult nature of acute care work with older people, and practitioners will need appropriate staffing, space and support to work in this way. Adequate support includes the provision of staffing levels, skill mix and other resources that reflect the needs of the patient population, clinical supervision and space for staff reflection on their work with older people, the communication of recognition and valuing by others of the work of staff who work with older people and the development of participative, non-hierarchical strategies for change and service development (Bridges et al., 2019, Bridges et al., 2017, Bridges et al., 2013).

The aim of the search strategy for this review was to be comprehensive, although some decisions made for pragmatic reasons, such as the limitation to items written in English and the focus in the searches on published items, may have meant some relevant items were not identified. The inclusion of mainly interview-based studies may have excluded people with communication or cognitive difficulties, but we identified greater representation from these groups in the findings from the updated searches, suggesting that more recent research has been more inclusive and this is a welcome development.

Conclusion

Older people's care experiences in hospital may be negative in the absence of relational work by nurses to maintain people's identity, establish caring connections and ensure that individual patient needs, preferences and values are honoured in the care that is delivered. Relational care by nurses and other frontline staff can mediate powerful institutional drivers that may otherwise result in negative experiences and poor care. Organisational and service-wide commitment are needed to create the culture and context in which relational care can flourish.

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Conflict of interest

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