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**Citation:** Bridges, J., Flatley, M. & Meyer, J. (2010). Older people's and relatives' experiences in acute care settings: systematic review and synthesis of qualitative studies. *International Journal of Nursing Studies*, 47(1), pp. 89-107. doi: 10.1016/j.ijnurstu.2009.09.009

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**Link to published version:** <https://doi.org/10.1016/j.ijnurstu.2009.09.009>

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

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**Published in International Journal of Nursing Studies Vol.46(1), pp.89-107, January 2010.**

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

**Abstract**

Objective

To explore older people's and their relatives' views on and experiences of acute health care.

Design

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.

Data sources

Worldwide grey and published literature written in English between January 1999 and June 2008 identified from databases: CINAHL, Medline, British Nursing Index, EMBASE Psychiatry, International Bibliography of the Social Sciences, PsychINFO, and AgeInfo.

Review methods

We conducted a systematic review and synthesis of qualitative studies describing older patients' and/or their relatives' experiences of care in acute hospital settings. 42 primary studies and 1 systematic review met the inclusion criteria.

Results

A number of themes emerged. The quality of technical care is often taken for granted by older patients, and good or bad experiences are described more in terms of relational aspects of care. Older patients in hospital may feel worthless, fearful or not in control of what happens, especially if they have impaired cognition, or communication difficulties. Three key features of care consistently mediated these negative feelings and were linked to more positive experiences: "creating communities: connect with me", "maintaining identity: see who I am" and "sharing decision-making: include me".

## Conclusion

These findings highlight the perspectives of older people and their relatives on the delivery of personalized and dignified care in acute settings. They lend support to previous calls for relationship-centred approaches to care and provide a useful experience-based framework for practice for those involved in care for older people.

## **Key words**

Aged

Aged, 80 and over

Hospitals

Human dignity

Professional-patient relations

Qualitative research

## **What is already known**

Acute hospital admission can be a significant event for older people and their relatives, 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 patients, staff and relatives.

## **What this paper adds**

This review confirms that relationship-centred approaches to care underpin more positive experiences of acute health care for older patients and relatives. It reports that older patients'

and relatives' experiences in acute care are shaped by the nature of the relationships between staff, patients and relatives. Patients' and relatives' priorities for care are "creating communities: connect with me"; "maintaining identity: see who I am"; and "sharing decision-making: involve me". These messages provide an experience-based practice framework for nurses and others involved care for older people.

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

**Introduction**

The number of frail older people in receipt of acute care services is increasing as the population ages. For instance, in the UK, two thirds of acute hospital beds are occupied by people aged 65 years and over (Department of Health 2000). In many developed countries, including the UK, Australia and USA, health and social care service developments and reconfigurations have led to a shorter length of hospital stay, resulting in a frailer in-patient population with more complex needs. Recognition is growing that current models of acute hospital care may not adequately meet older people's needs (Cheek & Gibson 2003; Flatley & Bridges 2008), but what we know about patient experiences has largely relied on survey results and anecdotal evidence.

Satisfaction surveys highlight that older people tend to evaluate care differently to younger people, often more positively (Ahmad & Alasad 2004; Cohen 1996; Commission for Healthcare Audit and Inspection 2006). These relatively positive evaluations may be because older people's expectations of care are lower than those of younger adults (Owens & Batchelor 1996; Spilsbury, et al. 1999), so it is appropriate to use qualitative methodologies to better understand older people's experiences of acute care. While there are now an increasing number of qualitative studies providing such insight, a systematic overview of this work has not been previously conducted.

This paper presents the findings from a systematic review of qualitative research focused on older people's and their relatives' views on and experiences of acute care. The review was undertaken to underpin the revision of a national set of guidelines on the nursing care for older people in acute settings, previously published in 2001 alongside the National Service Framework

for Older People (Standing Nursing and Midwifery Advisory Committee 2001b; Standing Nursing and Midwifery Advisory Committee 2001a).

## **Methods**

The synthesis of qualitative studies is in relatively early development and no consensus is in place on its correct execution (Britten et al. 2002; Thomas & Harden 2008). Systematic procedures were used for study selection and data extraction and analysis (Moher et al. 2009). 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 & King 2006; Thomas & Harden 2008). This approach of induction and interpretation mirrored the qualitative methods of the studies within the synthesis (Britten et al. 2002). PRISMA guidelines have been used here to guide reporting and a flow diagram is shown in figure 1 (Moher et al. 2009). Organisation of the review and synthesis was managed through EPPI-Reviewer, an on-line software tool (Thomas & Brunton 2006). A protocol was used to guide the review and this is available from the authors on request.

*Insert Figure 1 about here*

## Searching

We identified papers for possible inclusion by combining searches of electronic databases, hand searches of references 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, PsychINFO, and AgeInfo. We used medical subject headings and freetext searches related to older people, acute health services and qualitative research (see example in Figure 2). As mentioned above, this review was conducted with the purpose of updating national UK guidelines published in 2001. The publication of these guidelines took place during a period of widespread service change in the UK National Health Service that followed a change of government in 1997 but had gathered in pace and intensity by the year 2000. To enable an appraisal of contemporary experiences in acute care, searches were therefore restricted to papers published in English between January 1999 and June 2008.



*Insert Figure 2 about here*

### 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' or relatives' self-reported experiences of care in an acute hospital setting. We also included studies that used other approaches to understanding patient experience, 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 1301 hits. These results were added to 8 items already known to the reviewers. Scanning the bibliographies of all retrieved items (including those subsequently excluded) led to 26 further relevant items being identified. Review of titles and abstracts, and removal of duplicates led to the retrieval of a total of 111 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 111 items were then read and the inclusion and exclusion criteria applied. 63 items were excluded at this stage and a final sample of 48 items was obtained for synthesis, between them reporting on 42 primary studies and one systematic review.

### Quality assessment

Each primary study was appraised using the Critical Appraisal Skills Programme criteria for evaluating qualitative research (Critical Appraisal Skills Programme (CASP) 2006) in addition to an evaluation of the degree to which they represented participants' views (Thomas & 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 & Harden 2008), and it was felt that even low quality studies may be able to contribute to the findings. Study quality assessments were, however, used in sensitivity analyses (below).

### Data extraction

A single researcher (JB) undertook study selection, data extraction and analysis using EPPI-Reviewer. A second researcher (MF) advised on the search strategy, and performed selected data extraction, analysis and synthesis.

### 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 & Posner 1983; Thomas & Harden 2008). We used a comparative thematic approach to synthesis (Marston & King 2006; Thomas & Harden 2008) with a number of features adopted from the literature on meta-ethnography. 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 & 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.

Preliminary findings were shared with three groups of older people, and other members of the research team. This strategic involvement of others was aimed at advancing alternative perspectives and enriching the analysis accordingly. One group of older people (n=15) that

included service users and relatives (n=15), was a London-based voluntary Age Concern group that met regularly to engage in health issues in a variety of ways, for instance, lobbying activity. The two other groups, one of men (n=14) and one of women (n=9), were users of a day care centre for Bangladeshi older people in inner London. At each meeting, people were encouraged to tell their stories of recent acute care experiences, and these stories were compared with emerging review themes following the meeting. The second half of each meeting consisted of presenting the emerging review themes to those present and inviting people to comment on them and discuss the extent to which these findings met their own experiences and perceptions.

### Sensitivity

Sensitivity analyses showed that findings are robust in the absence of low quality studies (n=9), suggesting that they contribute little to the findings. Sensitivity analyses also reflect a robustness of findings regardless of country or clinical setting. This lends weight to the generalisability claimed for the findings and subsequent recommendations.

## **Results**

Most of the primary studies included were single-site (n=29 studies) interview studies (n=37) conducted on older patients' (n=38 studies) and relatives' (n=17) experiences of in-patient hospital care. The countries where studies were carried out are shown in Table 1. Other study characteristics are shown in [web-based] tables 2 and 3.

*Insert Table 1 about here*

The findings provide an in-depth understanding of older patients' and their relatives experiences of care in acute hospital settings. The remainder of this paper presents the findings from the review that focus on the features of care that are important to older people and their relatives.

Findings shared here reflect that the quality of technical care is often taken for granted, while patients and relatives comment more often on aspects of experiences and care mediated through

interpersonal relationships between staff, patients and relatives, referred to hereafter as relational aspects. Findings reflect that while patients often trust that staff have the expertise to ascertain and deliver the right treatment and advice on the right discharge plan, the narratives of their experiences concentrate very little on the technical aspects of care and on making transitions such as discharge planning. Accounts instead focus on the relational aspects of their experience. Findings suggest that a visit to an acute care hospital potentially engenders significant feelings of fear, worthlessness and lack of autonomy. A range of experiences are described in the studies reviewed, but three key features of care consistently emerged that appear to mediate these negative feelings and are linked to more positive experiences: “creating communities: connect with me”, “maintaining identity: see who I am” and “sharing decision-making: include me”. Table 4 illustrates how individual review items contributed to the development of the themes presented below.

*Insert Table 4 about here*

#### Creating communities: connect with me

With a notable frequency, patients and relatives describe the relationships they had with staff and each other as the key feature of their acute care experience. For patients, a ‘connected’ and reciprocal relationship with staff 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. Maintaining connections with family and social networks also helped patients feel supported and connected, especially where the patient had dementia, delirium and/or communication difficulties.

*“I was very comfortable, very relaxed, because at home I’m afraid all the time...I’m scared of getting a heart attack on my own...while I was in hospital I was very relaxed because I knew that the doctors were there, I could see the nurses. There is all this help in the ward” (Patient in Davies et al. 1999, p. 12)*

Relatives too reflected a need to be part of this community, not only to ensure that the patient was safe, significant and had continuity through family contact and continuing their normal life as

much as possible; but also to have their own needs recognized and met. Relatives seemed at particular risk of not feeling that their expertise and contribution is either recognized or valued by staff.

*"When you go into hospital it is one of the most vulnerable times of your life. You walk in and you are terrified of everything and you listen to every burp and murmur that nurses give you. I suppose you pick up on every thing nurses tell you. It's the time when you need someone to be nice to you, a little bit of tender loving care I suppose"*  
(Relative in Douglas-Dunbar & Gardiner 2007, p. 29)

Helpful interventions by staff are those that promote patients and relatives feeling cared for, respected and welcome, feeling that help will be given when it is needed, having a reciprocal relationship with staff, and maintaining contact with each other. Studies reviewed reflected that the absence of these interventions heightened feelings of anxiety.

#### Maintaining identity: see who I am

The process of becoming an in-patient can lead to loss of identity for patients, particularly if they have dementia. Findings showed that older patients need to be able to remember and relate to important people, events and things, and staff knowing about their life context, such as family and occupation, can help with this. Older people also want to feel that staff know about and accept their individual needs.

*"I can't even explain what I mean...It just seemed like they [staff] took away everything. It was just like you were at everybody's mercy, and you didn't count...When I was good and sick, it didn't matter, I guess. Their word was law."* (Patient in Jacelon 2004b, p. 31)

Relatives' priorities focused on the need for what they knew about their loved one to be valued by staff and applied to the individual's care, and the role that some relatives had in carrying out care in hospital.

*"We have a routine that we do at home. And I'm trying to keep that routine going here, too, as far as his showers go. I know the extent he can do things for himself, you know, and things he can't do for himself. So that helps. One thing I've noticed. . .I think he's still afraid to wash himself down here [surgical incision], so I have to [wash it for him]. But otherwise, he does pretty good in the shower. I wash his back. And because of the chair that he's on, I'll wash his bottom too. But at home, he washes everything but his back himself. (Relative in Li 2005a, p. 99).*

Helpful interventions identified include staff getting to know individuals and what is important to them, as well as protecting patients' privacy, personal space and belongings. Studies reviewed reflected that the absence of these interventions served to threaten an individual's identity and sense of worth.

#### Sharing decision-making: include me

This feature of care relates to participation in decision-making, a key concept identified in the systematic review on experiences of discharge (Social Care Institute for Excellence 2006), but also reflected in many of the studies reviewed on in-patient care. Studies reflected that older people tend to take a non-participative stance in which they do not understand or are not involved in decisions about their care or discharge.

Not feeling in control of decisions made may be tolerable to some patients and this may be dependent on whether or not they anticipate a full recovery, and the degree to which they feel they can trust others to be in control. In contrast, especially when patients have dementia, relatives seem to prefer a more active role in decision-making. Some findings suggest that a lack of patient participation may be related to social standing, level of education and feelings of dependency on others. Feelings of not being in control may also be exacerbated for patients with dementia or delirium, and communication problems, including language differences can also interfere with patient involvement.

While a desire and/or ability to participate actively may vary, findings reflect that anxiety can be lessened if patients and relatives feel they understand what is happening and what is planned.

*"I have seen a change in the doctors...The doctor sat on bed and explained everything they were doing and showed me the computer that showed my eye and everything. They've come a lot further than the first time. This makes me feel not as frightened. They've come a long way and they explain what can happen and would happen"*  
(Patient in Bridges 2008, p. 18)

Findings also reflect, however, that relevant information is not always provided. For instance, one study reports that many patients and relatives were not informed when staff determined that death was imminent, while two studies report patients undergoing surgery with little or no information.

*"I know that something's up, I mean they used to be checking my blood pressure and temperature and taking blood samples and doing all sorts of tests. Now they do nothing and during the ward round they look at me and smile and say nowt, oh I know what's going on alright"* (Patient in Costello 2001, p.64)

Relatives can also feel excluded by staff from explanations and decision-making.

These findings reflect that participation in decision-making needs to be individually and carefully negotiated with patients and relatives. This will include understanding each patient's expectations and wishes about their health and what will happen to them, and valuing what expertise they and their family have. Helpful interventions also include providing information in a way that responds to individual needs such as cognitive impairment or communication difficulties. Findings reflect that the absence of these interventions can lead to anxiety and feelings of not being in control.

In summary, older people and their relatives value three key approaches to care, all of which are relational in nature.

## **Discussion**

This review's findings indicate that relational approaches to care may underpin more positive experiences of acute health care. They echo the findings of other work that acute hospital

admission can threaten older people's sense of identity and involvement (Coyle 1999;Dill 1995;Social Care Institute for Excellence 2006). The three key messages link with themes identified elsewhere that support quality of life in care home settings, suggesting that the findings are more widely transferable to care for older people across settings (Owen & NCH&DF 2006). The findings also lend robust support to previous calls for 'relationship-centred' approaches to care and the findings of primary studies (Nolan et al. 2006;Tresolini & Pew-Fetzer Task Force 2000). Importantly, they also provide patients' and relatives' perspectives on how this type of care could be delivered.

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 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.

At a practical level, these findings highlight the perspectives of older people and their relatives on the delivery of personalized and dignified care in acute settings. A relationship-centred approach to care rejects the "individual, disease oriented, subspecialty-focused model that has led to a focus on cure at all costs, resulting in care that is fragmented, episodic, and often unsatisfying for both patients and practitioners" (Tresolini & Pew-Fetzer Task Force 2000, p. 16). This requires that clinicians focus on inviting patients to communicate openly with them and to respond meaningfully to what they find out. "Connect with me", "see who I am" and "involve me" are messages that guide practitioners in working in this way.

In this review's first theme "creating communities: connect with me", the importance of continuity with existing relationships with family members is established, as is the importance of creating reciprocal relationships with staff members that provide primarily a sense of security, but that also enhance an individual's sense of significance, belonging and continuity in particular (Nolan et al. 2006). Nicholson's study on the experiences of people living with frailty reports the importance of sustaining existing connections with previously known worlds to establish assurance and



significance, while also creating new connections (Nicholson 2009). The review's findings highlight how an acute care episode necessitates the creation of new connections and that these, plus the maintenance of existing connections, provide the community through which enriched care can be delivered.

The second theme "maintaining identity: see who I am" establishes the importance of appreciating and sustaining each person's identity. Coyle (1999) reports how hospital care can result in personal identity threats that include perceptions of dehumanization, objectification, stereotyping, disempowerment and devaluing. A relationship-centred approach requires "attention to each person in all of his or her complexity" (Tresolini & Pew-Fetzer Task Force 2000, p. 24) and for the practitioner to understand the meaning of health and illness to the individual. The literature on dignity also highlights the importance of dignity-of-self (Jacobson 2007) or dignity of identity (Nordenfelt & Edgar 2005). The review's findings highlight that meaningful responses to the patient's and relative's identity and individual needs are a central component of a positive experience.

The third theme "sharing decision-making: involve me" highlights the importance of equity between individuals involved in the caregiving enterprise. Inequities in power between health care providers, patients and relatives are well documented and this review reinforces findings from elsewhere that involvement in decision-making is a complex area, dependent on a myriad of factors. Coyle (1999) usefully highlights a distinction between power being willingly 'given up' where the individual feels they have little knowledge or expertise, feels unable to control the outcome or views the situation as life-threatening, and power being 'taken away' which leads to feelings of vulnerability and not being in control. A relationship-centred approach values "the person's right to self-determination in the context of his or her life and relationships" (Tresolini & Pew-Fetzer Task Force 2000, p. 29) and the findings from this review illustrate the importance of an equitable relationship through which information is openly shared and meaningful participation can take place.

This review did not explore staff experiences in acute care settings and this is a missing “piece of the puzzle”. A relationship-centred approach includes ensuring the well-being of staff as well as that of patients and relatives. Health care practice of the kind proposed here involves engaging more explicitly with the emotional and often difficult nature of acute care work with older people, and practitioners will need appropriate space and support to work in this way. Adequate support may include the provision of clinical supervision and space for reflection on their work with older people and relatives, the communication of recognition and valuing by others of the work they do and the development of participative, non-hierarchical strategies for change and service development (Cotter 1998;Halton 1994;Zagier Roberts 1994).

It is probable that supporting staff, patients and relatives to engage in a relationship-centred way will lead to more rewarding engagement for all. However, shifting the focus of acute health care away from the technical, target-based model that currently dominates health care in the UK is a challenging goal (Bridges & Meyer 2007;Fitzgerald et al. 2006) and the nursing profession has a role in influencing this change of direction. In addition, other review findings not reported here highlight several features of the acute care environment that can make relationship-centred care difficult to achieve such as frequent patient moves, short length of stay and nursing shift patterns. What is clear is that an organizational and service-wide commitment is required to create the culture and context in which relationship-centred care can flourish. Findings indicate that patients and relatives want relationships that engender reciprocity, recognition, and involvement and this reflects recognition that they too have an active role in shaping their own and others’ experiences. However, how best to facilitate the involvement of patients and relatives in creating and maintaining this culture and context has yet to be established.

Aside from this wider context, however, it is clear from the findings of this review that the actions of individual practitioners can make a clear difference to the experiences of patients and relatives. The findings shared here have been used to underpin a series of best practice statements on acute care for older people that make explicit what relationship-centred care looks like for this client group and that explores how nurses can prepare themselves and identify support for engaging in practice of this kind (Bridges et al. 2009b;Bridges et al. 2009a). 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 and relatives and shaped through interactions with a range of acute care staff. It may also be that the findings do not just relate to acute care for older people, but to other aspects of health and social care, and further work is needed to establish this.

It is also apparent from the findings of the review that people with dementia, delirium and communication difficulties are at particular risk of negative experiences of care. More primary research on the experiences of these patient groups would be of great value given the high numbers of older people with these needs. Finally, the review identified just one study focusing on end-of-life care and this is an area that merits extensive further research.

## **Acknowledgements**

Funded by the Burdett Trust for Nursing

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