



The challenges of achieving person-centred care in acute hospitals: A qualitative study of people with dementia and their families[☆]



Philip Clissett^{a,*}, Davina Porock^b, Rowan H. Harwood^c, John R.F. Gladman^d

^a School of Nursing, Midwifery and Physiotherapy, University of Nottingham, Nottingham NG7 2UH, UK

^b School of Nursing, State University of New York, Buffalo, NY 14214, USA

^c Health Care for Older People, Nottingham University Hospitals NHS Trust, Queens Medical Centre, Nottingham NG7 2UH, UK

^d Division of Rehabilitation and Ageing, University of Nottingham, Nottingham NG7 2UH, UK

ARTICLE INFO

Article history:

Received 12 July 2012

Received in revised form 4 March 2013

Accepted 5 March 2013

Keywords:

Delirium
Dementia
Frail elderly
Hospitals
General
Nursing
Person-centred care
Qualitative research

ABSTRACT

Background: Person-centred care has been identified as the ideal approach to caring for people with dementia. Developed in relation to long stay settings, there are challenges to its implementation in acute settings. However, international policy indicates that acute care for people with dementia should be informed by the principles of person-centred care and interventions should be designed to sustain their personhood.

Objectives: Using Kitwood's five dimensions of personhood as an *a priori* framework, the aim of this paper was to explore the way in which current approaches to care in acute settings had the potential to enhance personhood in older adults with dementia.

Design: Data collected to explore the current experiences of people with dementia, family carers and co-patients (patients sharing the ward with people with mental health problems) during hospitalisation for acute illness were analysed using a dementia framework that described core elements of person centred care for people with dementia.

Settings: Recruitment was from two major hospitals within the East Midlands region of the UK, focusing on patients who were admitted to general medical, health care for older people, and orthopaedic wards.

Participants: Participants were people aged over 70 on the identified acute wards, identified through a screening process as having possible mental health problems. 34 patients and their relatives were recruited: this analysis focused on the 29 patients with cognitive impairment.

Method: The study involved 72 h of ward-based non-participant observations of care complemented by 30 formal interviews after discharge concerning the experiences of the 29 patients with cognitive impairment. Analysis used the five domains of Kitwood's model of personhood as an *a priori* framework: identity, inclusion, attachment, comfort and occupation.

Results: While there were examples of good practice, health care professionals in acute settings were not grasping all opportunities to sustain personhood for people with dementia.

Conclusions: There is a need for the concept of person-centred care to be valued at the level of both the individual and the organisation/team for people with dementia to have appropriate care in acute settings.

© 2013 Elsevier Ltd. All rights reserved.

[☆] This project was funded by the National Institute for Health Research Health Services and Delivery Research Programme (project number 08/1809/227). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR Programme, NIHR, NHS or the Department of Health.

* Corresponding author.

E-mail address: philip.clissett@nottingham.ac.uk (P. Clissett).

What is already known about the topic?

- Person-centred care is widely recognised as the ideal approach for caring for people with dementia.
- There is a high prevalence of co-morbid mental health problems among older adults admitted to acute hospitals.
- Acute hospital settings struggle to provide care that values personhood and is person-centred.

What the paper adds

- This paper offers insight into the extent to which current practice regarding care for the person-with-dementia in acute settings is person-centred.
- This paper suggests ways in which care could be more person-centred for people with dementia in acute hospitals.
- This paper highlights the ways in which the philosophy behind person-centred care could transform individual actions to recognise a sense of personhood in the acute hospital setting.

1. Background

The work initiated by [Kitwood and Bredin \(1991\)](#) and developed by others such as [Brooker \(2003\)](#) about person-centred care has had a significant impact on the way many care settings approach their work with people with dementia. [Kitwood \(1997\)](#) in particular challenged the prevailing attitude to working with people with dementia, proposing that the experiences and actions of the person-with-dementia are affected by more than just the disease process. Instead, the dementia experience is the combination of: the stage of neurological impairment; their personal health and fitness level; their personal biography/life history; their personality and coping style; and the social psychology of the environment in which they live. Where there is a negative interplay between neurological and sociopsychological factors, these combine to deny the person-with-dementia a sense of personhood. This occurs as a result of care practices such as infantilisation, intimidation, stigmatisation and objectification which create the 'malignant social psychology' where the individual is depersonalised, invalidated and treated as an object.

The goal of person-centred approaches to care is to respect personhood despite cognitive impairment ([Skaalvik et al., 2010](#)). Where the personhood of the individual is recognised and valued, the person-with-dementia is awarded standing and status as a respected and valued social being ([Kitwood, 1997](#)). A key feature of settings where people-with-dementia have their personhood recognised is that they experience a sense of attachment, inclusion, identity, occupation and comfort ([Brooker, 2007](#), p. 95, see [Box 1](#)). This approach to the care of the person-with-dementia takes time to develop and is usually most easily achieved through consistent longer term relationships with caregivers.

In the UK, the [National Institute for Health and Clinical Excellence \(2006\)](#) embraced the principles of

Box 1. Conceptual definitions of the domains of personhood

Concept

Attachment

Attachment relates to bonding, connection, nurture, trust and security in relationships.

Inclusion

Inclusion is about being in or being brought into the social world either physically or verbally and making them feel part of the group.

Identity

Identity relates to the need to know who you are and having a sense of continuity with the past. It is about having a life story that is held and maintained either by the person-with-dementia or for them by others.

Occupation

Occupation relates to being involved in activity that is personally meaningful; a sense of agency and having control to make things happen.

Comfort

Comfort is about the provision of tenderness, closeness and soothing and is provided through physical touch, comforting words and gestures. Comfort also includes physical comfort with one's body and a pleasant environment.

Adapted from [Brooker \(2007\)](#), pp. 82–100.

person-centred care and instructed acute NHS Trusts to provide services that 'address the personal and social care needs and the mental and physical health of people-with-dementia who use acute hospital facilities for any reason' ([NICE, 2006, p. 11](#)). This was reinforced in the [National Dementia Strategy \(2009\)](#). A similar focus on person-centred care is demonstrated by its prominence in networks to promote excellence in dementia care in other countries, for example the Canadian Dementia Knowledge Transfer Network ([Canadian Dementia Resource and Knowledge Exchange, 2013](#); [Dalhousie University, 2012](#)). However, although much work has considered person-centred care in long term settings, relatively little has focused on acute hospitals. This is important because there are factors in acute hospitals that might be expected to make the delivery of person-centred care problematic because the priorities are rapid diagnosis and therapeutic intervention with short lengths of stay. As part of a wider study ([Gladman et al., 2012a,b](#)), this paper reports data focusing on the person-with-dementia using the five domains of Kitwood's model of personhood as an *a priori* framework for analysis with the aim of exploring the way in which current approaches to care in acute settings have potential to enhance personhood in older adults with dementia.

2. Methodology

The main study aimed to provide an in-depth qualitative view of the current experiences of patients, family carers and co-patients (patients sharing the ward with people with mental health problems) during hospitalisation for acute illness.

Recruitment was from two major hospitals which were part of one NHS Trust within the East Midlands region of the UK. Participants were patients admitted to general medical, health care for older people and orthopaedic wards, aged over 70, who had been screened as having a possible mental health problems (using brief tests of cognition, depression, alcohol misuse and a question asking if there was any other reason to believe a mental health diagnosis might be present), and had been recruited to the Medical Crises in Older People “Better Mental Health” (MCOP-BMH) cohort study (Goldberg et al., 2012). Patients were admitted with a variety of acute medical and functional problems, or fractures. Recruitment covered a total of 12 months. Of the 250 recruited to the MCOP-BMH study, 34 were recruited into an in-depth qualitative study: this analysis concerns the 29/34 people in the in-depth qualitative study with dementia or delirium.

The mean age of the 29 participants was 88 (range 70–99); 15 (52%) were female; 18 (62%) were widowed, 8 (27%) were married, 1 had never married, and 2 (7%) were divorced. Fifteen had previously lived alone, of whom 5 returned, 8 were discharged to a care home, and 2 died (a carer was interviewed). Nine had previously lived with family, of whom 3 returned, 4 went to a care home, and 2 died. Five had previously lived in a care home, three died in hospital, the rest returned. Four patients died between discharge and the time of the interview with their carer.

The relationship to the patient of 28 of the carers was: wife 8, daughter 6, son 7, niece 2, female friend 1, sister 2, son-in-law 1, and grand-daughter 1 (in one case the relationship was not recorded). The mean age of carers was 60 (range 46–79), and 19/29 were female.

Data collection involved observation and interview. 72 h of non-participant observations of care were conducted on 45 occasions on 11 wards of the study hospitals including orthopaedic, healthcare of older people and general medicine wards. Most observation periods lasted between 1 and 2 h, the shortest being 45 min and the longest 180 min. The observations were unstructured and conducted by two researchers. The aim of each observation was to produce a narrative account of the experiences of an identified individual with dementia. Field notes were maintained during the observation and were typed in detail as soon as the observation was concluded.

The interviews were conducted by two researchers in patients' homes with family caregivers and with the patient present wherever possible. Data collection occurred between June 2009 and December 2010. The full methods have been reported elsewhere (Gladman et al., 2012a,b).

Approval from a research ethics committee and hospital research governance department was obtained. To ensure the confidentiality of the information, all participants were allocated a pseudonym, code number and the wards and places similarly allocated pseudonyms. Transcription of recorded interviews was undertaken by experienced independent transcribers who signed written confidentiality agreements. The findings of the main study are outlined in Box 2.

While conducting the preliminary analysis, we noticed that we encountered much data that reflected aspects of

Box 2. The findings of the main study

The observation and interview study elaborated a “core problem” and a “core process”. The core problem was that admission to hospital of a confused older person was a disruption from normal routine for patients, their carers, staff and co-patients. The core process described was that patient, carer, staff and co-patient behaviours were often attempts to gain or give control to deal with the disruption (the core problem). Attempts to gain or give control could lead to good or poor outcomes for patients and their carers. Poor patient and carer outcomes were associated with staff not recognising the cognitive impairment which precipitated or complicated the admission and to diagnose its cause, and staff not recognising the importance of the relationship between the patient and their family carer. Better patient and carer outcomes were associated with a person-centred approach and early attention to good communication with carers.

care that was, to a greater or lesser extent, person-centred. As a result, we decided to revisit the data with the goal of exploring the extent to which interventions by health care professionals had the capacity to sustain personhood, using the core elements of person-centred care as defined by Brooker (2007) – attachment, inclusion, identity, occupation and comfort – as a framework.

Data were managed using N-Vivo 8 software (QSR International, 2008). Two researchers (PC, DP) coded the data and evaluated the extent to which interventions had the potential to give patients feelings of attachment, inclusion, identity, occupation or comfort (Brooker, 2007). Individual accounts of patient experiences and care interventions were reviewed by the researchers and relevant episodes were coded according to these five categories. The researchers worked together to do this analysis. Where an experience or intervention appeared to address more than one psychological need, it was coded in all relevant categories. Once this stage was completed, data were divided into three categories: good care, poor care and opportunities missed. For the purposes of this paper, poor care will not be discussed as other organisations such as the Alzheimer's Society (2009) have explored this in detail. Instead, the focus will be on interactions with the potential to promote a sense of personhood both where opportunities were taken and missed.

3. Findings

There was much to suggest that healthcare professionals promoted feelings of attachment and inclusion. On the other hand, there was little evidence that the professionals supported a sense of identity, occupation and comfort: indeed, there was more evidence of poor practice in these areas. Examples of good practice and the missed opportunities are worthy of further exploration as these will help in the understanding of how acute areas might become more person-centred. The findings are presented using the person-centred care framework where the good practice then the missed opportunities for each heading are described.

4. Attachment

Feelings of attachment between the person-with-dementia and members of nursing staff appeared to be achieved when there was consistency of staff over a period of time meaning that relationships were able to develop. Brenda argued that this had a positive impact on her mother, Helen:

'I think it may have been because they were there, they did longer shifts and ... my mother was under their wing so they developed a relationship to her which, to her, is very important. Whereas the other staff that I saw ... they hadn't got such a close relationship with her.'

In addition to the time spent together, expressions of warmth from the nurse to the person-with-dementia seemed to enhance this process. When asked if there were any members of staff that made a real difference to her mother, Alma identified two nurses in particular:

'They were really friendly to her all the time. They didn't just walk past her; they'd always speak to her. He'd have a laugh with her you know 'Come on Betty, let's get (you sorted)' ... if he took her to the toilet ... he said he was going to miss her when she was gone, and she said "I'm going to miss you too."

Another way of promoting a sense of attachment on the part of the person-with-dementia was by facilitating the relationships that appeared important to the individual. When Mary used to visit her mother Gillian, members of staff would help her mother out of bed so that she could sit with Mary:

'I said 'Well I'm here now, can we get (her) out now?' and they nearly always tried to ... they were particularly nice.'

4.1. Missed opportunities

There were occasions when opportunities presented themselves for healthcare professionals to make some connection with the person-with-dementia but they seemed unable or unwilling to do so, often by choosing to end the interaction as quickly as possible. In this observation Charlotte was struggling to understand what the doctor wanted from her, but she appeared to want to interact with him:

'The doctor returns ... he asks Charlotte 'Are you hot?' 'Not today, I'm freezing in here' she replies. 'Has the nurse done your temperature?' he asks. Charlotte ponders this but looks bemused and is clearly trying to please the doctor but unsure how to answer. She responds only with a smile ... the doctor doesn't respond except to walk away from the patient with his hands in the air, clearly frustrated.'

In a similar observation David seemed particularly unsettled in the run up to lunchtime and, as nurses were concerned about his stability, every time he stood up somebody had to deal with him:

'David ... tried to stand up and walk. The five members of staff who were near to him did not appear to notice.

Another nurse was walking past and tried to persuade him into his chair but he did not want to sit in it. Instead the nurse guided him to the dining room. He seemed happy to go there until he arrived and then resisted going in to sit down. They returned to his chair ... The nurse eventually succeeded in getting him to sit down and walked away extremely quickly.'

In both situations, the healthcare professional might have spent a little longer with the person to end the interaction less suddenly and to determine what the problem was from the patients' perspectives.

In summary, the key issues that enhanced or diminished the sense of attachment for the person-with-dementia were those of continuity of staff, the communication skills of the individual members of staff and the way in which they recognised the relationships that matter to the person-with-dementia. The importance of staff continuity is well documented (Roe et al., 2001; McGarry and Arthur, 2001) where continuity enables both carer and the person-with-dementia to become comfortable working together allowing the carer to get to know the person-with-dementia at a deeper level and use this knowledge to inform their work beneficially (Edvardsson et al., 2010). This establishes more trusting relationships (Edvardsson and Nay, 2009) which builds supportive social psychology and affirms personhood (Downs et al., 2006). Effective communication skills need to extend to all members of staff who deal with the person-with-dementia as positive social interaction is the cornerstone of effective person-centred care (Kontos and Naglie, 2007) and essential for maintaining a sense of self (Naue and Kroll, 2008). This means that the balance between the emphasis on the need to complete tasks and the need to sustain positive relationships needs to be reviewed. For people-with-dementia it may be more important that the experience of a task is positive than that it is completed efficiently (Edvardsson et al., 2008). Charlotte's encounter with the doctor appears to highlight the challenge of implementing person-centred care. The communication by the doctor seemed to indicate that he did not value the personhood of Charlotte and reflected elements of the malignant social psychology by invalidating her attempt to interact and indicating non-verbally that she was not worth acknowledgement and was, in fact, useless (Kitwood, 1997). This highlights the idea that person-centred care cannot be implemented with a one-off 'quick fix' (Manley and McCormack, 2008) but requires a change in the values of both the acute healthcare system and individual practitioners (Kontos and Naglie, 2007).

Where members of staff have recognised the relationships that matter to the person-with-dementia, this has promoted person-centre care. This is because people who have the most meaningful relationships with the person-with-dementia are best placed to provide the quality psychosocial contact and personal affirmation that is essential for the maintenance of personhood (Kontos, 2005). In addition, they possess the unique knowledge of the person-with-dementia to inform personalised plans of care (Stenwall et al., 2007).

Overall, a sense of attachment might be promoted in acute clinical areas by promoting continuity of staff working with individuals with dementia, all staff using appropriate communication with people-with-dementia and by recognising the relationships that are significant to the person-with-dementia.

5. Inclusion

A number of strategies deployed by healthcare workers appeared to have the net result of giving a sense of inclusion to the person-with-dementia: taking opportunities for engagement with the person-with-dementia; demonstrating that the welfare of the person was important; and ensuring that they were involved in making the key decisions about their future.

Some opportunities were seized on an opportunistic basis, when members of staff had a moment to talk. One such occasion occurred during an observation with Edith:

'Two domestics approached the bed and said hello to Edith. She replied 'What have you got for me', 'Nothing', 'Buzz off then'. The domestics stopped with Edith and had a chat with her. She showed them a leaflet about a care home that she would be moving into. One domestic commented that the home was near to her house. Edith invited herself for tea.'

Another way of including the person-with-dementia was by demonstrating that their well-being was important. Albert's family noted that members of nursing staff were particularly proactive when it came to food:

'Well I think if he wasn't eating, which he doesn't ... they would try their best to sort of tempt him and what have you. If he ate ice cream and wouldn't eat bread, they'd give him three ice creams ... they tried their best to get him to eat something.'

A key element in making people-with-dementia feel included was involvement in key decisions. April and her family were facing a major decision about her future care. Her son reported:

'We went into a small room. There was my brother, myself – my mother was with us because they said she was the person that was concerned she had to be there ... he said even though she may not understand what we're talking about, all of it, she has the right to be there because it concerns her. And we talked about it, there was a nurse, the doctor, my brother, myself and my mother, and that was the first time that had happened.'

5.1. Missed opportunities

There were occasions when opportunities presented themselves to make the person-with-dementia feel part of things and included, but members of staff chose not to do this. Tina stated that her father Eric tended to wake up in the middle of the night and, on one occasion, reported that he had found the nursing staff having a drink – an opportunity to invite him to join them for a while. However, they chose not to:

'He did say that he'd walked down to a little room at night time, because he does wander around about 4am, and all the nurses were in there ... having a cup of tea and that. I said 'Oh, did you get a cup of tea then Dad?' 'No, they brought me back and put me back in bed.'

From a slightly different perspective, some people-with-dementia appeared not to experience inclusion due to the location of their bed. Jill felt that her mother was being excluded from the community of the ward by being placed in a side room:

'Now the ward was beautiful ... can't fault that. When I went in, everyone knew what was happening, but she was in a room tucked in a corner at the end and forgotten.'

The decision to place someone with dementia in a single room rather than on a main ward is more complex. It is possible that this might be interpreted as banishment, especially if it is accompanied by periods of prolonged inactivity (Edvardsson et al., 2010). However, ward environments can offer stimulation that is beyond the capacity of some people-with-dementia to deal with, so the relative calm of a side ward might be more appropriate (Edvardsson and Nay, 2009).

However, it is not just side rooms that might exclude people-with-dementia – any location where there was a suggestion that things were happening around the individual might have this effect. During an observation, Mr Elliott was located in the corner of a bay:

'There was quite a lot of (appropriate) noise coming from the nurses' station. However, Mr Elliott could not see this so he would have heard a lot more action than he saw. Mr Elliott had nothing to do.'

Mr Elliott would have been given the impression that there was a lot going on around him but he did not have the opportunity either to watch or be part of this activity.

To summarise, the key interventions that appear to promote a sense of inclusion for the person-with-dementia included providing an environment that enabled the individual to feel part of things and to ensure that they were involved as much as is possible in all decisions. Data have been presented that highlights how some people were made to feel part of things and how others might have experienced feelings of exclusion. A key principle underpinning person-centred care is that the person is a valued human being with moral worth (Downs et al., 2006). Inclusion and offering a sense of belonging are indicators that people-with-dementia are being treated in a manner consistent with these principles (Brooker and Surr, 2006). Evidence suggests that quality-of-life for people-with-dementia arises out of feelings of inclusion (Adams, 2010) which requires acute hospital staff to take and create opportunities for this to happen.

6. Identity

A key indicator of the way in which hospital care preserved the sense of identity of the person-with-dementia was the nature of the relationship between

the member of staff and the individual. This included using the preferred name to address the individual but also encompassed the nature of the relationship between the person and the nurse.

There were situations when the 'official' name of the patient was not their preferred form of address. Freda explained about her stay in hospital:

'There were some young lads there... and they couldn't do enough for you ... (They said) 'What's your name?' I said 'Winifred, but nobody calls me that.' 'What do they call you?' I said 'Freda usually.' Up they went, put Freda on the top of the board above the bed.'

However, the main evidence of the work of healthcare staff to preserve the sense of identity stemmed from the warmth of relationship between the nurse and the individual, making them feel that they were being treated as a human being. Trevor's wife commented:

'There was one male (nurse) there and he was very good with Trev. He didn't talk to you as though you had dementia and that, or if he had he still spoke to him as a human being then, he didn't patronise him.'

Similarly, Mike explained:

'They were friendly, they were human. You know you weren't treated as a number and left to get on with it sort of thing, they did their damndest with the time they had available.'

6.1. Missed opportunities

There appeared to be a number of relatively small actions that healthcare workers might have taken to enhance the sense of identity of the individual. These included forms of address and the failure to use personal belongings. Linda reported that her husband Roger did not recognise his official first name, meaning that it was futile using this when communicating with him:

'I kept saying to them that, although he's down as Lewis Brown, he's always from a little boy been call Roger, so I always said his name is Roger ... they always spoke to him as Lewis and I said well you'll not get a connection.'

There were occasions where the bed area of the person-with-dementia seemed to be rather clinical and lacking in personal effects. During an observation, Clarence was staying in a side room:

'In side room three sat Clarence hunched over his table. His knuckles were in his mouth and he seemed to be intently chomping on them whilst staring out the window. There were no cards or personal effects in his room: it was Spartan and smelt of bleach'

This seems to be a description of an environment totally lacking in anything that might offer Clarence any personal comforts or a sense of identity.

It is widely recognised that hospitals serve to threaten personal identity (Davis et al., 2008; Naue and Kroll, 2008), especially in the face of cognitive impairment (Miller, 1999). We highlight two ways to counter this: the way in

which members of staff relate to people-with-dementia and the use of personal belongings and objects that are meaningful to the individual. Naue and Kroll (2008) discussed how the tendency to view people-with-dementia as some kind of 'other' affects the sense of identity of the individual leading them to feel in some way apart from the human race. Treating the individual as a human being gives people a greater sense of who they are (Martin and Younger, 2001).

There was little evidence within this study of any attempt to offer a personalised environment. The role of the environment in promoting person-centred care has been emphasised (Downs et al., 2006) and the presence of personal belongings such as photographs have been shown to assist the person-with-dementia in a number of ways: supporting the sense of identity and continuation of self; offering a meaningful conversation starter for members of staff and visitors who speak to the individual; serving to remind staff of the uniqueness of each person receiving care; and enabling recognition and feelings of being at home for the person-with-dementia (Edvardsson and Nay, 2009).

7. Occupation

The interviews did not contain any evidence relating to the promotion of occupation for people-with-dementia while they were in hospital. The observations contained a small amount of evidence, some of which appeared to be planned or at least proactive and some which was opportunistic.

During one observation, a nurse decided to spend a bit of time with David:

'David was sitting in his chair. A nurse had come to sit with him and have a chat. She had a friendly manner. After about five minutes that nurse was called away 'I'm going to see you later David.' She spent a little while longer with him ... The nurse went to his locker and took out a small carrier bag of belongings, including photographs and cards and went through them with David discussing them with him. She then tried to leave him, suggesting that he did some colouring and 'I'll be back to see how you've done in a few minutes.'

By contrast, there were other occasions where occupation was only used when the person-with-dementia appeared to be getting restless. During one observation, Flo was finding it difficult to settle and eventually left the ward, being followed by May, a nurse:

'She came back a good five minutes later, Flo proudly walking next to her, arms full of folded sheets. 'I'm helping out with the beds,' announced Flo. May confirmed this and the pair of them walked side by side into the top ladies' bay. Flo helped by sitting in a chair and was told to let May know when the bed making was not right.'

7.1. Missed opportunities

There were other situations when the lack of opportunities for people-with-dementia to engage in activity

seemed overwhelming. When discussing her father's stay in hospital, Amy commented:

'One thing we did feel that was lacking, there was no music on the ward ... It was deathly silence, there was nothing ... there was no televisions in the ward ... and there was no noise whatsoever, so everybody was just bored. They were literally bored out of their brains.'

It appeared that the lack of activity might have resulted in restlessness on the part of some people. During one observation, Dean had been sitting at his bedside with nothing to do:

'Dean wandered into the next bay and started to tug at the equipment which was on the wall at the end of the bay. He walked very close to one patient and the patient called out 'Get out, go away!' A student nurse took him back to his own bed area but he did not sit down.'

Overall, there appeared to be little evidence of attempts by healthcare staff to engage people-with-dementia in activity, despite evidence that the provision of activities have a positive effect on behaviour and social interaction (Edvardsson et al., 2008). This is reminiscent of work by Nolan et al. (1995) who found that patients on a long stay ward remained passive for 87% of the time. Similarly, there was no evidence within this study to contradict the view of McCarthy (2006) who found that nurse interaction with patients tended to serve two purposes: to allow access to patients through establishing superficial rapport, and to engage in task-related communication. The consequence of this is that people with cognitive impairment are vulnerable to becoming confused very rapidly (Armstrong-Esther et al., 1994). However, it has been identified that where healthcare staff ensure that people who are confused have something to do and feel occupied, fewer demands tend to be made on them (Dahlke and Phinney, 2008). Where activity is meaningful to the individual, it offers the possibility of meeting psychological needs and improving well-being (Harmer and Orrell, 2008).

8. Comfort

While the evidence of the promotion of comfort was limited within this study, the examples that were uncovered related both to physical and psychological comfort. From a physical perspective, Brenda found it comforting that the team were concerned about the pain her mother was experiencing. She had stated that the ward had made her mother feel safe and when asked to explain this responded:

'I think it was just the fact that they cared really, particularly the consultant who seemed ... very caring and sympathetic towards her frailty and the pain she was in. I think, just the fact that it was acknowledged.'

During an observation, Doris became unsettled and started to remove her clothing and asked the cleaner to help her sit up. The cleaner fetched a nurse:

'The nurse was very compassionate and covered her up with a towel. 'Oh Doris, we can't keep you happy today

at all can we? Tell me what's up?' 'I want my neck unfastened' stated Doris. 'OK, how about wearing your little cardigan instead of a night dress. We can pop some pants on too' replied the nurse. 'Oh don't you start up – I thought you were one of the straight ones. Now you are making a fool of me!' 'No Doris, I want you to be comfy. If you don't want things around your neck that's fine – we just don't want all your privates on show.'

During another observation, Phyllis had become very upset:

'Phyllis continued to cry ... the housekeeper went over to Phyllis 'Phyllis, now don't cry. It does you no good love. I'll make you a cup of tea. Your husband is coming soon like he always does.' The housekeeper wrapped both arms around Phyllis and rocked with her like a child, gradually slowing until the sobbing ceased.

8.1. Missed opportunities

By contrast, there were other occasions when both the physical and psychological comfort of people-with-dementia appeared to be overlooked but could have been addressed with relative ease. Angus was concerned that the condition of his mother's mouth affected her capacity to communicate:

'My mum's lips kept sticking together because she wasn't drinking and we had to constantly say 'Can somebody please swab them and clean them?' ... and I feel, may be, if someone could have just been a bit more on the ball there ...'

Similarly, Sally found that her mother had to wait for too long in the emergency department on a trolley, despite it being recognised by members of staff that this was an undesirable situation:

'She was on a hard bed, well one of those trolley things and ... she was seen relatively soon by somebody ... who said that she needed to be got as soon as possible onto a proper bed because this wasn't going to help her being on this thing. And I remember we sat and waited for ages.'

This is likely to have caused her mother physical discomfort as well as the psychological distress of being in the emergency department.

There were relatively few examples of care designed to enhance comfort within the data. Where caring interventions were observed, they tended to be associated with working in a caring manner to achieve physical tasks, as discussed by McCarthy (2006) – nurses tended to be caring but viewed care as being initiated by them and the patients as passive recipients. Where interventions were made that might promote comfort, physical discomfort took precedence over emotional discomfort (Willaims and Irurita, 2006). There was little evidence of nursing staff viewing distressed behaviours as symptoms of discomfort (Long, 2009) and therefore few attempts were made to discover the cause (Berg et al., 1998). Furthermore, nursing staff tended not to act in a person-centred proactive manner to address primary needs of hunger, thirst, incontinence,

inappropriate temperature, or restlessness. More starkly, there was little evidence of hospital staff using sensory interventions such as music, smell (Merl, 2006) or human touch (Bush, 2001) to promote psychological comfort for people with dementia.

9. Limitations of the study

There are a number of limitations to this study. Firstly, all data were collected in relation to time in hospital in one NHS Trust. This means that it offers insights into the practices of a limited range of healthcare practitioners. However, a significant volume of data was collected and we were satisfied that data saturation had been achieved.

As observation formed a significant part of the data collection, it is possible that the behaviour of the practitioners changed as a direct result of being observed. However, observations tended to last for between 1 and 2 h and it is difficult for practitioners in busy clinical areas to sustain a change in their practice for this length of time (Mulhall, 2003).

As this was part of a larger study, we collected data trying to uncover the way in which acute hospitalisation is experienced by people with dementia, their family carers and others. No explicit attempt was made to look for or record interventions on the basis of the degree to which they were person-centred. As a result, any judgements made regarding the extent to which care promoted a sense of personhood were our interpretations. Similarly, it should be emphasised that the NHS Trust made no specific claims to be delivering person-centred dementia care.

10. Implications and conclusion

This study supports assertions made elsewhere that health care professionals in acute settings are not grasping all opportunities to make their care person-centred (Douglas-Dunbar and Gardiner, 2007; Dahlke and Phinney, 2008; Edvardsson and Nay, 2009; McBrien, 2009). Good practice appears to be in 'pockets' as a result of individual practitioners rather than comprehensive and consistent across services (Royal College of Psychiatrists, 2011). It is possible that health care professionals do not understand person-centred care as a result of an ambiguous policy climate. In the UK, the highly influential National Service Framework for Older People (Department of Health, 2001) used the term person-centred care in terms of service organisation rather than individual or team approaches to care. Numerous subsequent studies indicate that nurses falsely believe that the task-based approaches to care that they are employing are person-centred (McCarthy, 2006; Skaalvik et al., 2010). Even where people have a desire to be person-centred in their approach, there is a wide range of interpretations of person-centred care across the professions (Bolster and Manias, 2010).

Within this study, however, it was particularly notable there was little evidence of a sense of identity, occupation or comfort being supported. While it is recognised that there are many challenges in promoting identity and occupation in acute settings (Davis et al., 2008; McCarthy, 2006), the promotion of comfort is believed to be a central

element of nursing (Wilby, 2005). Its relative absence cannot be attributed to a lack of understanding of person-centred care.

This raises questions related to the impact of the organisation. The health care climate has been identified as the primary determining factor influencing the capacity of nurses to deliver person-centred care (Edvardsson et al., 2009). As person-centred care places primacy of the relationship with the individual over the completion of tasks, organisations need to empower professionals to use this approach to care delivery. However, evidence suggests that organisational factors mitigate against this happening (Tadd et al., 2011), with health care organisations focusing on meeting financial and productivity targets at the expense of care which is person-centred (Francis, 2010, 2013).

Finally, it appears that hospital staff are ill prepared to deal with people with dementia (Raivio et al., 2011), considering many of the associated behaviours to be problematic, difficult to understand and challenging to deal with (Gladman et al., 2012a,b). Within this context, the delivery of care that is person-centred is unlikely. There is a need for existing health care professionals to develop a thorough understanding of dementia and become competent in delivering person-centred dementia care (Traynor et al., 2011). Looking to the future, pre-registration curricula need to place far greater emphasis on the development of the skills necessary for effective practice with people with dementia.

In conclusion, while this study identified some evidence of practice that reflected elements of person-centred care, it was clear that practitioners were not making the most of every opportunity to make every intervention person-centred. The net result of this is that acute hospitals remain potentially harmful places for people with dementia. There is a need for this concept to be valued at the level of both the individual and the organisation/team. At the individual level, professionals need to recognise that every encounter with a patient with dementia has the potential to either enhance or diminish their sense of personhood and act accordingly. At an organisational and team level, there is a need to embrace a philosophy of care that facilitates the promotion of personhood and equips practitioners with the skills to deliver more effective person-centred care.

Conflict of interest

No conflict of interest has been declared by the authors.

Acknowledgement

The authors acknowledge the work of Dr. Fiona Jürgens and Dr. Bella Robbins in contributing to data collection for this study.

References

- Adams, T., 2010. The applicability of a recovery approach to nursing people with dementia. *International Journal of Nursing Studies* 47 (5), 626–634.
- Alzheimer's Society, 2009. Counting the Cost: Caring for People with Dementia on Hospital Wards. Alzheimer's Society, London.

- Armstrong-Esther, C.A., Brown, K.D., McAfee, J.G., 1994. Elderly patients: still clean and sitting quietly. *Journal of Advanced Nursing* 19 (2), 264–271.
- Berg, A., Halberg, I.R., Norberg, A., 1998. Nurses reflections about dementia care, the patients, the care and themselves in their daily caregiving. *International Journal of Nursing Studies* 35 (5), 271–282.
- Bolster, D., Manias, E., 2010. Person-centred interactions between nurses and patients during medication activities in an acute hospital setting: Qualitative observation and interview study. *International Journal of Nursing Studies* 47 (2), 154–165.
- Brooker, D., 2003. What is person-centred care in dementia? *Reviews in Clinical Gerontology* 13 (3), 215–222.
- Brooker, D., 2007. *Person-centred Dementia Care*. Jessica Kingsley Publishers, London and Philadelphia.
- Brooker, D.J., Surr, C., 2006. Dementia Care Mapping (DCM): initial validation of DCM 8 in UK field trials. *International Journal of Geriatric Psychiatry* 21 (11), 1018–1025.
- Bush, E., 2001. The use of human touch to improve the well-being of older adults: a holistic intervention. *Journal of Holistic Nursing* 19 (3), 256–270.
- Canadian Dementia Resource and Knowledge Exchange, 2013. Knowledge Broker Q+A. Available from: <http://www.dementiaknowledgebroker.ca/questions> (accessed 25.02.13).
- Dahlke, S., Phinney, A., 2008. Caring for hospitalized older adults at risk for delirium: the silent unspoken piece of nursing practice. *Journal of Gerontological Nursing* 34 (6), 41–47.
- Dalhousie University, 2012. Canadian Dementia Knowledge Translation Network (CDKTN): CDKTN Goals. Available from: http://geriatricresearch.medicine.dal.ca/cdktn_goals.htm (accessed 25.02.13).
- Davis, S., Byers, S., Walsh, F., 2008. Measuring person-centred care in a sub-acute health care setting. *Australian Health Review* 32 (3), 496–504.
- Department of Health, 2001. *The National Service Framework for Older People*. Department of Health, London.
- Department of Health, 2009. *Living Well With Dementia: A National Dementia Strategy*. Department of Health, London.
- Douglas-Dunbar, M., Gardiner, P., 2007. Support for carers of people with dementia during hospital admission. *Nursing Older People* 19 (8), 27–30.
- Downs, M., Small, N., Froggatt, K., 2006. Explanatory models of dementia: links to end of life care. *International Journal of Palliative Nursing* 12 (5), 209–213.
- Edvardsson, D., Fetherstonhaugh, D., Nay, R., 2010. Promoting a continuation of self and normality: person-centred care described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing* 19 (17/18), 2611–2618.
- Edvardsson, D., Koch, S., Nay, R., 2009. Psychometric evaluation of the English Language Person-Centered Climate Questionnaire – patient version. *Western Journal of Nursing Research* 31 (2), 235–244.
- Edvardsson, D., Nay, R., 2009. Acute care and older people: challenges and ways forward. *Australian Journal of Advanced Nursing* 27 (2), 63–69.
- Edvardsson, D., Sandman, P., Rasmussen, B., 2008. Swedish Language Person-centred Climate Questionnaire – patient version: construction and psychometric evaluation. *Journal of Advanced Nursing* 63 (3), 302–309.
- Francis, R., 2010. Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005–March 2009. Available from: http://www.midstaffsinquiry.com/assets/docs/Inquiry_Report-Vol1.pdf (accessed 20.02.13).
- Francis, R., 2013. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry. Available from: <http://www.midstaffspublicinquiry.com/report> (accessed 20.02.13).
- Gladman, J., Harwood, R., Jones, R., Porock, D., Griffiths, A., Schneider, J., Lewis, S., 2012. Medical and Mental Health/Better Mental Health development study protocol. Available from: <http://www.nottingham.ac.uk/mcop/documents/papers/issue10-mcop-issn2044-4230.pdf> (accessed 03.07.12).
- Gladman, J., Porock, D., Griffiths, A., Clissett, P., Harwood, R., Knight, A., Jurgens, F., Jones, R., Schneider, J., Kearney, F., 2012. Care of Older People with Cognitive Impairment in General Hospitals. SDO funded project. Available from: <http://www.netssc.ac.uk/hshr/projdetails.php?ref=08-1809-227> (accessed 28.01.13).
- Goldberg, S., Whittamore, K., Harwood, R., Bradshaw, L., Gladman, J., Jones, R., 2012. The prevalence of mental health problems amongst older adults admitted as an emergency to a general hospital. *Age and Ageing* 41 (1), 80–86.
- Harmer, B.J., Orrell, M., 2008. What is meaningful activity for people with dementia who live in care homes? A comparison of the views of people with dementia, staff and family carers. *Aging and Mental Health* 12 (5), 548–558.
- Kitwood, T., 1997. *Dementia Reconsidered: The Person Comes First*. Open University Press, Buckingham.
- Kitwood, T., Bredin, K., 1991. *Person to Person: A Guide to the Care of Those with Failing Mental Powers*. Gale Centre, Loughton.
- Kontos, P.C., 2005. Embodied selfhood in Alzheimer's disease: rethinking person-centred care. *Dementia* 4 (4), 553–570.
- Kontos, P.C., Naglie, G., 2007. Bridging theory and practice: imagination, the body and person-centred dementia care. *Dementia* 6 (4), 549–569.
- Long, C.O., 2009. Palliative care for advanced dementia. *Journal of Gerontological Nursing* 35 (11), 19–24.
- Manley, K., McCormack, B., 2008. Person-centred care. *Nursing Management* 15 (8), 12–13.
- Martin, G.W., Younger, D., 2001. Person-centred care for people with dementia: a quality audit approach. *Journal of Psychiatric and Mental Health Nursing* 8 (5), 443–448.
- McBrien, B., 2009. Translating change: the development of a person-centred triage training programme for emergency nurses. *International Emergency Nursing* 17 (1), 31–37.
- McCarthy, B., 2006. Translating person-centred care: a case study of preceptor nurses and their teaching practices in acute areas. *Journal of Clinical Nursing* 15 (5), 629–638.
- McGarry, J., Arthur, A., 2001. Informal care in later life: a qualitative study of the experience of older carers. *Journal of Advanced Nursing* 33 (2), 182–189.
- Merl, H., 2006. End stage dementia – a rocky journey or a tranquil passage. *ACCNS Journal for Community Nurses* 11 (1), 7–8.
- Miller, C., 1999. *Nursing Care of Older Adults: Theory and Practice*. Lippincott, Philadelphia.
- Mulhall, A., 2003. In the field: notes on observation in qualitative research. *Journal of Advanced Nursing* 41 (3), 306–313.
- National Institute for Health and Clinical Excellence, 2006. *Dementia: Supporting People with Dementia and their Carers in Health and Social Care*. The Stationary Office, London.
- Naue, U., Kroll, T., 2008. 'The demented other': identity and difference in dementia. *Nursing Philosophy* 10 (1), 26–33.
- Nolan, M., Grant, G., Nolan, J., 1995. Busy doing nothing: activity and interactional levels amongst different populations of elderly patients. *Journal of Advanced Nursing* 22 (3), 528–538.
- QSR International, 2008. *N-Vivo 8 Fundamentals*. QSR International Pty Ltd.
- Raivio, M.M., Laakkonen, M.-L., Pitk, K.H., 2011. Alzheimer's patients' spouses critiques of the support services. *ISRN Nursing* 2011, 1–8.
- Roe, B., Whattam, M., Young, H., Dimond, M., 2001. Elder's perceptions of formal and informal care: aspects of getting and receiving help for their activities of living. *Journal of Clinical Nursing* 10 (3), 398–405.
- Royal College of Psychiatrists, 2011. In: Young, J., Hood, C., Woolley, R., Gandesha, A., Souza, R. (Eds.), *Report of the National Audit of Dementia Care in General Hospitals*. Healthcare Quality Improvement Partnership, London.
- Skaalvik, M.W., Normann, H.K., Henriksen, N., 2010. Student experiences in learning person-centred care of patients with Alzheimer's disease as perceived by nursing students and supervising nurses. *Journal of Clinical Nursing* 19 (17/18), 2639–2648.
- Stenwall, E., Sandberg, J., Jonhagen, M.E., Fagerberg, I., 2007. Encountering the older confused patient: professional carers' experiences. *Scandinavian Journal of Caring Science* 21 (4), 515–522.
- Tadd, W., Hillman, A., Calnan, M., Bayer, T., Read, S., 2011. Right place – wrong person: dignity in the acute care of older people. *Quality in Ageing and Older Adults* 12 (1), 33–43.
- Traynor, V., Inoue, K., Crookes, P., 2011. Literature review: understanding nursing competence in dementia care. *Journal of Clinical Nursing* 20 (13/14), 1948–1960.
- Wilby, M.L., 2005. Cancer patients' descriptions of comforting and dis-comforting nursing actions. *International Journal for Human Caring* 9 (4), 59–63.
- Williams, A.M., Irurita, V.F., 2006. Emotional comfort: the patient's perspective of a therapeutic context. *International Journal of Nursing Studies* 43 (4), 405–415.