Journal of Research in Nursing http://jrn.sagepub.com/

Observations of the experiences of people with dementia on general hospital wards Rachel Norman

Journal of Research in Nursing 2006 11: 453 DOI: 10.1177/1744987106065684

The online version of this article can be found at: http://jrn.sagepub.com/content/11/5/453

Published by: \$SAGE

http://www.sagepublications.com

Additional services and information for Journal of Research in Nursing can be found at:

Email Alerts: http://jrn.sagepub.com/cgi/alerts

Subscriptions: http://jrn.sagepub.com/subscriptions

Reprints: http://www.sagepub.com/journalsReprints.nav

Permissions: http://www.sagepub.com/journalsPermissions.nav

Citations: http://jrn.sagepub.com/content/11/5/453.refs.html

>> Version of Record - Sep 28, 2006
What is This?

Observations of the experiences of people with dementia on general hospital wards



Journal of Research in Nursing © 2006 SAGE PUBLICATIONS London, Thousand Oaks, New Delhi VOL 11(5) 453−465 DOI: 10.1177/ 1744987106065684

Rachel Norman PhD, BN(Hons), RN

Post-doctoral research fellow

University of the West of England, Bristol, Faculty of Health and Social Care

Abstract This paper is based on research that aimed to explore how people with dementia are cared for in general hospital wards in the United Kingdom (UK). The paper details findings from one phase of data collection, ward based observations. The observations elucidated the ways in which persons with dementia express and portray their 'selves', the interpretations made by nurses about the patients with dementia they cared for and the constructions of roles and care environments. The findings demonstrate how a variety of influences affect the way a person with dementia experiences a hospital admission. Nurses' positive or negative interpretations of a person with dementia can lead to the 'constraint' or 'realisation' of a person's portrayal of self. In an ageing global society, improving the care of older people is a priority. The findings illuminate the central importance of promoting two-way relationships in which the actions of people with dementia are recognised as portraying individuality and identity. The study highlights a need for practice development to enhance nursing care for medical and surgical patients with a coincidental diagnosis of dementia.

Keywords acute hospital, dementia, constraint, interaction, observations, realisation

Introduction

Health and social care provision for older people in the United Kingdom has faced much criticism since the late 1990s, including anecdotal accounts of inadequate care for people with dementia in general hospital settings (Alzheimer's Society, 1997a, b, c; Anon., 1997a). In an attempt to address these criticisms (HAS, 1998) and to improve the care experiences of older people, in 2001 the Department of Health (DoH) began a process of service development with the introduction of The National Service Framework for Older People (DoH, 2001).

This paper discusses the observational phase of a research project exploring the care provided to people with dementia in hospital. The observational phase was one of three methods of data collection undertaken during the research. Focus group discussions with nursing staff and post-discharge interviews with patients with dementia and carers completed the data collection.

Journal of Research in Nursing 11(5)

The observational phase was central to the process of theory building in the study. Field notes were gathered from over 30 observation sessions in three ward settings, totalling more than 100 hours. The aim of the observations was to explore what happens to a person with dementia when admitted to a ward in a general hospital. The observations generated large quantities of data, the analysis of which led to the development of five categories detailing the relationships between patients, nursing staff and the care environment:

- The person with dementia expressing 'self'.
- The nurse identifying and acting towards the person with dementia.
- The dynamic interactive process.
- Nurses' roles and work.
- The hospital environment.

Literature review

Over the past twenty years, perceptions of the process of ageing have shifted (Phillipson, 1998) towards considering older people as consumers (Gilleard and Higgs, 2000), rather than victims of the political economy (Phillipson, 1992), structural dependence (Baldock, 1993) or medical determinism. Nevertheless, dementia appears to continue to objectify common stereotypes of 'old age' as a period of decline, ill-health and dependency. For many years the term 'dementia' was synonymous with the expression 'senility'. It came to exemplify what was seen as the natural deterioration of the physical and mental capabilities with age (Janicki and Dalton, 1999). Gradually, this perception of ageing was challenged and deterioration in cognitive functioning was recognised as a specific disease process (World Health Organisation, 1992; American Psychiatric Association, 1994).

The Alzheimer's Society (2005) has estimated that dementia affects over three-quarters-of-a-million people in the United Kingdom and over 18 million people worldwide. In the late 1990s, the Health Advisory Service (HAS, 1998) published a report criticising the care received by older people within the UK general hospital system, whilst the inadequate hospital care of people with dementia was highlighted by anecdotal accounts published by the Observer newspaper (Anon, 1997a) and Alzheimer's Society Newsletters (1997a, b, c). Hospital episode statistics for the year 2003–2004 suggested that people with a primary diagnosis of dementia made use of over one-and-a-quarter million bed days annually in the English acute general hospital sector (DoH, 2005).

In the United Kingdom the National Service Framework (NSF) for Older People (DoH, 2001) demanded reform in service provision in order to eradicate age discrimination and ensure person-centred care for older healthcare recipients. Standard Four, the General Hospital Care Standard, aimed to ensure that appropriate care was offered to older people in hospital by staff equipped with the skills necessary to meet their needs. Special note was taken in the standard of the mental health of older people, specifically those with dementia, and adequate training was recommended in order to develop the skills and expertise necessary to deliver appropriate care to these patients.

In 1999, Tolson et al. published a report into the 'components of best nursing practice in the care of the acutely ill hospitalised people with coincidental dementia'. This research considered three distinct issues within acute units, including nurses'

recognition of dementia, care planning and service users' views of favourable and unfavourable aspects of nursing care. Four main themes emerged from the research. The first of these was 'settling in'; the process of adjusting to the environment. The second was 'visible love' or the need to demonstrate a bond between patients and their family in an environment that had the potential to make the person appear worthless. The third was 'reaching me, reaching you' which relates to connecting with, sharing and knowing between the nurse, patient and visitor. The final theme was 'my condition', which stressed the need to consider both the acute and existing health problems of patients.

Research into the general hospital care of people with dementia has been conducted in the international arena; however, studies have focused on the effect of the person with dementia on the care environment (Dinkle and Lebok, 1997), professionally defined outcomes (Park et al., 2004) or made comparisons between the endof-life care provided to people with advanced dementia and those with end-stage cancer (Ahronheim et al., 1996). Guidance for nurses caring for people with dementia in general hospital settings has been produced (see, for example, Saunders, 1993; Olds, 1995a, b; Dewing, 2001; Pritchard and Dewing, 2001). Yet these have again tended to be practitioner or resource focused (Kikuta, 1991, Anon, 1997b, Wade, 2000) and tackled unacceptable behaviours defined as such by professional carers (Allan, 1994; Allison and Marshall, 1994; Holden, 1994; Roberts, 1999; Eriksson and Saveman, 2002). In addition, guidance has adapted knowledge from other care settings (McCloskey, 2004). Resources designed specifically to improve care, such as The Royal College of Nursing and Help the Aged resource, Dignity on the Ward: a Pocket Guide for Staff (2000), have been dominated by medical discourses (Hopkin, 2000) and consequently the lack of research focusing directly on the care provided to, and the experiences of people with dementia has limited practice development for this group of patients.

Methodology

The original aim of the research was to explore the ways in which people with dementia were cared for when admitted to general hospital settings. The objective of the observation phase was to observe the processes and care provision that occur during the hospital stay of patients with dementia and consider the patients' responses. In order to identify and explore a variety of stakeholder perspectives and to enable these to lead the development of the research, a grounded theory (Glaser and Strauss, 1967; Strauss and Corbin, 1990, 1998) approach to data collection was undertaken.

The observational method — a hybrid participant/ non-participant approach

An observational method of data collection was adopted in order to meet this objective. For the purpose of the research, a hybrid of the two accepted approaches to observation (non-participant observer and participant observer) was developed, in which a 'volunteer' role was taken, adapted from the work of Junker (1960) and Gold (1958). This approach saw the researcher move from the position of observer to participant and back again, as and when was required, and is championed by Hammersley and Atkinson (1993) as enabling researchers to explore and discover the impact of their presence in the observation setting.

Trustworthiness and authenticity

To enhance the authenticity and trustworthiness of data collection and analysis, a process termed 'situating the self' (Norman, 2003) was used. The motivations and life experiences of the researcher that had the potential to impact on the process of data collection and analysis were recorded and considered so as to enable successful reflexivity and to acknowledge the researcher within the process of qualitative research. As stated above, the hybrid observation method enabled the impact of the observer to be considered and the credibility of the participants' responses were secured by the use of their own words and actions within the presented data and theory building directly from them.

Settings, participants and consent processes

Observations were carried out in three ward settings including surgical and medical wards and admissions and longer stay units in a large general hospital in the South West of England.

Participants were recruited using a convenience sample of patients in the observation settings. Nursing staff were requested to identify potential participants and hand-over sessions were attended to identify further potential participants. No formal assessment was carried out to judge whether a participant had a positive diagnosis of dementia. Instead it was considered that nurses' perceptions that a patient had dementia would lead to them receiving similar care to those with a formal diagnosis. Those patients identified by the nurses were approached and asked to become involved in the research. Eight participants (n=8) were recruited for the observational phase (see Table 1).

Table 1

Settings (n = 3)	Participant $(n = 8)$	No. of observations $(n = 31)$
A	Beatrice — admitted under the Mental Health Act,	
	deemed unable to care for herself	4
	Celia — admitted following a collapse at home	4
	Delilah - admitted following a collapse	1
	Edward — admitted unable to swallow	8
В	Frieda — admitted with a head injury following a fall	
	Georgina — admitted following a fall and back	4
	injury	1
	Harriet — admitted for investigation of a possible	
	bowel obstruction	1
С	Isobel — transferred from another hospital	
	following a fractured ankle	8

For the purpose of the research, the terms 'nursing staff' and 'nurses' were used to represent healthcare assistants (HCAs), student nurses and qualified nursing staff. All nursing staff working in the observation settings were invited to become research participants.

Consent processes

To enable the participants with dementia to become engaged in making decisions on their involvement in the research, a consent procedure entitled the 'cyclical consent

process' (Norman, 2003) was developed. The process took into account the alternative methods of communication that participants used to suggest or withdraw their agreement to participation, including physical gestures suggesting agreement, the avoidance of discussions about the research and comments and non-verbal gestures during observation sessions. Nursing staff were required to give their informed consent for involvement in the research and ethical approval for the study was obtained from the Local Research Ethics Committee.

Data collection and analysis

The evaluative tool 'Dementia care mapping' (DCM — Bradford Dementia Group, 1997) was originally considered as a data collection method. However the approach was ultimately rejected as it is designed to be facilitated by a minimum of two trained 'mappers'. Data collection therefore took the form of detailed, contemporaneous field notes.

The use of grounded theory (Glaser and Strauss, 1967; Strauss and Corbin, 1990, 1998) enabled data analysis to move away from descriptive categorisation of phenomena towards abstracted theory. The data management software, ATLAS.ti (2002), was used to support data analysis and identify when data saturation had been achieved.

Results

Five key themes were generated following data analysis, and these are presented below. The observational data reflected patients' physical, verbal and emotional responses to care practices and interactions with nursing staff. Their responses were considered as expressions of their experiences of care (Bradford Dementia Group, 1997).

The person with dementia expressing 'self'

It became evident that the participants with dementia used a variety of ways to define and express themselves. Through their actions, their words and their attempts at autonomy and passivity, participants attempted to control the care provision they experienced and displayed their identities within the care environment.

Delilah was observed repeatedly changing her position. Her actions appeared to suggest a level of discomfort and uncertainty and she could be heard asking staff whether everything was 'alright'.

Delilah has sat in bed for a short time and is now pulling at the sheets in an agitated manner. She calls over a healthcare assistant (HCA) who tidies the sheet. She seems a little calmed.

[later] She calls over the HCA. Delilah appears anxious and asks repeatedly if things are 'alright?' such as where her slippers are and how the bed is made.

(Observation 1 — Delilah).

Participants were observed attempting to exert control over the treatment they received, for example, Harriet, who appeared unhappy with her nasogastric tube:

The student nurse can be heard behind the curtains discussing with Harriet her dislike of the nasogastric tube.

[later]Harriet rubs the side of her face with her hand and appears to tug at the tube. Suddenly Harriet reaches out and grabs the side rails. Her tube has gone.

(Observation 1 — Harriet)

In contrast to Harriet's attempt to control care provision, Celia used passivity to express her intended withdrawal from involvement in care:

Two HCAs enter Celia's bed area and close the curtains. I noted that when the HCAs approached Celia, she closed her eyes.

(Observation 5 — Celia)

The nurse identifying and acting towards the person with dementia

Throughout the study it became clear that nursing staff viewed patients with dementia on the basis of their previous knowledge and experience of caring for people with dementia, their emotions of caring for this group of patients and their understanding and constructions of each of the individual participants.

The observational data suggested that, generally, participants were seen to belong to one of two groups, either 'positive and acceptable patients' or 'negative and unacceptable patients'. Positive acceptable patients tended to be viewed as 'whole individuals', and were compliant and relatively independent. In contrast, those identified negatively were reduced to their parts, with needs or actions to be performed for them, and at times it appeared that nursing staff did not acknowledge the presence of the person when providing care and support:

The HCA continues to pack Harriet's bag. A nurse cadet comes to the end of Harriet's bed. Harriet opens her eyes. The cadet asks why Harriet has a nasogastric tube in situ. The HCA replies, 'Probably a CVA [cerebrovascular accident] they usually have one.' Harriet is staring at the HCA who is talking to the cadet. The HCA leaves and Harriet closes her eyes.

(Observation 1 — Harriet)

Such participants were seen to belong to an homogenous group, such as 'the heavies' — 'I'll help with the heavies in a minute' (Observation 8 — Edward).

As a consequence of these definitions, as positive or negative patients, participants were observed experiencing 'constraint' or 'realisation'. 'Negative and unacceptable' patients often faced emotional and physical constraint, through the use of bedside trolleys to restrict their movement or infantalisation (Kitwood, 1997) — being treated in a childlike manner.

The nurse takes the chocolate bar from Isobel saying, 'You know what we have to tell the children, eat your dinner first, chocolate after.'

(Observation 6 — Isobel)

Yet those participants viewed in a more 'positive and acceptable' light experienced 'realisation' — the maintenance of their identities through low-level autonomy, increasingly egalitarian interactions and the respect and enhancement of their choices. For example:

A [male] nurse has now entered the bay and goes behind the curtains. The nurse tells an HCA what needs to be done. The [male] nurse leaves, it appears that Georgina did not wish a male nurse to carry out the dressing change. She can be heard asking 'Is that a man or a woman?' The dressing change is carried out by a female HCA.

(Observation 1 — Georgina)

It is interesting to note that the negative or positive judgements made by the nursing

staff did not appear consistent and often variations were observed over time and between nurses. Although respondents in an earlier phase of data collection had suggested that previous knowledge and experience of patients with dementia influence the way in which they approached patients with dementia, the latter's own actions were often used by the nurses to re-define their acceptability. Frieda frequently experienced constraint by being returned to her chair when she attempted to walk around the ward. Yet, in contrast, she also experienced episodes of realisation in the form of shared and egalitarian interactions and low-level decision-making:

At this time there is a student nurse conversing with Frieda. Their discussions centre around the flowers that she has on her trolley. The student asks who has given her the flowers.

A housekeeper places some toast on Frieda's trolley, the student asks 'Do you want butter on your toast?' The student butters the toast as Frieda answers that she would. The student then asks 'Do you want it cut into four or halves?'

(Observation 1 — Frieda)

The dynamic interactive process

The observations elucidated the processes of interactions that occurred between patients and nursing staff. These ranged from shared interactions, in which both parties participated on relatively equal terms, to staff-led interactions, which were initiated, dominated and controlled by the nursing staff.

Nurse: 'It's just toothpaste' Celia: 'Oh no . . . ' [Whimper]

Nurse: 'Your mouth just needs a little clean.'

Celia: 'But I don't want it.'

Nurse: 'Just one more, you're not drinking, what do you expect if . . .'

Celia: 'But I don't want it.' Nurse: 'Your mouth looks awful.'

Celia: 'Don't keep on about it, ohh.' [whimper]

(Observation 2 — Celia)

However, other participants experienced more connected and shared interactions, such as Edward, who interestingly displayed many of the attributes of a negative and unacceptable patients, such as dependence, and encountered physical constraint by the use of side rails around his bed. Many of the interactions between Edward and the nursing staff were instructional and prescriptive; however, the skills portrayed by one healthcare assistant enabled Edward to experience meaningful engagement:

An HCA approaches Edward and speaks in a few words of Italian, his first language. Edward smiles widely. The HCA asks him a question and Edward responds verbally.

The conversation continues, Edward mostly nods his head and verbalises at times. His facial expressions are varied throughout the interaction. The HCA allows him time to respond to questions and moves close to him to direct the questions at him.

(Observation 3 — Edward)

Nurses roles and work

In addition to observing the interactions between the participants and the nursing staff, it became clear that it was necessary to consider constructions of nurses' work and roles. In an earlier phase of data collection (focus groups with nursing staff),

```
Journal of Research in Nursing 11(5)
```

nurses had stressed that neither the hospital setting nor their training equipped them to look after people with dementia. On observation, the work conducted with the participants could be categorised into two distinct types — 'practical' and 'emotional' work. Practical work was defined by minimal collaboration with the participant, in which a provider—receiver relationship prevailed, even at the expense of the patients wishes. For example:

```
'Ready, come on, 1, 2, 3 . . .'

The staff lift her.

'Ok get yourself in' — nurse.

Isobel is asked to move up the bed.

'No I'm alright,' she replies.

'Lift your bottom up' — nurse.

'Up . . . this bit' — nurse.

'That's it' — nurse.

Isobel moves up the bed.'

(Observation 5 — Isobel)
```

In contrast, emotional work saw higher levels of collaboration with the patients and a degree of recognition and prioritisation of the needs of the patient. In contrast to episodes of 'practical work' which saw the nursing staff focused on the tasks they were undertaking, the following interaction details how one healthcare assistant was able to recognise a participant's emotional needs and offer support alongside practice:

```
Delilah calls over an HCA and speaks with her, the HCA replies, 'Oh you want to get into bed?'
```

Delilah appears anxious and asks repeatedly if things are 'alright' such as where her slippers are and how the bed is made.

```
The HCA tidies the sheets and Delilah thanks her — 'Thank you, you are good.'
```

[Later the HCA returns to take Delilah's blood pressure] Delilah asks, 'Am I sat here, daft?' The HCA states that she is fine, 'We'd tell you if you are sat daft but I don't think you are.' Delilah — 'I'm not daft.'

HCA — 'No.'

Delilah — 'Too old for blood pressure.'

HCA — 'You're never too old, here we are all done, nothing to worry about.' Delilah — 'All done? Thank you.'

HCA — 'that's alright.'

(Observation 1 — Delilah)

The hospital environment

Whilst the construction of the roles of the nursing staff appeared to influence the ways in which the participants experienced their admission to hospital, constructions of the environment also impacted on how care was provided and received. A care setting construed as a living environment by the participants, yet seen as a working environment by the nursing staff, had the potential to influence the ways in which the nurses viewed caring for people with dementia. An action such as walking within the ward tended to be viewed as unacceptable by staff:

Frieda leaves the bed area, the nurse joins her. They walk hand in hand along the corridor into bay one. As she returns to bay four she says, 'This is absolutely ridiculous, let go', and

breaks hands with the nurse . . . 'I'm going to get my coat,' says Frieda. The nurse replies that she should sit down in her chair.

(Observation 3 — Frieda)

A number of participants saw the environment as a place to explore or leave. Through their actions the participants appeared to define the ward as a place in which they were 'living'; however, such actions were viewed as problematic and inappropriate by the staff working within the wards.

Discussion

The findings from the analysis of the observational data suggest that a variety of influences can effect the way that a person with dementia experiences an admission to hospital. The variety of methods that the participants used to express and portray their 'selves' appeared to be important to the way in which the nursing staff defined them and provided care. These 'selves', expressed through actions, attempts at autonomy or passivity and in interactions with staff, represent what is referred to by Sabat and Harre (1992) as 'the selves that are publicly presented in the episodes of interpersonal interaction in the everyday world' (1992: 445). The 'selves' portrayed by the participants, and subsequently interpreted by the nursing staff, were constrained or realised by the actions taken by the nurses, and appeared to be based on the judgements the nurses made about the way the person acted or responded, as well as their previous experiences of caring for people with dementia. Actions, such as participants' withdrawal from interactions and their dependency, were viewed as meaningless or problematic and consequently interpreted by the nurses as failing to portray a form of self. This interpretation of the patient as a reduced and dependent person led to the constraint of the participant, hence reinforcing the definition ascribed to them, that of failing to portray any form of 'self'.

In contrast, some actions were given meaning and interpreted as a representation of self. These included attempts at independence, compliance, engaged interaction and even problematic behaviours such as 'wandering'. Given meaning, these actions encouraged the realisation of participants. They enhanced the person's individuality and affirmed the nurses' interpretations of the person's portrayal of their 'selves'.

Since the early 1970s, writers have debated the constructions of the 'unpopular' and 'popular' patient (Stockwell, 1972; Kelly and May, 1982; Johnson and Webb, 1995). Stockwell (1972) argued that definable traits could predict the popularity of patients. This was challenged by Johnson and Webb (1995) who defined labelling in the context of a nurse–patient relationship as 'social judgement', which related to the 'powerful social influences' that nurses are exposed to, rather than the traits of the patient. These social influences include the 'power of healthcare professionals' (1995: 474) and the judgements that nurses make as to a patient's 'social worth . . . when balancing competing claims on our time and other health resources' (1995: 474).

Whilst both Stockwell's (1972) and Johnson and Webb's (1995) concepts of the unpopular patient appeared to be relevant for this research, the observations did not appear to support a consistent approach to the construction of dementia patients. The outcome of the relationship was not dependent primarily on inherent (Stockwell, 1972) or constructed (Johnson and Webb, 1992) popularity. It was more closely linked to the way the person portrayed his or her 'selves' and the nurses' interpretation of this. Interpretations by nurses appeared to be based on a combination of how

they defined the action or inaction of the person and their previously held perceptions of dementia. Nurses appeared to define the patient (as dependent and reduced, or as whole and individual) based on their portrayal of self, the nurse's perceptions of dementia and the nurse—patient communication process that the parties engaged in.

Those participants who appeared to reinforce a construction of people with dementia as not portraying a 'self' were seen in terms of their dependency, reduced to their parts and constrained. Those who challenged this construction through the portrayal of their 'selves' were seen as whole, individual and realised within the boundaries of the environment and nursing roles.

Nevertheless, as suggested by Johnson and Webb (1995), nurses' work and the ward environment were also seen to influence the experience of hospitalisation for the person with dementia. The observations suggested that both the environment and the roles of the nurses within it were constructed to a considerable degree by the stakeholders. There are many debates underway as to what constitutes nursing (for example, for the purpose of defining free long-term care), and consequently the act of 'nursing' in itself is open to various interpretations. Clifford (1995) suggests that nursing is dominated by its practical components, and Gray and Smith (1999) suggest that socialisation into the role of a nurse is bound up in the undertaking of practical tasks. White (2002), however, suggests that nursing is a vocation, which 'requires a duty to care for patients' (2002: 280), so that nursing is more than work or a job, but is a 'personal identification and personal engagement with the values and ideals suited to a vocation' (2002: 282). From this perspective, nursing is much more than its practical application, but a moral and emotional responsibility. As was observed, divisions along such lines appeared to further impact on the experiences of the participants. Practical work was constructed in such a way that there was minimal collaboration with the participant. The emotional work observed, and closely aligned to the concept of 'emotional labour' (Hochschild, 1983; James, 1992; Smith, 1992; Staden, 1998; Bolton, 2000; Scott, 2000; McQueen, 2004) appeared to reflect White's (2002) suggestions of vocation and personal and emotional responsibility.

Communication between patients and nurses has been widely discussed in nursing literature (Armstrong-Esther and Brown, 1986; Edwards, 1995; Jarret and Payne, 1995; Richter et al., 1995; Caris-Verhallen et al., 1997, 1999; Rowe, 1999). Caris -Verhallen et al. (1999) suggest that the quality of care received by patients from nurses can be enhanced through improved communication. (1999: 1107). Their research investigated three variables affecting the quality and quantity of nurse-patient communication (those related to the nurse, those related to the patient and those linked to care-setting characteristics). They concluded that, as time pressures increase for nurses, they were less able to engage in conversations with patients on 'lifestyle and emotions' (1999:1115). As suggested by the observational data from this research, emotional work enabled more collaboration and connection with participants, whilst practical work appeared to be more task- and nurse-focused. Connected and egalitarian interactions tended to enable the participants to engage more readily with the staff and hence portray and reinforce the participants' 'selves'. Yet those interactions that were dominated by the nursing staff appeared to focus on direction and instruction-giving and reinforced the nurses' perceptions of a lack of participants' 'selves'.

Limitations

This research does not claim to represent the entire experience of hospitalisation for people with dementia, in so far as it has concentrated solely on the nursing care provided to patients in acute care settings. Medical intervention, the care provided by other hospital departments, admission and discharge procedures and the experience of death in acute care settings for people with dementia are each areas that have not been investigated in this research and, as such, offer new and unique challenges for research in the future.

Due to the adoption of the grounded theory methodology, which is traditionally underpinned by a symbolic interactionist perspective, many of the issues raised are focused on interactional relationships. Whilst grounded theory (Glaser and Strauss, 1967; Strauss and Corbin, 1990, 1998) supports such selectivity in allowing data to lead theory, a consideration of the wider constructions of illness, ageing, professional roles and the meanings of hospitalisation for patients may have offered further context to the findings.

Time constraints led to only eight participants being recruited into the observational phase and, due to the differing practices observed by various members of the nursing team, a more detailed investigation of each member of the team's experience, qualifications and attitudes towards caring for people with dementia may have offered a greater insight into the reasons behind these variations. The observational method itself has a number of limitations and specifically in this research, the dual role of 'volunteer' and 'researcher' led to complexities in integrating into some care settings. The researchers' presence impacted on the experiences of all of the observed participants. Consequently, questions can be raised regarding the potential for care practice and responses to these to have been different had the observations not been conducted. Nevertheless the research has raised a series of key points for nurses working with older patients with dementia in acute settings.

Conclusions

The findings from the observational phase of the research suggest the importance of nursing practice that moves away from the constraint of patients with dementia, and towards their realisation. The theoretical findings of the research can be used to develop practice that challenges nurses to consider the actions of people with dementia as methods of communication, and to consider prioritising the needs of the person when care planning. To meet the need for targeted practice development, a resource for nursing staff has been developed, focusing on the key themes from the research findings (Norman, 2005). Through engaging in a two-way relationship with people with dementia, in which their actions are recognised as a portrayal of 'selves', their individuality, identity and self-determination can be enhanced and, consequently, their experiences of hospitalisation improved.

Key points

- Attitudes and approaches to dementia in acute settings need to be reconsidered to recognise the 'self' of patients with dementia
- The individuality and wholeness of patients with dementia in acute settings should be recognised from the initial contact with nursing staff
- Nursing practice that 'realises' and not 'constrains' should be developed and encouraged
- Future research could include investigations of patients' own definitions of and emotions towards constraint and realisation and the construction of care roles and settings

Acknowledgements

Funding to support the author's PhD was secured from the Mental Health Foundation with the support of AXA Sunlife.

References

- Ahronhein, J., Morrision, S., Baskin, S., Morris, J., Meier, D. (1996) Treatment of the dying in the acute care hospital: advanced dementia and metastatic cancer. Archive of Internal Medicine 156: 18, 2094—2100.
- Allan, K. (1994) Dementia in acute units: wandering. Nursing Standard **9**:8, 32–34.
- Allison, A., Marshall, M. (1994) Dementia in acute units: the issues. Nursing Standard **8**:52, 28-30.
- Alzheimer's Disease Society (1997a) Letters. The Alzheimer's Disease Society Newsletter May: 8.
- Alzheimer's Disease Society (1997b) Ellen The Alzheimer's Disease Society Newsletter July: 8.
- Alzheimer's Disease Society (1997c) Letters. The Alzheimer's Disease Society Newsletter August: 8.
- Alzheimer's Society (2005) Policy Positions—Demography.
 Available from: www.alzheimers.org.uk/News_and_
 Campaigns/Policy_Watch/demography.htm (accessed 3
 November 2006).
- $American\ Psychiatric\ Association\ (1994)\ DSM-IV:\ Diagnostic \\ and\ Statistical\ Manual\ of\ Mental\ Disorders,\ 4th\ edition.$
- Washington, DC: American Psychiatric Association.

 Anon. (1997a) Dignity on the ward: readers' experiences.

 The Observer 12 October: 18.
- Anon. (1997b) Caring for patients with Alzheimer's disease. R.N. **60**:12, 16b–16d.
- Armstrong-Ester, C., Brown, K. (1986) The influence of elderly patients' mental impairment on nurse—patient interaction. Journal of Advanced Nursing 11: 379–387.
- ATLAS.ti Scientific Software Development GmbH (2002) Atlas.ti v4.1 (now updated to version 5.0).

 Available from: www.atlasti.com (accessed 3 November
- Baldock, J., (1993) Old age. In: Dallos, R., McLaughlin, E. (eds) Social Problems and the Family. London: Sage, 123–154.
- Bolton, S. (2000) Who cares? Offering emotion work as a 'gift' in the nursing labour process. Journal of Advanced Nursing 32:2, 580–586.
- Bradford Dementia Group, University of Bradford (1997)

 Dementia Care Mapping, 7th Edition. Bradford: Bradford

 Dementia Group.
- Caris-Verhallen, W., Kerkstra, A., Bensing, J. (1997) The role of communication in nursing care for elderly

- people: a review of the literature. Journal of Advanced Nursing **25**:5, 915-933.
- Caris-Verhallen, W., de Gruijter, I., Kerkstra, A., Bensing, J. (1999) Factors related to nurse communication with elderly people. Journal of Advanced Nursing 30:5, 1106–1117.
- Clifford, C. (1995) Caring: fitting the concept to nursing practice. Journal of Clinical Nursing 4: 37-41.
- Department of Health (2001) National Service Framework for Older People: Modern Standards and Service Models. Available from: www.dh.gov.uk/assetRoot/04/07/12/83/04071283.p df (accessed 3 November 2005).
- Department of Health (2005) Hospital Episodes Statistics. England: 2003–2004. Available from: www.hesonline.nhs. uk/Ease/servlet/DynamicPageBuild?siteID=1802&categ oryID=202&catName=Primary%20diagnosis:%20summ ary (accessed 3 November 2005).
- Dewing, J. (2001) Care for older people with dementia in acute hospital settings. Nursing Older People 13:3, 18–20.
- Dinkle, R., Lebok, U. (1997) The effects of dementia in German acute hospitals. Dementia and Geriatric Cognitive Disorders 8: 314–319.
- Edwards, H. (1995) Communication predicaments of older health care consumers: what can 'we' do about it? Social Alternatives 14:2, 33–36.
- Eriksson, C., Saveman, B. (2002) Nurses experiences of abusive/non-abusive caring for demented patients in acute care settings. Scandinavian Journal of Caring Sciences 16:1, 79-8c.
- Gilleard, C., Higgs, P. (2000) Cultures of Ageing: Self, Citizen and the Body. London: Prentice Hall.
- Glaser, B., Strauss, A. (1967) The Discovery of Grounded Theory: Strategies for Qualitative Research. New York: Aldine du Gruyter.
- Gold, R. (1958) Roles in sociological field observations. Social Forces **36**: 217–223.
- Gray, M., Smith, L. (1999) The professional socialisation of diploma of higher education in nursing students (Project 2000): a longitudinal qualitative study. Journal of Advanced Nursing 29:3, 639–647.
- Hammersley, M., Atkinson, P. (1993) Ethnography. London: Routledge.

Norman Experiences of people with dementia

- Health Advisory Service (HAS) (1998) Not Because They Are Old: a Report of HAS 2000. London: HAS.
- Hochschild, A. (1983) The Managed Heart: Commercialization of Human Feeling. Berkeley: University of California Press.
- Holden, U. (1994) Dementia in acute units: aggression. Nursing Standard **9**:11, 37–39.
- Hopkin, R. (2000) Dignity on the ward: improving the experience of acute hospital care for older people with dementia or confusion. A pocket guide for hospital staff. A critique. Generations Review 11:2, 4–6.
- James, N. (1992) Care = organisation + physical labour + emotional labour. Sociology of Health and Illness 14:4, 488-509.
- Janicki, M., Dalton, A. (1999) Dementia, Ageing and Intellectual Disabilities: a Handbook. London: Bruner/Mazel.
- Jarret, N., Payne, S. (1995) A selective review of the literature on nurse–patient communication: has the patients' contribution been neglected? Journal of Advanced Nursing 22:1, 72–78.
- Johnson, M., Webb, C. (1995) Rediscovering unpopular patients: the concept of social judgement. Journal of Advanced Nursing 21:3, 466–475.
- Junker, B. (1960) Fieldwork: an Introduction to the Social Sciences. Chicago: the Chicago University Press.
- Kelly, M., May, D. (1982) Good and bad patients: a review of the literature and a theoretical critique. Journal of Advanced Nursing 7:147–156.
- Kikuta, S. (1991) Clinically managing disruptive behaviour on the ward. Journal of Gerontological Nursing 17:8, 4-8.
- Kitwood, T. (1997) Dementia Reconsidered. Buckinghamshire: Open University Press.
- McCloskey, R. (2004) Caring for patients with dementia in an acute care environment. *Geriatric* Nursing **25**:3, 139–144.
- McQueen, A. (2004) Emotional intelligence in nursing work. Journal of Advance Nursing 47:1, 101–108.
- Norman, R. (2003) Acute nursing care for people with dementia: what happens when a person with dementia is admitted to hospital for acute care? Unpublished PhD thesis, University of the West of England, Bristol.
- Norman, R. (2005) Acute Nursing Care for People with Dementia: Developing Practice Guidance — Dementia Care in Acute Hospital Settings. University of the West of England, Bristol, The Change Agent Team, The Mental Health Foundation, UK. Available from:
- www.changeagentteam.org.uk/index.cfm?pid=250 (accessed 3 November 2005).
- Olds, J. (1995a) The care of patients with dementia in general wards. Professional Nurse 10:7, 430-431.
- Olds, J. (1995b) Strategies of care for patients with dementia. Professional Nurse 10:9, 585–587.
- Park, M., Delaney, C., Maas, M., Reed, D. (2004) Using a nursing minimum data set with older adults with

dementia in an acute care setting. Journal of Advanced Nursing 47:3, 329-339.

- Phillipson. C. (1992) Capitalism and the Construction of Old Age. London: Macmillan.
- Phillipson, C. (1998) Reconstructing Old Age: New Agendas in Social Theory and Practice. London: Sage.
- Pritchard, E., Dewing, J. (2001) Older people with dementia in acute settings. Nursing Older People 12:10, 21-25.
- Richter, J., Roberto, K., Bottenberg, D. (1995) Communicating with persons with Alzheimers disease: experiences of family and formal caregivers. Archives of Psychiatric Nursing 9:2, 279–285.
- Roberts, C. (1999) The management of wandering in older people with dementia. Journal of Clinical Nursing 8:3, 322–323.
- Rowe, J. (1999) Self-awareness: improving nurse—client interactions. Nursing Standard 14:8, 37—40.
- Royal College of Nursing and Help the Aged (2000) Dignity on the Ward: Improving the Experience of Acute Hospital Care for Older People with Dementia or Confusion. A Pocket Guide for Staff. London: Help the Aged.
- Sabat, S., Harre, R. (1992) The construction and deconstruction of the self in Alzheimer's disease. Ageing and Society 12:4, 443-461.
- Saunders, P. (1993) Caring for confused people in the general hospital setting. Nursing Times **91**:47, 27–29.
- Scott, P.A. (2000) Emotion, moral perception, and nursing practice. Nursing Philosophy 1:123-133.
- Smith, P. (1992) The Emotional Labour of Nursing. Basingstoke: Macmillan.
- Staden, H. (1998) Alertness to the needs of others: a study of the emotional labour of caring. Journal of Advanced Nursing 27:147-156.
- Stockwell, F. (1972) The Unpopular Patient. London: Royal College of Nursing.
- Strauss, A., Corbin, J. (1990) Basics of Qualitative Research: Grounded Theory Procedures and Techniques, 1st edition . London:
- Strauss, A., Corbin, J. (1998) Basics of Qualitative Research: Grounded Theory Procedures and Techniques, 2nd edition. London: Sage.
- Tolson, D., Smith, M., Knight, P. (1999) Investigation of components of best nursing practice in the care of acutely ill hospital patients with dementia. *Journal of Advanced Nursing* 30:5, 1127–1136.
- Wade, S. (2000) Nursing older people: the key to success. Nursing Times 13:96, 42-44.
- White, K. (2002) Nursing as a vocation. Nursing Ethics 9:3, 279–290.
- World Health Organisation (1992) ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptors and Diagnosis Guidelines. Geneva: World Health Organisation.

Correspondence should be addressed to:

Rachel Norman

University of the West of England, Bristol Faculty of health and social care.

Email: Rachel2.Norman@uwe.ac.uk