How healthcare professionals in acute settings construct identities for people with dementia
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Abstract

Background Healthcare professionals working in acute settings lack education and training in dementia care, resulting in people living with dementia receiving a reduced quality of care. Discourses are ways of communicating through written and spoken language, and healthcare professionals often adopt ageist discourses when constructing the identities of people living with dementia.

Aim To explore how healthcare professionals working in acute settings construct the identities of people living with dementia.

Method Semi-structured interviews were conducted with nine participants working in acute settings in the Republic of Ireland.

Findings Participants adopted two main discourse areas to construct the identities of people with dementia. The first discourse area related to the act of caring and the second discourse area, described as ‘identity discourses’, centred on the everyday language used by healthcare professionals. While participants strived to be person-centred the culture of acute settings was often task orientated.

Conclusion Caring for people with dementia is challenging in the acute healthcare setting. There is a need for ongoing training and effective continuing professional development strategies.

Keywords ageism, continuing professional development, dementia, discrimination, diversity, education, neurology, older people, professional issues, qualitative research, research, staff attitudes
older people undesirably, which can have a negative effect on attitudes and beliefs (Fealy and McNamara 2009). Negative attitudes towards people with dementia are detrimental to their care in the acute setting (Hanson 2014).

Language helps people understand society, and discourses are ways of communicating through written and spoken language. People with dementia are often associated with words such as ‘infirm’, ‘vulnerable’, ‘victims’ and ‘frail’ (Fealy and McNamara 2009, Mitchell et al 2013). As a result of these predominant discourses, healthcare professionals and society as a whole may have preconceived notions about people with dementia.

Since negative language can perpetuate the stigma associated with dementia, the Dementia Engagement and Empowerment Project (DEEP) (2014) has developed language guidelines for organisations. DEEP argues that people with dementia prefer that more balanced language is used to describe their diagnosis. Kate Swaffer, who has dementia and lives in Australia, writes extensively on the importance of language in dementia care. Kate highlights critical issues in the current management of dementia from the perspective of someone living with the condition. Her accounts of dementia are aimed at a wide audience; for people living with dementia, for their families, for healthcare professionals and for policy makers. She documents the effect of negative language and labels, such as ‘dementia sufferer’ (Swaffer 2017).

An Australian study by Kim et al (2015) found participants lacked education in dementia, and their attitudes to developing dementia involved fear, cynicism and irrational perceptions. According to Allen and Ranger (2013), society’s attitudes have a negative effect on older people, who develop ‘ageist’ beliefs that may reduce the likelihood of them seeking help or their responses to therapeutic interventions.

Charter and Hughes (2012) claim when people with dementia are admitted to the acute healthcare environment their needs are almost forgotten about as nurses focus on the acute condition. Additionally, they feel this is due to inadequate education and training and negative staff attitudes.

**Aim**
The aim of this study was to explore how healthcare professionals working in acute settings construct the identities of people with dementia.

**Method**
A qualitative exploratory methodology was used to recognise the individuality of people and to explore participant constructions of dementia. Purposive sampling (n=9) was used to recruit the participants who were acute healthcare professionals working in medical, surgical and care of the older person wards in three different hospitals in the Republic of Ireland. All participants were registered general nurses and healthcare assistants with varying levels of experience.

An in-depth interview was carried out with each participant to explore the nuanced and diverse language used by healthcare professionals to describe people with dementia. The rules that were applied to the narrative interview are from Jovchelovitch and Bauer’s (2000) rules.

All interviews were conducted during a four-week period and lasted about one hour. Interviews were recorded for subsequent verbatim transcription, and were uploaded, transcribed and analysed using NVivo 11 software. Discourse analysis, defined by Taylor (2013) as ‘the close study of language and language use as evidence of aspects of society and social life’, was adopted to analyse the interviews. The Ritchie and Spencer (1994) framework was used to analyse interviews. This framework was chosen because it provides clear steps when producing an organised summary of the data (Gale et al 2013). Thus, the data are organised and reduced. Through the development of a framework matrix, it allows the analyst to look down and look across the matrix (Spencer et al 2014). This allows the analyst to comprehensively review the data and emerging themes. Another reason for adopting this framework is that an original link through NVivo can be maintained to the data at all stages of the analysis process.

**Ethical considerations**
Ethical approval was sought through the researchers’ institutional ethics research committee and the research ethics committee of each healthcare site.

**Findings**
To ensure confidentiality, participants were assigned pseudonyms. Accounts of participants’ experiences are included to enhance the presentation of these findings. Participants adopted two main discourse areas to construct people with dementia. The first discourse area related to the act of caring for people with dementia and the second discourse...
Discourses on caring

Competency in caring

The first discourse reflects a strong desire by the participants to care effectively for people with dementia in challenging environments.

One participant, Alisha, compared the qualities of a carer to that of a technician who was task-focused and the other as more educated in caring for older people and better able to interact with people with dementia.

Another participant, Càit, said: ‘I believe it is a specialty. I have come across nurses and healthcare assistants that cannot look after someone with dementia.’

All participants acknowledged the importance of competent healthcare professionals delivering care to people with dementia. For Cahill et al (2012), acute healthcare professionals will find caring for people with dementia stressful and challenging without the necessary training and upskilling.

A dominant area of discussion was the role of ‘specialling’ and the qualities necessary to fulfil that role. Specialling involves the constant supervision of a patient by a healthcare professional in order to prevent the patient from harm or injury. Alisha thought that education was paramount for specialling and alluded to management’s direction of ‘they need more instructions than just to sit there and do not let them fall’. Another participant, Bronagh, viewed specialling as a solution because it offers reassurance to anxious and disorientated people with dementia, thereby maintaining their safety. Similarly, Càit thought that ‘there needs to be something in place for their [older people with dementia] safety and to reduce the workload of nurses’.

All participants said that specialling was warranted due to hectic ward environments and staff shortages. This exercise, according to Dewing and Dijk (2014) misses out on the meaningful engagement by healthcare professionals in caring for individuals with dementia.

All participants spoke about the importance of family involvement with people with dementia in acute settings to improve their healthcare experience. One participant, Emma, referred to contacting family in times of heightened distress, resulting in family engagement and more effective treatment, as a result of the familiarity of family. Emma said: ‘She was out of her environment. It was out of character for her. So we asked the family to stay. Families are great.’

Alisha said that caring for people with dementia as an added burden. Alisha reflected on her initial thoughts and feelings when she realised the next person to care for on the ‘list’ was someone with dementia. Phrases used by Alisha were ‘more difficult’, ‘this will take longer’, ‘it will slow us down’ and ‘we will get out of here later’.

Another participant, Triona, asked: ‘Am I going to need more staff?’ and ‘how will I cope with them all?’, adding ‘this is extra work’. Finally, Càit said: ‘You could have three or four patients with dementia wandering and then you have your nursing notes to do’. This discourse of burden indicates the everyday realities for healthcare professionals in acute settings. Participants acknowledged the difficulties they encountered, the burden to care and their own coping strategies.

The second discourse related to the coping strategies adopted to overcome difficulties in caring for people with dementia. All participants agreed with Càit when she explained that caring for people with dementia was emotionally and physically demanding: ‘I have had days where I say I just want to go home’, ‘I go off into a room and take deep breaths and cry’ and ‘You feel exhausted, you feel inadequate’. Emma described a situation in which she felt ‘frustrated’ due to time and staff shortages. She thought that education and training were paramount to overcoming these challenging emotions, and to ‘do better next time’.

Organisational culture

Participants spoke at length of the effect of the acute healthcare environment on people with dementia. Additionally, participants discussed the busy schedule of the acute setting and the effects of management’s decisions on patient care.

Participants discussing the culture of the organisation referred to the hectic working setting...
schedule, ward layout and placement of people with dementia. Alisha explained that the ethos of care and culture in the day ward was task focused: ‘Day ward is a fast-moving unit and spending time talking to people with dementia is not something we do.’

All participants had a shared understanding that the structural layout of the environment was not conducive to the provision of optimum healthcare, and that this influenced how they planned and delivered care. Participants felt reassured when they had tried their best to overcome these deficits. They spoke about trying to individualise care but referred to a strict routine in the acute setting. For example, Bronagh said: ‘We just have to fall in with that routine’. According to McCormack et al (2013) healthcare professionals need to become self-aware, thus not accepting the ritualised and taken for granted practice, instead laying out standard best practice within an organisation, which in turn will lead to change of attitudes and behaviour.

Participants drew on the discourse of organisational culture to emphasise the role of management and the influence of its decisions on ward culture. Predominantly, participants spoke about management reviewing the number of patients on the ward and deciding on staffing levels based on this figure. Participants thought that management does not consider patients’ backgrounds, but instead refers to them as numbers when deciding on staffing levels. In this context, the Francis Report (Francis 2013) warns that organisations’ preoccupation with savings, targets and processes can lead to patient neglect.

Identity discourses

Maternalistic

When describing people with dementia, participants tended to adopt mothering instincts and create child-like identities for the people they cared for. Alisha said: ‘If it keeps them happy and calm, then I am happy.’ Emma commented: ‘You need someone there to encourage them and maintain their safety.’ Cáit said: ‘Sure, it is like minding a child.’

Another participant, Bronagh, displayed her maternal instincts by saying: ‘They know what they like, how they like to be tucked into bed. The staff in the nursing home know all those little quirks, which comes with continuity of care and familiarity.’ This discourse suggests that among carers’ main concerns are pacifying people with dementia, doing things for them and maintaining their safety, all functions associated with maternal nurturing.

Paternalistic

Most participants adopted paternalistic language when describing incidents, resulting in the constructions of disempowered, weak and fragile images. Cáit said: ‘The minute the patient moves they [the care worker] say “Go on, get back into bed”’. The context was that of protection and preventing patient harm, thereby disempowering the individual with dementia through their dominance in decision making. Another participant, Lorraine, said: ‘Their [the patients’] choice is kind of taken away from them a little bit due to their dementia and we make all the choices for them.’ The participants who adopted a paternalistic discourse limited the autonomy of people with dementia, thereby creating the identity of a weak and fragile person.

Prejudicial

Participants adopted a prejudicial discourse by constructing a prejudiced identity for people with dementia. Some examples of prejudicial language include: Cáit referring to delayed discharges as ‘bed blockers’; another participant, Máire, using the phrase ‘mentally very unstable’; and another participant, Triona, used language such as ‘dementia patient’, ‘demented patient’, ‘poor woman’ and ‘…but this poor man, no matter what you did with him he still looked filthy. Because it was just the way he was’.

The language and descriptions used by some participants were negative, prejudicial and paternalistic, and do not reflect the philosophical underpinnings of best care practice. This may be because of the task-focused culture in the acute setting, which has a negative effect on the overall performance of the acute healthcare setting and healthcare professionals’ morale.

Medicalised and person-centred

Participants adopted medicalised and person-centred discourses when describing their experiences of caring for people with dementia. Bronagh provided examples of person-centred discourses when she stated, ‘the lady was’ or ‘the gentleman’, in contrast to ‘dementia sufferer’ (Cáit) or ‘demented patient’ (Triona). Emma focused on a medical discourse: ‘It’s sad they are vulnerable... because we are a busy medical ward it’s hard… to give them the time that they need.’

In contrast, Natalie focused on person-centred discourse and constructed a person-centred identity of an individual with dementia: ‘[it] does not matter if the patient has dementia, everyone has to be cared for
either way and they are a person and not to lose sight of that is very important.’
Medicalised discourses used by participants were task focused and resulted in a medicalised identity of the person with dementia, in which the patient assumed a passive role and the professional assumed an identity of an expert. From this perspective, McKinlay and McVitie (2011) claim that patients are expected to demonstrate illness, while professionals make decisions on the well-being of these patients and decide on the appropriate course of action.

Discussion
The qualitative aspect of this study provided participants with the opportunity to focus and draw on specific discourses that outlined important pillars for caring for people with dementia. The three pillars of competency in caring for people with dementia, emotional challenges and organisational culture are integrally linked and reflect a strong heuristic framework on the current discourses used by participants.

Participants drew on the discourse of competency to care as they acknowledged their own competency deficits. Healthcare professionals need to remain committed to continuing professional development (CPD). The Irish National Dementia Strategy (DH 2014) stated that it is essential for all healthcare professionals working with people with dementia to have knowledge and awareness of dementia and to possess the appropriate skills to deliver optimum care.

Participants talked about the effects of family involvement, specialising and caring for people with dementia as if they were part of their own families. Drawing on the competency to care discourse emphasised participants’ heightened sense of the need for appropriate nationally agreed standards of care for people with dementia.

The discourse of emotional challenges to caring touched on the everyday realities for healthcare professionals in the acute setting. Participants drew on this discourse as they acknowledged the difficulties encountered, the burden to care and their own coping strategies. Perhaps participants drew on this discourse as they were reflecting on the cognitive dissonance they experienced while caring for people with dementia. On the one hand trying their very best to deliver optimum patient care but on the other hand restricted in doing so thus, resulting in emotional challenges in caring for individuals with dementia.

Healthcare professionals must engage in critical self-reflection to improve their practice and to overcome the challenges of the acute environment. Nursing can be emotionally demanding, and reflection is an opportunity to address the negative feelings that may otherwise overwhelm nurses (Caldwell and Grobel 2013).

The discourse of culture is important and affects care delivery and the overall development of policy and guidelines. Organisational culture influences an organisation’s effectiveness and is dependent on values, beliefs and attitudes (Aktas, et al 2011). Organisational culture needs to change for practice to change. Healthcare professionals are striving to deliver person-centred care, but their efforts are foiled by a culture that continues to be driven by the medical model. A medical culture dominates care delivery, which challenges nurses to be instigators of change and enact a more person-centred approach.

This qualitative study also identified specific discourses that constructed identities. Subjective identity, or who we are to ourselves, and projected identity, or how we want to be seen by others, were considered. Along with social desirability, participants may have wanted to display their projected identities throughout this study. This theme was analysed using thematic analysis and resulted in the creation of different themes which focused on specific discourses and related identities. According to Evans (2014a), constructed identities may influence behaviours and as a result policy development.

Maternalistic and paternalistic discourses were adopted and resulted in specific identity constructions of individuals with dementia. The adoption of these discourses disempowers the person with dementia and fails to recognise their life experiences or their uniqueness, despite healthcare professionals’ intentions. According to Evans (2014b), identities are constructed in specific sociocultural contexts.

Participants adopted prejudiced language to describe hostile or unfavourable comments about people with dementia, and subsequently a prejudiced identity was constructed. Prejudicial and negative discourses capture the burden of caring for people with dementia in the acute setting. Participants undervalued and undermined the capabilities of people with dementia and seemed unaware that, through their own storytelling, they occasionally constructed people with dementia in negative and prejudicial terms when focusing on aspects of caring, therefore reinforcing a negative identity.

Medicalised discourses created an identity of a sick patient. Person-centred discourses
resulted in an empowered identity of the person with dementia. There are several solutions to reverse the negative constructions of medicalised discourses, including education and training, and individualised care planning in the acute healthcare setting. McCormack et al (2013) discuss the need to disrupt practices associated with routine and ritual care, and aim instead for individualised approaches to practice. The discourses associated with the interaction and care of people with dementia may have had a direct or indirect link to the identities constructed for people with dementia.

Limitations
This study was undertaken in one health region in Ireland; cultural influences and organisational variables may have influenced results. A different location, setting, culture and experiences could produce different findings. In addition, due to the relatively small sample size, broad generalisation of the results was precluded.

Conclusion
Healthcare professionals strive to be person-centred but often are task orientated. It is difficult to focus on person-centred care when there is a prevailing culture based on the medical model: admit, diagnose, treat and discharge home. This study provides an awareness of the acute healthcare experience of people with dementia. Caring for people with dementia is challenging in the acute healthcare setting and this study reinforces the need for ongoing training and effective strategies on CPD. The importance of person-centred care is clear, but is it aspirational to practise a person-centred ethos of care in the acute healthcare setting?

References

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