Preferences of residents with dementia for end of life care


Abstract

Aim To explore the preferences of residents with dementia for their end of life care, and nurses’ perceptions of these preferences.

Method Residents’ preferences were compared with nurses’ perceptions of their preferences in a qualitatively designed study in which the nominal group technique was adopted for data collection.

Findings Some of the residents’ preferences for their end of life care matched nurses’ perceptions of their preferences, but differences were identified. Residents emphasised comfort, family presence, familiar staff and surroundings; nurses thought that residents would want good communication, pain management, advance care planning, being cared for by knowledgeable staff and the inclusion of their families.

Conclusion End of life care needs are individual and a generic approach is not a sufficient standard of care for people with dementia. Patients should be included in studies about their needs and preferences for future care to provide a holistic approach to end of life care, and to develop evidence-based standards.

Keywords
dementia, end of life care, long-term care, resident nursing, nominal group technique

Dementia affects people’s memory, thinking, comprehension and judgement; therefore, we should record the needs and wishes of each person with dementia in the early stages of the condition (World Health Organization (WHO) 2016). The National Institute for Health and Care Excellence (2010, 2014) guidance for dementia recommends a palliative approach from the time of diagnosis. Healthcare professionals, particularly nursing staff, must decide on patient-centred care for people with dementia before the development of communication problems (Davies et al 2014). To do this they must know the preferences for end of life care for each person they care for.

Literature review

Many people with dementia make no formal plans for their end of life care (Dickinson et al 2013) and healthcare professionals often make decisions on behalf of patients (Goodman et al 2013). Nurses may not always consider dementia as a palliative care diagnosis (Kaasalainen et al 2007) or know when to introduce palliative care for people with dementia (Thuné-Boyle et al 2010). McCarron et al (2010) point out that knowing a patient is essential to providing him or her with quality care at end of life, and Sims-Gould et al (2010) found that family-like bonds aid patient-centred care. Davies et al (2014) suggests that the varying palliative care needs of patients with dementia can affect care delivery.

Reasons for poor palliative care include: nursing workload (Johnson et al 2014), poor communication (Sims-Gould et al 2010, Johnson et al 2014), task orientation where the focus is on the task rather than on the person (Sims-Gould et al 2010) and lack of staff education (McCarron et al 2010, Sims-Gould et al 2010, Thuné-Boyle et al 2010). Reamy et al (2011) found that, according to people with dementia, important aspects of end of life care include autonomy and control, family involvement and not being a burden. Sims-Gould et al (2010) state that staff should be comfortable with open discussions about end of life care, yet only a few studies on the subject have included patients with dementia or reflect their preferences.
Aim
The aim of this study was to explore the preferences of residents with dementia for their end of life care, and nurses’ perceptions of these preferences.

Method
People with dementia living in a residential care facility and their nurses were recruited with the permission of the facility’s manager. The nominal group technique, a semi-evaluation method involving qualitative and quantitative approaches (Harvey and Holmes 2012), was adopted for the study. There are five stages to the nominal group technique (Table 1) and all stages were completed for this study.

Two nominal groups of six residents diagnosed with dementia and six nurses took part in separate discussions in one long-term care facility. The residents were clinically diagnosed with mild dementia based on a Mini Mental State Examination score of 18 or over and the ability to provide informed consent (Folstein et al 1975).

All the nurses involved had worked in long-term care for at least six months. Group discussions were audio recorded with the permission of participants. The researchers documented the main points of the discussion and ranked the preferences of the participants. Data were coded using a manifest content analysis method (Vaismoradi et al 2013).

Ethical considerations
The residents with dementia were provided with appropriate written information on the study and their informed consent to take part was obtained. An independent advocate was present during the resident focus groups and the study was approved by the local research ethics committee.

TABLE 1. Nominal group technique stages

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
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<tbody>
<tr>
<td>1 Brainstorming and generating</td>
<td>Generation of ideas on the research question; the researcher recorded these on a flip chart</td>
</tr>
<tr>
<td>2 Recording</td>
<td>Group discussion on the research question; discussion to clarify and rationalise ideas from stage one. Ensured all participants had been given a chance to participate; further generation of ideas</td>
</tr>
<tr>
<td>3 Discussing</td>
<td>Further discussion and generation of ideas; post hearing the idea of others</td>
</tr>
<tr>
<td>4 Analysing</td>
<td>Ideas noted; ideas from stages 1 to 3 were discussed further and justified</td>
</tr>
<tr>
<td>5 Ranking</td>
<td>Ideas were ranked individually by each participant and a consensus formulated</td>
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(Harvey and Holmes 2012)

Findings

Ranking of preferences and ideas
The residents’ preferences for end of life care and the nurses’ perceptions of their preferences are ranked in Table 2. The groups ranked their preferences differently, with the nurses focusing on the clinical and professional aspects of care, and the residents’ preferences reflecting fundamental human needs. Both groups identified ‘communication’ and ‘family involvement’ as important.

Residents’ preferences
Comfort and peace
Comfort at end of life was described as ‘pain free, worry free’ and ‘quiet and peaceful surroundings, not too much noise’. It was understood to be physical and emotional, and to involve ‘being at ease, no stress’. One participant said that he would go to hospital only if he had to. I don’t want to be moving around’.

My family
Participants were unanimous about the importance of family. One resident stated: ‘I’d like my family there, all of them. The most important thing to me is my family.’ Another explained that he wanted to be ‘surrounded by people who know and love me’. Another included friends: ‘You’d want friends calling, but not too many.’

Reflecting on a conversation with his daughter, one participant said: ‘It’s not a great thing to talk about but it happens to us all. My daughter asked me once about funeral arrangements and I told her exactly what’s to happen.’

My own things
Residents deemed having their belongings and a room of their own as important.
As one resident said: ‘I want to be able to do my own thing and remain in my own room undisturbed.’ Many residents identified items that they wanted in their environments. These were mainly items of personal meaning or items that offered comfort. As one participant suggested: ‘I would like to be surrounded by my family photos of times gone by.’ Another participant said that ‘when you can’t be at home, your room is the nearest thing to being home.’ Residents placed great emphasis on reminders of their past.

I want you to talk to me
Throughout all phases of data collection, residents reiterated the importance of communication and their wish to be kept informed – ‘I’d like to know what’s happening around me’ – in spite of receiving end of life care. Others thought that staff may withdraw from them at end of life: ‘I want staff to still talk to me too, you, know.’ Poignantly, one participant expressed a wish not to be alone: ‘Not being alone is important to me, my wife already passed away and I made sure she wasn’t alone. I want visitors. Everything is important in your last few days.’

People that know me
Familiar staff were seen as important. Most residents referred to the staff as ‘companions’ and ‘kind, staff who know me’. One resident feared that staff would step away and hoped that ‘the staff here would call on me’. Others stressed the importance of staff knowing what they wanted.

One resident said: ‘I’d like people to know what I want. You’d want them to know you, wouldn’t you, if they are there when you are dying?’ Another resident said: ‘I wouldn’t like to be cared for by people I don’t know.’ The importance of creating the right atmosphere was articulated: ‘Staff are important; they can make the place.’

Nurses’ perceptions of resident preferences

Effective communication
The nurses thought that open communication, support and reassurance were important in end of life care. For example, one said that nurses should be aware of communication deficits: ‘Non-verbal cues such as agitation, crying, restlessness may help indicate a care need not being met.’

Another nurse emphasised that patients with dementia may be at risk of poor quality care if they cannot communicate: ‘They can be quite vulnerable as a group of people and you don’t want them to receive lesser care.’

Another nurse highlighted the importance of patient information and disclosure, saying that ‘the doctor needs to be included in diagnosis disclosure or discussions’.

Pain management
Pain management was introduced by nurses as an important aspect of end of life care. They discussed pain assessments such as ‘the Abbey pain scale and the WHO pain chart’ (Abbey et al 2004, WHO 2017). One participant stressed that nurses’ knowledge of the ‘assessment of non-verbal patients is key’. Another stressed the importance ‘of support and reassurance’.

Advance care planning
Nurses emphasised the importance of ‘establishing preferences, especially when the patient is first admitted to the long-term care facility’. Another nurse thought it was important to ‘embrace spiritual care, not just religious care’.

Care planning was advocated to ‘prevent unnecessary actions’. As one nurse said: ‘An end of life care plan is essential – something in place outlining what their preference would be as the disease progresses.’ The importance of early planning was stressed: ‘It would be best if their preferences were discussed at the early stage of dementia.’ Another nurse emphasised the importance of recording specific details: ‘You have to ask them if they want to die here in the nursing home or whether they want to go to the hospital if they get sick.’ However, early planning can be challenging for staff, as one nurse explained: ‘The sad thing about it is that it is often taboo to discuss end of life care for someone with Alzheimer’s as progression can be gradual.’

Family inclusion
Nurses considered ‘inclusion of family members, and engaging with them and their families verbally and regularly, as especially important’.

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**TABLE 2. Rankings of residents’ preferences for end of life care and nurses’ perceptions of their preferences**

<table>
<thead>
<tr>
<th>Ranking</th>
<th>Residents’ preferences</th>
<th>Nurses’ perceptions of residents’ preferences</th>
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<tbody>
<tr>
<td>1st</td>
<td>Comfort</td>
<td>Communication</td>
</tr>
<tr>
<td>2nd</td>
<td>Family involvement</td>
<td>Pain management</td>
</tr>
<tr>
<td>3rd</td>
<td>Familiar surroundings</td>
<td>Advance care planning</td>
</tr>
<tr>
<td>4th</td>
<td>Communication</td>
<td>Family involvement</td>
</tr>
<tr>
<td>5th</td>
<td>Familiar staff</td>
<td>Staff knowledge</td>
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One nurse described the importance of ‘an initial family meeting to include the resident’. Another nurse was concerned about family decisions on whether to disclose a diagnosis to a resident: ‘Families sometimes don’t want you to tell the patient that they have dementia and this is something that needs an open debate. It’s a big learning curve for people.’ The nurse added: ‘It might be easier for the residents if they knew. Some don’t realise that they have dementia and their family don’t want them to know.’

Another nurse had an alternative view: ‘It’s all well and good saying I have to tell the resident their diagnosis, but you are overriding their family’s wishes, and that is a hard thing to do when you want to gain their trust and support.’

**Staff knowledge**

During the course of the discussion nurses questioned their own knowledge and confidence in providing palliative care. As one participant stated: ‘Sometimes, I don’t feel knowledgeable about end of life care. I would like more education and discussion. It opens my eyes.’

Nurses also discussed the importance of having support from ‘chaplancy counselling services’ or ‘advocacy services’. Nurses thought that these services are important because they allow them to deliver on patient preferences. The importance of ‘the life history from the person themselves if they can give it and, if not, from their families’ was also stressed.

**Discussion**

The results of this study reflect other research in the area. Comfort is an important component of end of life care, as noted by Casey et al (2011). In our study, the comfort needs expressed by residents were of a holistic nature – they discussed being pain free and at peace, with no worries – while the nurses focused on pain assessment and management. Casey et al (2011) acknowledge the importance of symptom and pain management as essential components of care at end of life.

The nurses in our study noted that it is important to be aware of behavioural cues to distinguish pain because recognising pain in dementia is often difficult. Albrecht et al (2013) found that pain is noted in patients with dementia less frequently than those without dementia, while Lee et al (2013) note that nursing staff may lack knowledge about pain management for people with dementia. Lee et al (2013) also note that staff do not always disclose terminal diagnoses to patients.

The challenge of disclosure was highlighted by nurses in our study too, and their opinions on the family’s role in deciding on whether to disclose the diagnosis were divided. An understanding of the dementia trajectory may help residents, families and nurses with end of life care.

Nurses identified poor communication as a barrier to providing holistic care, which is consistent with the findings of previous research (Sims-Gould et al 2010, Johnson et al 2014).

One important result from this study is the preference expressed by the residents for familiar surroundings and having their own things around them. This preference was not overtly identified by the nurses, even though palliative care in familiar surroundings is considered a goal of good end of life care (Goddard et al 2013, Reyniers et al 2014). Both sets of participants ranked the involvement of family as important. While nurses valued families for their knowledge of the residents, the residents valued the presence of families at the end of life, as other studies have described (Thuné-Boyle et al 2010, Reamy et al 2011, Dening et al 2013, Dickinson et al 2013, Johnson et al 2014).

These studies also acknowledge that communication is vital to palliative care. Most residents wanted to be kept informed, even if they were to experience reduced cognition. Some residents expressed hopes that nursing staff would continue to communicate with them when they are dying. This is important because it suggests that people with dementia may need reassurance that nurses will not withdraw from them at this crucial time. Advance care planning did not feature in the residents’ discussions. Nevertheless, while residents did not use the terminology, they could articulate their preferences about end of life care. This finding emphasises the importance of consulting patients while they can talk about their preferences.

Van Soest-Poortvliet et al (2015) found that discussion on advance care planning when people are admitted to a residential home increases their overall satisfaction with the care they receive. However, while people with dementia often make formal plans for their practical and financial futures, they do not often make formal plans for their future healthcare (Dickinson et al 2013).

Many people with dementia find it difficult to comprehend the future, and therefore cannot understand how expressing preferences and wishes for their end of life would help with future care.
Nevertheless, it is imperative that healthcare professionals develop patient-centred care plans with patients who have dementia before any communication and cognition problems make this difficult (Davies et al 2014).

Knowing the person and developing a relationship are crucial to quality end of life care (Casey et al 2011), and can prevent unnecessary hospitalisation (Li et al 2013).

Knowing the person allows staff to interpret treatment and care wishes if the patient develops communication difficulties, and allows staff to distinguish behaviour from distress (Brazil et al 2012).

Findings from our study suggest that residents recognised the importance of staff being familiar with them to enable them to achieve their preferences. The busy environments in which nurses work can make the delivery of palliative care difficult (Casey et al 2011, Johnson et al 2014), and staff need time to establish relationships and gain residents’ trust. This echoes Dening et al’s (2013) finding that dissatisfaction with end of life care for people with dementia is associated with poor education, while other researchers note that nurses do not always view dementia as a palliative care diagnosis (Kaasalainen et al 2007, Casey et al 2011).

Limitations
This study was conducted with a small sample of residents and nurses in one care facility, and the results may not be generally applicable to all people with mild dementia and their nursing staff. However, the nominal group technique provides a structured process to assist participation by individuals, establish priorities and reach a consensus. This is especially important in research involving people with dementia who are likely to have problems with communication and recall.

Conclusion
Nurses should ensure they listen to people with dementia, and reassure them that contact and communication will continue at end of life. People with dementia are more likely to feel safe in places they know as home, surrounded by their possessions and with people that they know. The inclusion of people with dementia in decisions about their end of life care is central to meeting individual care needs.

References


National Institute for Health and Care Excellence (2014) Dementia Overview Pathway. pathways.nice.org.uk/pathways/dementia-overview.xml&content=view-index


