Nursing home residents' views on dying and death: nursing home employee's perspective

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Aim. To reveal nursing home employees' views on dying and death among older people they cared for.

Background. Palliative care stakeholders recently included more groups in their definition of palliative care; older people constitute one such group. Consequently, palliative care systems, which will serve a large, aging cohort, will require new skills. The first stage in skills acquisition is to gather current views on dying and death.

Design. Qualitative descriptive study that uses focus group discussions for data collection; 20 employees in 4 Swedish nursing homes participated.

Method. Data were analysed using qualitative content analysis.

Results. The following categories were conceptualised: alleviating suffering and pain; finding meaning in everyday life; revealing thoughts and attitudes about death; taking care of the dead person's body; and coping with the gap between personal ideals and reality.

Conclusions. A deeper understanding of the palliative care philosophy is needed to further develop and tailor care for the dying persons in nursing homes.

Relevance to clinical practice. To get public support for palliative care, the silence surrounding dying and death must be broken. Employees must receive education to prepare for all aspects of their work, and management must account for employees' situation when planning the care.

Key words: content analysis, death and dying, end-of-life care, nursing home, older people, palliative care

Introduction

One fundamental palliative care principle is provision for an individual's physical, psychological, social and spiritual needs (WHO, 2004). In recent years, palliative care stakeholders expanded and included groups other than cancer patients (WHO, 2004), namely, older people. This creates new challenges and opportunities and puts new demands on staffing skills within care systems for older persons (Seymour *et al.*, 2004; WHO, 2004; Gott *et al.*, 2008). Older people often suffer from many varying illnesses and several functional impairments (WHO, 2004; Gott *et al.*, 2008). This can lead to a multifaceted dying process – in comparison with younger persons (Borglin *et al.*, 2005; Gott *et al.*, 2008). As western populations age, older people will increasingly end their lives in nursing homes (Phillips *et al.*, 2006). Consequently, nursing homes will become significant facilities during this process (Froggatt, 2001; Froggatt & Payne, 2006; Pleschberger, 2007; Wowchuk *et al.*, 2007).

Other fundamental palliative care principles are (1) to view death as a natural part of life and (2) to enable a *good death* (WHO, 2004). Weisman and Kastenbaum (1968) states that an *appropriate death* – often called a *good death* – is a death that a person might choose, if given the option. So the dying person is the only person who knows what a good death means to him or her. Consequently, care must be based on the dying person and their self-image, identity, needs and wills (Ternstedt *et al.*, 2002). Studies show that *good end-of-life care* among older people enables them to retain their self-image and identity and to experience a meaningful existence (Choi *et al.*, 2008; Fischer *et al.*, 2008). Other studies describe a meaningful existence in end-of-life care as the result of receiving support and being able to express thoughts and feelings about death (Fry, 1990; Rappaport *et al.*, 1993; Chan & Pang, 2007). While in recent years, research focused on end-of-life care among older people, little research has been done on meaning that nursing home employees assign to dying and death of older people.

Aims

The study's overall aim was to reveal nursing home employees' views about dying and death among older people for whom they provided care.

Objectives

The study's objectives were to:

- Gather thoughts (and subsequently new knowledge) about caring for older persons in nursing homes as they go through dying and death.
- Find out what Nursing Assistants (NAs) and Registered Nurses (RNs) believe is 'good' care at the end of life.
- Use possible gathered knowledge to implement change within palliative care in nursing homes.

Methodology

A qualitative approach was selected to reveal employees' views on dying and death. We hypothesised that interaction among employees could encourage discussion of (1) complex phenomena involved in caring for dying persons and (2) what the employees knew about the dying persons. So data were generated from focus group discussions (FGDs), which are deemed suitable when concerns, experiences, attitudes and perceptions related to a clearly defined topic or concept are sought (Webb & Kevern, 2001; Barbour, 2005). FGDs are also relevant when interaction and group processes can aid in clarifying perceptions that are important for the results (Kitzinger, 1995).

Participants

After receiving information about the study's aim, 16 NAs and 4 RNs (16 females and 4 males) in four nursing homes in a Swedish town agreed to participate. The RN's had basic nursing training, including 3 years from nursing school. Depending on which school they had graduated from the focus on older people varied. Education levels varied among the NAs (from a 2-year course mainly focused on care for

Table 1 FGD participants' characteristics

Gender	RNs (<i>n</i> = 4)	NAs (<i>n</i> = 16)
Female	4	12
Male	0	4
Age (30–40 years)	30–40	18–40
Education related to older people	4	9
Earlier experience caring for older people	4	12

older people to no education on the care of older people). Years of experience also varied: NAs' experience in caring for older people in a palliative care setting ranged from 0 to 20 years; this range for RNs was from 3 to 10 years. See Table 1 for more details.

Data collection

Seven FGDs were held. In each discussion, participants were asked to reflect on what they knew about an older person and the person's dying and death. Professional transcribers documented six, taped discussions and one live discussion (due to recorder problems). The documented discussions described the dying and death of 6 women and 1 man, aged 83–95.

The six Ss

In this study, six key words facilitated collection of each deceased person's end of life. The six Ss are inspired by Weisman (1974, p. 150) who formulated six questions as a method for analysing peoples dying and death. This method has been further developed and adjusted to a palliative nursing context, and are abbreviated in six keywords: self-image, self-determination, social relationships, symptom control, synthesis/sense of coherence and surrender (Hermansson & Ternestedt, 2000). The six Ss are described as an operationalisation of the palliative care philosophy and are described useful in care planning, documentation and evaluation of care (Ternestedt *et al.*, 2002; Ternestedt, 2009). The method, which covers physical, psychological, social, existential and spiritual needs, is intended for promoting implementation of the palliative care philosophy. The keywords are considered an integrated whole, which originates from an individual's self-image, identity and lifestyle (Table 2).

Focus group discussions

The FGDs occurred in a secluded area in the nursing home; they focused on deepening understanding of the dying person

as an individual and the person's dying process. Open-ended questions (conversation starters) were asked in relation to each key word. This method enabled the authors to (1) collect thoughts about caring for older persons and (2) find out what FGD participants believe is good care at the end of life – knowledge that might be implemented in care of older persons.

The RNs and NAs introduced the person whose death, dying and care they were going to focus on. One criterion for an FGD was that all group members had cared for the person at the end of the person's life. A moderator (LLD) and one observer (BMT) led the FGDs that started with a short introduction of the study's aims. During the FGDs, many conversations naturally referred to areas that pertain to the six Ss. For FGDs, in which an area did not naturally arise, further questions such as these were asked:

- Who was Anna (all names in this paper are fictitious)? Please tell me about her.
- What did she like to do in everyday life?
- How did you perceive the end of her life?
- What had been important to her in earlier life?
- What were her thoughts about death?

Two to five employees from the same unit participated in each FGD. When planning the study, the intention was to include five to six employees, which proved impossible due to organisational factors. The number of participants depended on the workload and number of employees at work on the day the FGD occurred. NAs were overrepresented in relation to RNs in all nursing homes. This overrepresentation paralleled participation in the FGDs, which lasted between 1 and 2 hours and were held on a single occasion between 2 weeks and 4 months after a person's death.

Data analysis

Qualitative content analysis (Patton, 2002) was used for analysis of the FGDs:

- 1 Text from each FGD was read through in an open manner to get an impression of the whole.

Table 2 The six Ss, a method for gathering information

Self-image	Self-determination	Social relationships	Symptom control	Synthesis or sense of coherence	Surrender
What was known about the person? What had been and what was important to him or her?	What did the person wish to do in every day life? What decisions were important for the person to be involved in?	What relationships were important to uphold for the person?	What symptom relief did the person have? Did it help?	What provided meaning at the end of the person's life?	What did the person need to prepare for before death?

Table 3 Procedure for analysing employees' views on dying and death

Codes	Codes related to six Ss	Main concepts
She read magazines... yes lots of magazines and she also watched a lot of TV Did she speak about her life at all?	Self-image Social relationship Self-determination	Finding meaning in everyday life
Sometimes she did, when we had coffee It changed totally from one day to the next. It was so quick... she decided not to live any more	Surrender	
Her son was abroad and due back a week later. It seemed that she would have died much earlier if she had not waited for him to come home. From Monday until Wednesday she was <i>unconscious</i> , totally in her own world, she just lay in bed. On Thursday, some close friends came ... and it seemed as if she knew that they were there. ... When I went to her room and told her that her son would soon be here, it was almost as if she understood and for a little while she was with us again. When he finally arrived on Friday and had been with her for about 15 minutes, she died	Social relationship Synthesis Surrender Self-determination	Revealing thoughts and attitudes about death
Esther was not really alone, but we should have been there for her because we knew that she was dying	Social relationships Surrender Synthesis	Coping with the perceived gap between personal ideals of dignified care at the end of life and what they could provide in reality
She was given paracetamol, but I don't think that is sufficient for pain relief, I mean I worked in a hospital No, she was also given other types of pain relief but her bowels started to bother her	Symptom control	Alleviating suffering and pain

2 Codes related to the six Ss were sought and marked in the text to capture areas relevant to the aim; see Table 3.

3 The codes shed light on significant words, statements and key phrases concerning experiences related to the study's aim.

4 The codes were grouped, and concepts were developed. Relationships among concepts were identified and sorted into core elements and thereafter into five main concepts.

Ethical considerations

Managers at three nursing homes asked NAs and RNs if they would be interested in participating in the study. Those who volunteered were scheduled for FGDs. The participants received information about the study, confidentiality and the right to withdraw at any time. Although some grammatical changes were made when the quotations were translated from Swedish into English, great care was taken to avoid changing their content. The local research ethics committee approved the study (application number 171-01).

Results

The results are based on employees' descriptions of dying and death of six females and one male. Of these older persons, two had lived in the nursing home between 6 months to

1 year and 4 had lived in the nursing home up to 2 years. All suffered from physical and psychological illnesses before their deaths. NAs mainly cared for them. RNs supervised several wards at the same time and were not involved in basic personal care. Five main categories were conceptualised from the analysis: (1) Alleviating suffering and pain. (2) Finding meaning in everyday life. (3) Revealing thoughts and attitudes about death. (4) Caring for the dead person's body. (5) Coping with the perceived gap between personal ideals of dignified care at the end of life and what they could provide in reality.

Summary of the findings

Of the five categories, participants said that category 1 and 2 were important for a good death: *alleviating suffering and pain* and *finding meaning in everyday life*. When employees talked about the deceased person's end-of-life care, death was mainly described as an expected outcome and was not given special attention. Varying opinions were expressed regarding what was considered to be adequate pain relief, which led to disagreements among FGD participants. Meaning was mainly described in terms of family and friends, relationships and the time they spent together with the dying person. Category 3 *Revealing thoughts and attitudes about death* reveals that the NAs and RNs did not know the dying person's thoughts,

attitudes, and feelings about dying and death. Category 4 *caring for the dead person's body* describes how the dead person was cared for. Routines for taking care of the dead body appeared to have existed in each unit, mainly based on the staff members' beliefs about what older persons would have wanted. Category 5 *Coping with the perceived gap between personal ideals of dignified care at the end of life and what they could provide in reality*. This category relates to ethical issues that NAs and RNs encountered in their daily work. Ethical reasoning mainly dealt with how they coped with the perceived gap between their personal ideals of dignified care at the end of life and what they were able to provide in reality.

Alleviating suffering and pain

The older people suffered from multiple illnesses and other health problems. FGD participants said that they were not always diagnosed medically but all were in great need of help – need that increased during the final months. Some participants said that many of the older people suffered from back problems and joint pain. Insecurity was a common feeling among participants when describing the older person's illness and health problems, even when the participants initiated the discussion. Some believed that they lacked the knowledge and education to discuss such a subject.

Discussions generated from the *symptom control* key word revealed a sensitive issue in three of the seven FGDs, namely, whether or not the older person's pain relief had been optimal. Discussions among some participants became quite heated and led to a tense atmosphere.

FGD case

Varying opinions about the older person having sufficient pain relief led to disagreement among FGD participants. This excerpt covers Anna's care; she suffered from pain for about 2 years:

Celia (NA): She was given paracetamol, but I don't think that's sufficient for pain relief. I mean I worked in a hospital.

Karen (RN): No. She was also given other types of pain relief, but her bowels started to bother her.

Celia: I don't think she had sufficient pain relief. I wouldn't want the end of my life to be like hers.

Karen: But they couldn't give her any more.

Celia: I don't know. Maybe it's lack of knowledge. I still think that she didn't get enough pain relief.

Karen: But that is something that we can't really do anything about. We can report it – that's all.

Karen felt that they had done what they could to meet Anna's pain relief needs, and she described feeling angry and sad because she felt Celia had attacked her. The discussion between them affected other FGD participants who chose not to get involved. But some felt that the pain relief was not as good, because RNs no longer actively participated in the care. A similar discussion occurred in another FGD in another unit and nursing home, and group interaction was affected in a similar way. According to the NAs, it was relatively common for the older person to suffer from pain before death. They said that the RNs and the physicians who made decisions about extra pain relief did not have personal contact with the person in pain and thus lacked enough knowledge of the dying person's everyday life. An uncertain attitude toward the older person's pain was described in terms of feeling powerless regarding symptom control. Some FGD participants thought that they lacked the knowledge or education to comment on this factor. According to the FGD participants, most older people suffered from pain at the end of their lives.

Finding meaning in everyday life

FGD participants emphasised that visits from family members and friends constituted the most important factor for providing meaning in the older person's everyday life. These visits were described as bringing light and happiness into the older person's life. FGD participants described one woman whose face lit up when her husband arrived; they agreed that to feel loved was meaningful. Visits from next of kin also improved the older person's sense of safety.

FGD case

Ruth, age 95, was very popular among the FGD participants. She found meaning in doing what she always had done, namely, reading magazines and watching TV.

Sara (NA): She was tired. Some days she just did not want to get out of bed and that's OK, I guess [chuckle]. I mean if you're 90 plus, then I think that's OK as long as you're *not* in bed all day, every day.

Susanne (NA): It was like that when she was at home as well, one week she would just stay in bed and then she was up and running again.

Sara (NA): It varied from day to day.

Susanne (NA): And the days she was awake, she read magazines ... Yes lots of magazines. And she watched a lot of TV – especially in the beginning.

FGD moderator: Did she speak about her life at all?

Susanne (NA): Sometimes she did, when we had coffee. But it was really difficult because she was deaf. It was difficult to hold a conversation because she couldn't hear anything.

This discussion shows how Ruth's experience of the meaning of everyday care shifted from day to day – mainly due to her physical strength. Some days she had a need to be with others, while on other days, she wanted to be alone and rest. Some FGD participants implicitly expressed that they tried to interpret what Ruth wanted and thus respect her as a person and preserve her self-image and identity. While holding a conversation wasn't easy, the FGD participants had learned, for example, to communicate with Ruth through body language.

FGD case

Some FGD participants suggested that a threat to the older person's sense of meaning was the fear of being alone, i.e. what the authors interpreted as *existential anxiety*. For example, one participant reported:

Arlene didn't like being alone. She wanted someone to come and visit her and talk to her all the time. When she was alone, she used her alarm and wanted to get out of bed and join us in the kitchen ... She only used the alarm when she was lonely and wanted someone to sit down with her and talk – if nothing else.

Arlene had a need to talk about her life and to be around others. When she was left alone, she became anxious and worried. The FGD participants said that it was rare for them to have enough time to sit with her and listen to her stories. But when it happened, her well-being seemed to increase. In this FGD, the person's wishes were explicitly or implicitly concerned with social relationships.

Revealing thoughts and attitudes about death

Lack of knowing the person in terms of knowing what he or she thought about their imminent death and whether or not they wished to arrange anything beforehand was expressed in all FGDs. Although FGD participants did not talk about death with the older person, they had beliefs about older persons' attitudes toward death in general. One was that sometimes, when older persons decided when to die, they stopped eating and drinking. This was exemplified in all FGDs and was seen as a breaking point in the older person's health.

FGD case

After Pat decided not to eat or drink, death came quickly. FGD participants described how some older persons seemed

to prolong or hold onto their lives and resist death until their children or someone close to them could be by their sides when they died as in the case of Pat's death:

Janet (NA): She was sitting up on Sunday. I think she ate pretty well and on Monday, she only ate a little bit. After that, she refused to eat or drink. Her son was abroad and due back a week later. It seemed that she would have died much earlier if she had not waited for him to come home. From Monday until Wednesday she was 'unconscious' – totally in her own world, she just stayed in bed. On Thursday some close friends came ... and it seemed as if she knew that they were there ... When I went to her room and told her that her son would soon be here, it was almost as if she understood and for a little while she was with us again. When he finally arrived on Friday and had been with her for about 15 minutes, she died.

Chris (NA): I think she was aware of how bad her condition was but she never mentioned death ... I have no impression of her being worried or scared ... She had a will to live, but all of a sudden she just stopped ... I think that's why it seemed so dramatic – the sudden change in her status. It changed totally from one day to the next. It was so quick ... she decided not to live any longer.

A need to understand what Pat was thinking and how she had reflected on herself and her life characterised the FGD interaction. Her story reveals that FGD participants believed that Pat waited to die until her son came home. The participants also reflected on Pat's zest for life and had the same understanding of the end of her life.

As per the FGD participants, death was often assumed to be relief from suffering. They characterised the end of life as slow deterioration of varying physical and mental functions. As a result, many of the older persons' deaths were expected, although the deaths could also be sudden and unexpected.

Caring for the dead person's body

In dealing with the dead person, FGD participants described various rituals that were very similar and did not seem to be connected to the specific unit in which the person lived. Instead, the rituals reflected FGD participants' beliefs and experiences. The varying rituals appeared within the same unit and became obvious when FGD participants reflected on them. Whether the dead person should be dressed in a white shirt or ordinary clothes was one example of variation in FGD participants' perceptions.

All participants stated that they tried to do what the older person or next of kin wanted in an attempt to make death into something more pleasant. The rituals involved washing the dead person if necessary, tidying up the person's room,

lighting a candle, putting a flower into the dead person's hand when crossed over the chest and placing a Bible on the bedside table. After a person's death, participants could grieve the dead person and experience a feeling of emptiness due to their relationship with that person.

FGD participants revealed that existential issues were not extensively talked about, other than when the older person raised the issue. Silence surrounded the death. And there was FGD consensus regarding the issue of older persons' abilities to decide when they wanted to die (surrender). Rituals related to taking care of a dead person's body were rarely discussed, and in some FGDs, a wish was expressed for common policy and agreement on how to care for the dead person.

Coping with the gap between personal ideals and reality

The analysis showed that many FGD participants wished that they would have done more for the dead person. They argued that cutbacks had resulted in reduced staff and nurses no longer playing an active role in the care. This was seen as lack of support from managers and employers. Another moral dilemma concerned the issue of dying alone. Some FGD participants expressed feelings of guilt because they had not been with the person when he or she died and were upset that the person had died alone. Such cases were often described and discussed in the FGDs; here is one example.

FGD case

Wendy (NA): I think all of us were hoping that she would stop holding onto life.

Jane (NA): I believe that to some extent, you can decide when it's time to die. You have a choice when it comes to death.

Helen (NA): I feel anxious when I think about Esther's death. She was in constant pain.

Jane (NA): What were we supposed to do? ... If you don't know what to do you can't do anything.

Wendy (NA): I think we could've done more.

Marie (NA): Esther wasn't really alone. But we should have been there for her because we knew that she was dying.

Whitney (RN): But she had someone with her all night; she had someone sitting beside her since the previous night.

Wendy (NA): Yes. But none of us stayed with her. I wish that I could've done more for her. I didn't do enough and that doesn't feel too good. But you can't be everywhere. I keep thinking that I should

have done this and that. I wanted to, but it wasn't possible because there were so many other things to do. There were other people who had to be looked after. But I felt that I wanted to be with Esther but it was impossible. It feels horrible.

A long conversation ensued about doing one's best within the organisational framework. To improve care for older people, some participants believed that the organisation must accept that nursing homes are places where people die. One FGD participant explained:

You must realize that death is a part of this job. I mean you shouldn't be surprised that people die here. Some colleagues may need more training. New staff members need help to be able to provide good care, part of which is the realisation that people die here ... but no one wants to talk about it.

This discussion pointed out that death is seen as a natural process. And it illustrated that meeting each person's individual needs during the dying process is difficult, which in turn upset the FGD participants.

Discussion

The aim of this study was to reveal nursing home employees' views on dying and death among older people for whom they provided care. The FGDs revealed that to some extent, study participants reflected on the dying and death of older persons during the FGDs. But dying and death was rarely brought to their attention in their daily work.

Rinell Hermansson (1990), Whitaker (2004), and Dwyer (2008) state that silence surrounds the care of older people. Oliver *et al.* (2006) describe how nursing home employees deal with death in what they call the *backstage* room (behind the scenes). This is because the process is mainly shared with other RNs or NAs and rarely extends into the organisation; consequently, issues related to this process never emerge.

Several studies disclose inadequate care and pain relief at the end of older people's lives (Lynn, 1997; Lynn *et al.*, 1997; Costantini *et al.*, 2002). FGDs in this study also revealed insufficient pain management for older people. One of many reasons for this seems to be insufficient knowledge (Dwyer *et al.*, 2009). Heals (2008) noted that few nursing home employees have sufficient training and education for providing end-of-life care (e.g. communication skills and pain management).

Watson *et al.* (2006) suggest that the reason for the silence and invisibility associated with death in nursing homes might relate to insufficient understanding of the palliative care philosophy. Allen *et al.* (2008) suggested nursing home

employees are not always aware of contemporary discourses related to caring for the dying.

Prentice and Black (2007) demonstrated that some RNs, who work with the care of older people, stay with their jobs out of convenience. While other RNs stay because they appreciate the caring relationships that develop over time with the older people they care for. This dichotomy regarding why people work with older people can be an indicator of why implementation of the palliative care philosophy in systems that care for older people would serve a purpose.

According to Oudshoorn *et al.* (2007) dynamic relationships among clients, their families and staff are part of the palliative care philosophy. Munn *et al.* (2008) suggest that promoting collaborative relationships among older persons and staff members may enhance the end of a person's life. As demonstrated in this study, the FGD participants said that meaning (for older dying people) primarily exists in their relationship with family members and friends.

In their study on quality of life in long-term care facilities, Chan and Pang (2007) report that older people welcomed discussions about dying and death. Initiating discussions about dying and death could possibly result in care that is based on the individual person's needs. In this study, palliative care was not mentioned in the FGDs. This may indicate that the expansion of the palliative care philosophy – to incorporate the care of older people has not yet been implemented in a range of nursing home settings – which could be helpful in meeting new demands on staffing skills, which, in turn, enable care providers to facilitate better care for older dying people (Seymour *et al.*, 2004; WHO, 2004; Gott *et al.*, 2008). A few FGD participants emphasised the importance of recognising that nursing homes are places in which people live and die – an observation related to the palliative philosophy. But lack of conversation, especially about existential issues, characterised relationships between FGD participants and the older people. And no participants knew the older persons' thoughts and wishes when it comes to their dying and death. This is surprising, because many of the older people, who were discussed in the FGDs, had lived in the nursing home for up to 2 years.

Nearly 20 years ago, Andersson-Segesten (1989) presented similar findings. Her study was based on an analysis of end-of-life care and death (that involved 12 patients), and she revealed that the staff lacked knowledge about the dead person's religious beliefs, perceptions of impending death, meaning, fear and joy. As in the present study, FGD participants were unaware of the patients' thoughts, feelings and reactions. These findings are aligned with previous studies (Franklin *et al.*, 2006; Dwyer *et al.*, 2008).

FGD participants also reported frustration and dissatisfaction with not being able to provide the care they wished for. This raises the important question of how knowledge of palliative care and its philosophy has been implemented in contemporary society. If the aim of end-of-life care for older people is to provide a *good* death – based on personal needs and wishes – then there is a need to find ways that help knowing the dying person for who he or she is including past, present, and future, i.e. thoughts of death.

The six Ss method is one example that can help improve end-of-life care for older people. Chochinov *et al.* (2002a,b) provided another theoretical framework that focuses on the person and developed the dignity-promoting model. Both models could be useful in striving to provide a meaningful existence and a *good* death for older people as per the palliative care philosophy.

According to Frogatt (2006), the goal of *good* end-of-life care (in which individual needs are met) can be achieved only when the palliative care philosophy is implemented in nursing homes. Hallberg (2006) suggests that the philosophy could serve as a framework for older people and should include focus on the older person's common fears of dying and death. Ronaldson *et al.* (2008) suggest ongoing palliative care education for employees who work in units that care for older people. In this study, it is relatively obvious that employees lack resources and tools to provide such care and in this respect the views of older people can be seen as mirrored by current societal values that in many ways marginalise older people (Strandberg, 2002; Lloyd, 2004). Studies show a gap between societal intentions and capacity to implement and provide person-focused, end-of-life-care for older people (Wetle *et al.*, 2005). Interaction between FGD participants in this study demonstrated that there is a need for a deeper understanding among staff of the fundamental palliative care principles: the provision of an individual's physical, psychological, social and spiritual needs (WHO, 2004). Further the results demonstrate a need of better knowledge about the dying process in relation to older people and their in many cases multifaceted dying (Borglin *et al.*, 2005; Gott *et al.*, 2008). Certain questions pertaining to organisational control are especially sensitive and can lead to disagreement. This implies that the organisation can be an obstacle to provision of good palliative care and that staff education and support is critical. The views expressed by the employees in this study of what can be experienced as difficult when caring for dying older people supports the discussion about nursing home care meeting new challenges and demands (Seymour *et al.*, 2004; WHO, 2004; Gott *et al.*, 2008). This can be seen as important knowledge for future development of palliative care for older people.

Credibility

Because issues of rigour and credibility are key considerations when using qualitative methods, the authors' pre-understanding and the research process were described as accurately as possible and quotations were included to support the findings (Patton, 2002). The main concepts were discussed among the authors, and the analysis proceeded until consensus was reached. The authors' pre-understanding is based on practical experience of nursing older people (LLD), palliative care research (BMT, BA, and GH). But throughout data collection and analysis, the authors strived to remain open to the text.

Methodological reflections

Our impression is that the FGDs stimulated dialogue and raised important thoughts, reflections and opinions about caring for dying people. Although, the NAs were over-represented in this study, the discussions revealed varying views on the dying process. The discussions also provided insight into various FGD participants' jobs and experiences – and provided time to talk about them. Although some FGDs only included as little as two participants, the authors still chose to include them in the study because it was impossible to reach the goal of six to eight participants with experience from caring for the same person in each FGD.

Conclusion

As these results show a need for a deeper understanding of the older persons dying process there is reason to believe that nursing homes are not always viewed as places of dying and death. The new challenges and demands on nursing home care for older dying people need to be in focus when the resources needed to provide such care are discussed. Until nursing homes are recognised as places for dying and death, the care system cannot be developed and tailored to meet the needs of the dying older person. The organisation must support the staff in continuous education and supervision. To develop end-of-life care for older dying people, there is a need to implement methods that focus on person-centred care within nursing home care.

One way to do this could be to implement the six Ss and palliative care philosophy in nursing homes. Implementation of this philosophy could increase awareness of dying persons' multiple needs, which might contribute to older persons receiving good quality care irrespective of the setting.

Relevance to clinical practice

To get public support for palliative care, the silence surrounding dying and death must be broken. Employees must receive education to prepare for all aspects of their work, and management must account for employees' situation when planning the care. The method – the six Ss – is currently used in different hospices in Sweden, and an implementation of the method in nursing homes is in progress. The knowledge gathered from this study will contribute to further development of this method.

Implications for practice

- To be able to meet future needs of dying persons in nursing homes employees need to be offered continuous education and support in this area.
- Attention needs to be given to ethical issues related to employee's experiences of a gap between ideal and reality.
- The six Ss could be used in promoting a person-centered end-of-life care and death.

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