

## **HAVING TO FOCUS ON DOING RATHER THAN BEING**

**- Nurse assistants' experience of palliative care in municipal residential care settings**

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## **ABSTRACT**

*Background:* Palliative care should be provided, irrespective of setting to all patients facing a life-threatening illness and to their families. The situation and needs of older people differ from those of younger people since they often have several co-existing diseases and health complaints. This implies an extensive need for care and for longer periods of palliative care. The main providers of palliative care for older people are nurse assistants, who are also those with the shortest education.

*Aim:* The aim of this study was to illuminate nurse assistants' experience of palliative care for older people in residential care.

*Design:* The study had an explorative, descriptive design.

*Settings:* Thirteen residential care units in three different districts in a large city in southern Sweden.

*Participants:* Twenty-five nurse assistants selected to represent variations in age, gender workplace and work experience.

*Methods:* Data was collected from six focus-group interviews and subjected to content analysis to gain an understanding of the phenomenon.

*Results:* The nurse assistants described palliative care as a contrast to the everyday care they performed in that they had a legitimate possibility to provide the care needed and a clear assignment in relation to relatives. Palliative care also meant having to face death and dying while feeling simultaneous that it was unnatural to talk about death and having to deal with their own emotions. They emphasised that they were in need of support and experienced leadership as invisible and opaque, but gained strength from being recognized.

*Conclusion:*

In order to support nurse assistants in providing high quality end-of-life care, more focus is needed on the trajectory of older peoples' dying, on the importance of involving relatives throughout the period of care provision, and on support when encountering death and dying. There is also a need for engaged care leaders, both registered nurses and managers, to recognize the work of nurse assistants and to support care provision for older people within the framework of palliative care philosophy.

**Keywords:** Focus group, Frail elderly, Nursing assistants, Nursing homes, Palliative care, Support

**What is already known about the topic?**

- Nurse assistants, who have the shortest education also have the closest contact with older peoples' deaths and dying
- Staff in municipal care of the aged experience difficulties concerning ethical and existential issues and distance themselves from death and dying
- Staff working in municipal care are at risk of developing stress of conscience when unable to provide the care needed

**What this paper adds**

- Nurse assistants have difficulties focusing on 'being' with the residents, as the main discourse in residential care of older people focuses on 'doing'

- Nurse assistants perceive palliative care as lasting only for a short and limited time, even though in older people, dying is an ongoing and prolonged process
- Nurse assistants are largely left alone in the provision of care and receive only limited recognition and support from managers and registered nurses

## **INTRODUCTION**

The philosophy of palliative care was primarily developed to cater to the needs of younger people with cancer diseases. The concept has been expanded to include older people with disorders other than cancer (Council of Europe, Davies and Higginson, 2004, SOU 2001:6).

The situation and needs of older people differ from those of younger people, for example in that they often have several co-existing diseases and health complaints making it unclear when palliative care should be initiated. Older people in need of long-term care and services in Sweden mainly receive municipal care (National Board of Health and Welfare, 2010).

Research concerning the situation of staff working with end-of-life care has, however, focused primarily on registered nurses working in hospitals and/or in relation to younger people with cancer (*National Board of Health and Welfare, 2007*). There is thus a lack of knowledge about staff experience of working with older people in the late stages of life. Such knowledge is important for an understanding of their situation and the demands they experience when providing palliative care. This, in turn, can guide the design of support and education that will meet their needs.

## **BACKGROUND**

The palliative care approach aims to improve the quality of life for patients and their families facing problems associated with a life-threatening illness. For example, this means improving the quality of life through the relief of suffering by means of early identification, assessment and treatment of physical, psychosocial and spiritual needs. According to the palliative care approach, interdisciplinary teamwork should be used in addressing the needs of patients and their families during the illness and bereavement (WHO, 2002). There is significant agreement across research papers and guidelines concerning the core elements of palliative care (Council of Europe, Ferrell, 2005, National Consensus Project, 2009). These include the requirement that palliative care should (a) prevent and relieve suffering, (b) include all patients with a life-threatening illness, irrespective of disease and age, (c) be provided irrespective of place, i.e. in home care as well as in hospitals and nursing homes; and (d) start at when the life-threatening condition is diagnosed and continue throughout the family's bereavement period (e) emphasise communication with all those individuals involved in the care of the patients and their families. The core principles also emphasise addressing the unique needs of each individual patient and family, *i.e.* care should be patient- and family-centred. As these objectives have to be appropriate for the specific healthcare system and the culture, the manner in which they are met will vary from one country, or even region, to another. For example Froggatt (2001) identified two different approaches for promoting palliative care in nursing homes in the UK. The first was to use specialist palliative care practitioners who acted as advisors to staff in nursing homes. The second was more formal education in palliative care for staff in nursing homes. However, in both approaches, the content was based on knowledge about people dying from cancer, and was not adjusted to the needs of older people who often have multiple diagnoses and where the process of death and

dying is very different. It is also important to remember that the context of specialist oncology care differs from that of nursing-home care for older people, and that knowledge of the former has limited transferability to the latter.

Palliative care in Sweden is mainly carried out by the County Councils who are the regional providers of health-care, as specialised palliative care is usually a part of advanced homecare, and is guided by physicians. But palliative care is also carried out by the municipalities responsible for care of older people, mainly in the case of older people in their own homes or in residential care units, and is guided by registered nurses (National Board of Health and Welfare, 2006). The main providers of care and service in the municipalities are nurse assistants; the ratio of employment is around sixteen nurse assistants per registered nurse (SALAR, 2008). The municipality's responsibility does not include care provided by physicians, as they are employed by the County Councils (SFS 1982:763). Since the 1990s, care for older people in Sweden has been provided according to the "aging in place" ideology, meaning that people should not have to move when their care needs increase. The primary goal is to make aging at home possible through collaboration between basic and more advanced nursing care (SOU:2008:113). The 'aging in place' ideology, which helps older people to remain at home as long as possible, has also meant that the number of beds in residential care units has decreased over the last 10 years, while homecare has increased (National Board of Health and Welfare, 2010). The aging in place ideology also means that people should not have to move from residential care, once they have moved in. Those now in residential care are older people who need nursing care and service around the clock. The main reasons for moving into residential care during 2000 were, for example, being unable to

be alone for longer periods and/or having an extensive need of nursing care (Westlund and Persson, 2006). People who enter residential care units are also quite frail and eight out of ten are aged 80 years or older (SALAR, 2009); the turnover in residents is almost 40 per cent during a nine-month period (National Board of Health and Welfare, 2010). A study which investigated the place of death among old people receiving care from the municipality during their last year of life, either at home or in residential care units, showed that significantly more people living at home died in hospital compared to those living in residential care units who mainly remained in place (Andersson et al., 2007). This implies that it is municipal staff, predominantly nurse assistants, working in residential care units who largely provide the care for frail old people in the last stage of life. At the same time these nurse assistants have the least education; among those employed in Swedish municipalities, ninety per cent have an upper secondary education and sixty-seven per cent have been educated in nursing care (SALAR, 2008). The Swedish government (SOU 2007:88) has highlighted the need for increased competence among nurse assistants concerning, for example, ethics and values and end-of-life care as these are important aspects in palliative care provision.

Earlier research has shown that death and dying among residents is a source of stress in the carers as that they find it difficult to provide high quality care for the residents (Katz et al., 2001). A study by Casey et al. (2011) focusing on staff perspectives on the current provision of end-of-life care, found that a 'good death' was the core of high quality in such care. The staff, however, felt unsupported and experienced a tension between what they believed to be best practice and 'reality'. Knowing the person and creating a close relationship was experienced as key to the quality of care but it was rare that the participants openly discussed

death and dying with the residents. These findings are in line with results from studies in Swedish residential care units, for example by Albinsson and Strang (2002) who showed that staff felt powerless in discussions with residents and their relatives about the meaning of life and dying and death. A study concerning staff reasoning about death and dying in a nursing home, showed that the nursing-home discourse distanced death and dying from life and represented a movement between avoidance and confrontation of death and dying (Österlind et al., 2011). This might be a result of lack of support in facing these difficult issues. The results from Dwyer et al. (2009), focusing on dignity in the end of life, showed that nursing-home staff felt that they were ignored, lacked resources and experienced a conflict between their ideals and the reality, which together constituted a threat to the older person's dignity. This is in line with findings from dementia care where staff felt that they lacked opportunities to provide the care they wanted to give, and therefore experienced strain (Edberg et al., 2008). The tension between the care someone wants to provide and their limited possibilities of providing it, is often described in terms of moral distress (Lutzen et al., 2003) and stress of conscience (Glasberg et al., 2007). Dahlquist and co-workers (2009) found that stress of conscience includes a struggle with self-respect and can lead to the staff unintentionally deceiving the patient. Thus, if staff are unable to provide the care they want to provide, their emotional distress affects not only themselves but also the patients in their care. This is supported by the findings from a study by Edvardsson et al. (2008) that staff's well-being in turn influences the residents' wellbeing. Earlier studies indicate that staff caring for older people at the end of life are frustrated and feel that they do not have the possibilities to provide the care they wish to, with the risk that this in turn will affect the people in their care. It is therefore very important to elucidate nurse assistants' experience of care provision in the

last phase of life in order to be able to identify areas needing improvement and the support required.

## **AIM**

The aim of the study was to illuminate nurse assistants' experience of palliative care for older people in residential care.

## **METHOD**

### **Context**

In Sweden, the care of older people is primarily a public responsibility and the provision of care and service for older people is mainly financed through taxes (Ministry of Health and Social Affairs, 2007). Residential care units are homelike residential care facilities for older people, with mainly one-bed rooms, that provide round-the-clock care, and resemble what are known internationally as nursing homes. In the units nurse assistants are on duty round the clock while the manager, usually a social worker, occupational therapists, physiotherapists and registered nurses work daytime during weekdays. A registered nurse is on call and accessible for the remaining time. Most residents have a responsible primary care physician, employed by the Country Council and located at the local healthcare centre (SALAR, 2009). Nurse assistants who work in residential care units provide regular as well as palliative care.

## **Design**

The study had an explorative descriptive design using focus-group interviews as the method for data collection. Focus-group interviews are based on the idea that when people who have something in common come together in a group they influence and are influenced by each other with the result that they share their feelings, thoughts and perceptions about the issue in focus more willingly. On the other hand, they should not know each other too well, as this might limit their discussions (Krueger and Casey, 2009).

## *Participants*

The 25 participants came from three districts in a larger city in southern Sweden. The districts were selected because they had focused particularly on education in palliative care to the staff. The education consisted of three, three-hour seminars focusing on palliative care in the final stage, when death was imminent. Coordinators in each district received written and oral information about the study which they further distributed to nurse assistants and asked for volunteers to participate in a focus group interview. They were asked to select participants from among the volunteers, to represent variations in age, workplace, work experience and gender. The coordinators then sent the researchers a list of names for each interview. Four nurse assistants did not attend at the interview, mainly due to heavy workload the particular day. In all six focus-group interviews with 25 nurse assistants, 22 women and three men working in 13 different residential care units were collected during 2008-2009. The age of the nurse assistants varied between 25 and 63 years (median 41, mean 43 years) and their work experience between 2 and 39

years (median 14, mean 18 years). All participants except one had an upper secondary education in nursing care. Nine of the participants had participated in the above-mentioned seminars about palliative care provided by the municipality.

### *Ethical considerations*

The study was performed in accordance with the ethical guidelines laid down in the Helsinki Declaration (WMA, 2008) and the Swedish Act governing ethical aspects in research involving humans (SFS 2003:460, with later amendments). All participants received written and oral information about the study prior to or at the time of the interviews, and both their right to withdraw at any time and to confidentiality in the reporting of the data were emphasised. The researchers had no relations to the participants prior to the study.

### *Focus group interview*

Six focus-group interviews (Krueger and Casey, 2009) were carried out with two to six nurse assistants from different residential care units in the same district in each group. The interviews were conducted in a separate room connected to, or outside, their workplace and lasted for 75-140 minutes. The first or the second author functioned as moderator during the interviews, and had the main responsibility for facilitating discussion (Krueger and Casey, 2009). The discussions were guided by the moderator using open questions such as 'What does palliative care mean for you?', 'Can you tell us about a situation when you provided palliative care?', 'What are the major difficulties when providing palliative care?' In each interview, one of the other authors served as an

assistant. Their responsibility was to listen, take notes and follow up discussions that needed clarification or elaboration (Krueger and Casey, 2009). The interviews were recorded and transcribed verbatim by the first author or a secretary and checked for accuracy by the first author. The research team had different perspectives on the material and came from different research fields *i.e.* social work, medical ethics and nursing.

### *Analysis*

A conventional qualitative content analysis was used to analyse the interviews.

Conventional content analysis is described as suitable for use in the study of lesser known phenomena in order to provide knowledge and understanding of the specific phenomenon under study (Hsieh and Shannon, 2005). Conventional content analysis is often used when research literature in the area is limited. It is important that categories and themes are derived from data and that the researchers become immersed in the data allowing new insights to emerge (Hsieh and Shannon, 2005).

The analysis was carried out in several steps. The first step included reading the text as a whole to gain general understanding of it. This was done independently by all four authors who then came together to discuss their views of the text. In the second step, meaning units related to the aim of the study were identified. In the third step, the meaning units were condensed while preserving their core. In the fourth step, the content of the meaning units was abstracted and codes and categories were developed. The second and the third steps were carried out mainly by the first author in discussions with the fourth author. In the fourth step, all four authors came together and agreed on the way

the data should be labelled and abstracted. The analysis resulted in one theme and three categories with sub-categories encapsulating the nurse assistants' experience. The categorisation was thereafter presented to representatives from the focus groups who corroborated the description and interpretation of their experience.

## **FINDINGS**

The overall impression of the text was that the nurse assistants had to focus on tasks, even if they saw the need and wanted to focus on relationship aspects. However, the organisation reinforced and rewarded task-oriented activities and the nurse assistants had only a limited ability to change this. An overall theme which captured their discourse about providing care for older people in a municipal context was that they *had to focus on doing rather than being*. Their wish to focus more on their relationship with the residents while at the same time having to meet the expectations of relatives, managers and registered nurses created a dilemma. They also felt guilty when being unable to provide the care that they wanted to and when they had to admit that the care they provided was sometimes experienced as unworthy. The nurse assistants' experience of palliative care for older people in residential care was understood as: *Palliative care as a contrast to everyday care; To face death and dying and Being in need of recognition and support*. Internal variations were seen as sub-categories (Table 1).

INSERT TABLE 1 ABOUT HERE

**Experiencing palliative care as a contrast to every day care**

Palliative care for older residents was described as being something that contrasted to everyday care. Everyday care was described as being based on a more ‘activating’ approach which focused on health and independence, even if a majority of the residents were frail and needed extensive support in daily life. In everyday care, residents were encouraged to do most things by themselves. Palliative care implied assisting the resident as much as possible and, with its increased focus on the relationship, symptom relief, and support for relatives, was not initiated until the residents’ very last days of life, *i.e.* when the residents refused to eat or drink, despite support from nurse assistants. This was also the point when the nurse assistants stopped ‘activating’ the residents, and the relatives became visible as people to whom they should provide support. When the formal decision about palliative care was taken, pharmacological treatment was also ended and extra resources could be provided, such as increased staffing. Palliative care, in contrast to everyday care, embraced two sub-categories: *Palliative care means having a mandate to provide the care needed* and *Having a clear assignment in relation to relatives*.

*Palliative care means having a mandate to provide the help needed.*

The decision about palliative care was the starting point for a phase in which they felt that they could do everything they wanted to for the residents in question and could focus all their resources on that resident. It also meant that the group had a shared and common goal in the provision of care; *i.e.* that the resident should not suffer or be left alone.

Palliative care also meant that the resident should be allowed to ‘die in peace’ *i.e.* not be transferred to hospital, not take their usual medication, not have to change their position in the bed or to do things themselves. Palliative care was also described as being based on

the residents' wishes, even if, according to the nurse assistants, they had hardly any requests. Palliative care also meant care based on guidelines and routines, which gave them a sense of security as they knew what to do. Care provision was focused on the resident's bodily needs but also on the importance of residents being calm and free from pain. According to the nurse assistants, palliative care also included taking care of the resident after death. The nurse assistants' main view was that the residents in their care received high quality palliative care.

*'...when they no longer eat or drink, when they just lie in bed. Palliative care is cleaning their mouth and bathing them in bed [...]. It is at the end of life, when we try to do everything for them, we provide the best care. We also support the others, but we know that they have time, they will live longer. When we see that they are in need of palliative care, we might give 'something extra' (6)*

During the residents' last days of life the nurse assistants tried to be close and accessible, which was described as one of the main tasks in palliative care and provided an opportunity to focus on the relationship with the resident. The nurse assistants said this gave them a sense of 'control'. But if a resident was upset or in pain, they felt insecure and 'out of control' as they had only a limited possibility of providing any relief. In these situations they had to contact the registered nurse and were thus in their hands concerning decisions about medication. It sometimes happened that a resident received no relief from anxiety or pain, which made them question the effects of the medication or the competence of the registered nurse or the responsible physician. The nurse assistants

stressed that because of their previous education concerning palliative care they knew the residents had a right to pain relief and they saw it as their responsibility to safeguard this. On the other hand there were also those who questioned the quality of the palliative care they provided, as they did feel they had neither the time nor the competence needed to carry out their assignment.

*Palliative care means having a clear assignment in relation to relatives*

During the residents' last days of life the nurse assistants paid extra attention to the needs of their family. This contrasted with everyday care, when relatives with special needs were seen as 'demanding'. They saw relatives as being important for the resident in the last stage of life and supported their presence, if they wished to be there. They also highlighted the relatives' importance for the residents, as this meant there was no risk of their being left alone. They did not insist, however, if the relative did not want to be present or if it was inconvenient for practical reasons. The nurse assistants described the support they provided to the relatives during this phase as similar to that given the residents, *i.e.* being accessible and providing the opportunity for 'small talks'. They described the relatives' need for information about the resident's situation as well as practical things during and after the resident's death, and they felt confident during these conversations. They did not, however, provide the relatives with any structured support during the last phase, or concerning their bereavement.

*'It is an important task to be there, just so that they can feel confident, they talk a lot and have many questions [...] so we support them [...] when talking to relatives, we don't really talk about death, it is more about practical things' (5)*

### **Having to face death and dying**

Even if residential care was described as the 'last stop' for the residents it was not something they talked about with either residents or relatives. From their discussions it became clear that they thought it was much easier to provide 'practical care' than to talk about existential and emotional problems or needs as they were not sure what to say. The nurse assistants also described their need for support in managing their own feelings concerning these aspects. To meet death and dying embraced two sub-categories, *Unnatural to talk about death* and *Having to deal with one's own emotions*.

#### *Unnatural to talk about death*

Even if knowledge about the residents' and relatives' wishes concerning care at the end of life was considered to be important as a basis for care provision, the nurse assistants still said that these conversations felt unnatural and they felt unsure about how to bring up aspects of death and dying during conversation as it felt to be a difficult and emotionally demanding task for which they lacked competence. It was also an unspoken rule not to talk about death and dying unless someone in the unit just had died. This meant that if residents themselves brought up the subject by saying 'I am going to die'

the nurse assistants often tried to ignore their wish to talk about their inevitable future and answered instead that it would probably 'take a long time' or that it was 'nothing they had to worry about'. The same strategy was used in relation to relatives' thoughts and emotions about death, and the nurse assistants did not encourage them to talk about these aspects. The only time it seemed to be easy to talk about death and dying with relatives was just after a residents' death, unless the resident had died suddenly, as then no one was prepared.

*'We encourage them by talking about other things, if they say that they will not live for long, we say, no, no, you have time left, you will not die yet. But some residents say that they can't take it anymore, they often say that...'* (6)

#### *Having to deal with one's own emotions*

Having to deal with all the emotions aroused by caring for someone who was dependent, in the last stage of life and for whom the nurses thought life was meaningless, was hard. It was even more difficult if the resident had children of their own age, as it then came even closer to them emotionally. It was also upsetting to watch someone suffer or be bedridden for a long time and in these cases the nurse assistants wanted the process of dying to go quickly. But it was also hard for them to cope with quick and unexpected deaths. However, some nurse assistants saw residents' deaths as a 'relief' and they felt no need to talk about them or to need support.

*'My experience if our residents die is, well, maybe not relief, it sounds terrible, but I feel relieved, it is nice that they have eventually found peace. I don't need to talk to others about this, not in that way. But we are all different...'* (3)

In the discussions it was clear that many nurse assistants became very close to the residents and after their death needed time to mourn, just as if a close friend had died. They needed time for reflection, but as beds in residential care are in great demand, it was hard for them to find this time before a new resident moved in. The nurse assistants also emphasised the importance of trying to 'leave their feelings' at work, and not take them home. It was, therefore, very important to have the possibility to say a proper farewell to someone who was dying or had just died, or to talk to colleagues.

### **Being in need of recognition and support**

Recognition and support were described by the nurse assistants as important aspects. They needed proof that they provided high quality care which gave them the strength to cope with their work. The recognition they received came mainly from grateful relatives and residents, but they longed for recognition from their manager and the registered nurses. They also received recognition and support from their colleagues, especially when they had done a good job, which sometimes functioned as a substitute when recognition from others had failed to materialise. Being in need of recognition and support embraced two sub-categories; *Gaining strength from being recognized* and *Experiencing invisible and opaque leadership*.

*Gaining strength from being recognized*

Appreciation and recognition from residents and relatives were described as an important in gaining the strength to carry on with their work. This could happen, for example, when 'hale and hearty' residents missed them during their vacation, or praised them for doing a better job than the others. They also received recognition from relatives when they had done the laundry or cleaned the apartment. They felt that the relatives seemed to appreciate these tasks more than their paying attention to the resident her-/himself.

Relatives who were grateful for the care they provided, could also give them flowers, cookies or thank-you cards or even a thank-you in the newspaper after a resident's death. These gestures of appreciation were important for the nurse assistants as it confirmed that they had done a good job.

*'When this resident passed away, and I thought that I had close contact with him, his wife was probably in shock, even if he had been sick for a long time, and we received no gratitude at all...but then she came with a gift voucher, she did not need to...but then you feel appreciated' (2)*

Receiving recognition and support from colleagues was also important, especially from close colleagues, and those who recognized that they were doing good work, or with whom they could discuss their own emotions concerning a resident's death or dying. The nurse assistants felt confident about talking to their colleagues and felt that they trusted them. This kind of everyday support and recognition, could be provided during ordinary work hours. But there were also those who needed to talk about their experience of care

provision and the feelings that it evoked in another forum, guided by a skilled external supervisor, in order to further develop their caring skills.

*'We are used to this, sometimes we have a very hard time, but we discuss it and try to support each other and have fun together [...]...we try to provide the best care, but we don't always succeed. [...] But when it concerns end-of-life care one must prioritise this (6)*

Another form of recognition was when the registered nurse delegated medical tasks to them. They saw it as a confirmation of their competence as otherwise the registered nurse would not have handled over these tasks. The nurse assistants also said that the registered nurse recognized and supported them in other ways but this seemed to be related more to the personality of the nurse than to the role itself. They also described how they longed for the day when their manager would see them and give them support by saying 'that was a good job you did today', which they said gave them the energy to cope with their work. When instead the manager paid a lot of attention to the relatives' needs, some of them felt frustrated, as they thought that relatives sometimes received more attention than they did themselves.

*'There can be very irritated discussions among us, about how to do or not to do something. We, therefore, need someone to grab us and say to us – you have done good work! There is **never anyone** who says that we are doing something good. Well, relatives do, but none of the managers...' (4)*

### *Experiencing invisible and opaque leadership*

The nurse assistants' description of the leadership in residential care and in relation to palliative care was that it was somewhat invisible and opaque. The registered nurse was described as having a leading role concerning nursing care, while the manager of the unit, who was the formal leader, had the main responsibility for contact with the relatives and administrative duties. Registered nurses who were felt to be leaders listened to them, instructed them and took responsibility for the residents' care, while registered nurses who did not listen to them or acknowledged their knowledge, were not seen as leaders. In these cases the nurse assistants felt the registered nurse was a team member rather than a leader.

*'The organisation wants us to arrange most things by ourselves, as we have no constant access to the registered nurses. So it is a big responsibility for us, we have to take a lot of decisions by ourselves. We distribute the medication, administer insulin and so on...'* (1)

The nurse assistants described the manager as an important and valuable source of recognition and support, but felt that their manager was powerless in the face of organisational changes. This in turn had an impact on the care provision, for example when they needed extra staffing. Instead of support, they could receive additional tasks from the manager such as calling in extra staff when someone was on sick leave. But when they got permission to bring in extra staff or when the manager defended them in front of relatives who complained about their work, the nurse assistants appreciated the leadership.

## **DISCUSSION**

The aim of this study was to illuminate nurse assistants' experience of palliative care for older people in residential care. The findings showed that, *palliative care was experienced as a contrast to everyday care*, that the nurse assistants had *to face death and dying* and that they were in *need of recognition and support*. The discourse concerning care provision was that they *had to focus on doing rather than being*.

### **Methodological considerations**

Homogeneity and heterogeneity are two important aspects to consider when using focus-group interviews as a method for data collection (Krueger and Casey, 2009). In this study homogeneity was reinforced by the common experience the nurse assistants had concerning palliative care in residential care. They all worked in residential care and had experience of providing palliative care for older people. However, in order to ensure that they did not know each other too well (Krueger and Casey, 2009), the participants in each focus group came from different units. To increase heterogeneity, participants were selected from different districts, different units and varied regarding gender, age and work experience. Thus the possibility of illuminating the topic from different perspectives was increased (Creswell, 2007, Krueger and Casey, 2009) while at the same time allowing the participants to have deeper discussions concerning their experiences. Because of late drop outs one 'group' consisted of only two participants, creating a risk of limited experience and perspectives in this 'group'.

Two different moderators were used during the period of data collection, creating a risk of inconsistency in the performance of the interviews. To reduce this risk the same interview guide was used in all groups. As there were different researchers involved in the process of analysis, the influence of any one individual researchers' pre-understanding was probably reduced, while the possibility of illuminating the findings from different perspectives was increased. During the process of analysis, there was a constant movement between confirming and challenging the interpretation of the data, thus reducing the risk of a biased interpretation. The credibility of the results was also increased through member checks, where representatives of the participants confirmed the descriptions and interpretation of the data.

### **Discussion of the findings**

Palliative care was experienced as a contrast to everyday care and an approach to be used during the very last days of the residents' lives, even if they had been frail and dependent on excessive help for a long time. It seemed as if the 'activating' approach, where the residents were encouraged to do everything by themselves was used regardless of the resident's state. The contrast to the palliative care approach thereby became very sharp, as a few days before death the residents suddenly received all possible support. The palliative care approach thus provided a means by which the staff could increasingly focus on the residents' and relatives' needs. However, palliative care is intended to cover all the time from diagnosis of a life threatening illness to death (Council of Europe, Ferrell, 2005, National Consensus Project, 2009). It is well known from the literature (Coventry et al., 2005, Paroz and Santos-Eggimann, 2009) that it is difficult to predict the

trajectories of chronic illnesses and the multimorbidity that older people suffer from. Murray et al. (2005) describe various chronic illness trajectories where cancer usually has a steady progression with a clear terminal phase; respiratory or heart failure usually have a gradual decline with episodes of acute deterioration and some recovery with more sudden unexpected deaths; while the trajectory for frail old people or older people with dementia often takes the form of a prolonged gradual decline. As the provision of palliative care in residential care has mainly been transferred directly from oncological care, the ideas about when, and for how long, palliative care should be provided seems to correspond to the trajectory for cancer illness rather than that for older people. Thus, there is a need, in line with suggestions by Hallberg (2006), to provide care in residential care facilities for older, frail people within the frame of a palliative care philosophy. This includes support for staff, making it legitimate for them to focus on the residents' specific physical, psychosocial and spiritual needs and on communication with and support for relatives over a longer period of time. Froggatt and Payne (2006) also argues that nursing home staff need to become more comfortable about living with the uncertainty of not knowing when death will occur. There is a need to widen the view of palliative care among the staff *i.e.* nurse assistants, so that an increased focus on relationship aspects can be prioritised throughout the stay in residential care, not just during the very last days of the residents' lives. If no changes are made concerning the view of palliative care provision in residential care facilities for older people, there is a risk that they will not receive the care they are entitled to, as the prolonged process of their death and dying will not be acknowledged.

The view of the relatives' role and importance changed once a resident was acknowledged as being in a palliative phase, from having no central position to being important and included in the nurse assistants' assignments. This might stem from the Swedish Social Services Act that does not acknowledge relatives as a focus of care and service performance (SFS 2001:453) in contrast to the palliative care approach, where relatives are highlighted as important. The result of this study also shows that the nurse assistants had limited training in how to meet relatives' emotional and existential needs, meaning that even if relatives were seen as important, they still had only a limited ability to meet or identify their needs. Prior to the very last phase of the residents' lives, relatives were not included as important partners in the care, which in turn limited the possibility of building a trusting relationship that could develop over time. This is further supported in studies focusing on relatives' experiences, showing that relatives feel that they are not seen, and feel like outsiders (Andershed, 2006, Andersson et al., 2010, Brobäck and Berterö, 2003) which can mean that they become critical and distressed, feel unsafe and that they have to 'keep on eye' on both the resident and the staff (Whitaker, 2004). It thus seems important to increase the focus on relatives and their needs from the moment the resident moves into residential care, which involves acknowledging them as competent partners in care provision.

It seemed that the nurse assistants viewed palliative care as mainly focused on bodily aspects and tasks, such as pain relief and personal care, and emotional and existential aspects of nursing care were not acknowledged. This was probably one of the reasons behind their opinion that they provided high quality palliative care. This might also be

related to the context they were in, where 'doing' was rewarded, while 'being' was more invisible. Some authors, for example Thornstam (2005), argue that Western society's focus on high activity and productivity prevents the carer from seeing other needs. A socio-pedagogic approach is also used in many care facilities, where the 'receiver' should learn the importance of being able to do as much as they can on their own, and the staff's role is seen as teaching the old person how to care for themselves (Damberg, 2010). The nurse assistants' focus on task-oriented activities, however, might also be a result of lack of support or their withdrawal from emotionally difficult situations to protect themselves. Sandgren et al. (2006) show that nurses working in palliative care in a general hospital sought emotional survival through so-called shielding as a protection from emotionally difficult events; either in the form of a professional shield, meaning not getting too emotionally involved with patients and relatives, or a shield of coldness, meaning hiding behind their profession and keeping a distance between themselves and patients and relatives. The shielding implied a tension between detachment and involvement in the care. Sandgren et al. (2006) further show that confirmation-seeking and chatting were other ways for the nurses to handle emotional aspects and process their emotions. This is in line with the results from our study, where the nurse assistants highlighted the importance of the recognition they received from each other during their ordinary work, sometimes as a substitute for the lack of recognition from the management. If practice is to change, managers and registered nurses need to be more involved in the care provision and to acknowledge the nurse assistants' complex situation. It also seems to be of the utmost importance to provide support structures that will enable the nurse assistants to focus on relationship aspects in care provision, in the form of clinical supervision or

regular reflective discussions concerning difficult issues for example, but also to have a clear and defined philosophy of care to work towards.

Further, this study confirmed previous research showing that nursing home staff have difficulties in facing death and dying as well as ethical and existential issues leading to them distancing themselves from death and dying (Albinsson and Strang, 2002, Casey et al., 2011, Österlind et al., 2011). A literature review (Hallberg, 2004) about older people's views on death and dying showed that older people need to narrate their thoughts of death and dying and that they had not prepared themselves for aspects concerning end-of-life care. In order to be able to meet older people's desires needs to reflect over these existential and emotional issues there is an urgent need to develop support structures to strengthen nurse assistants working in residential care so that they can adequately meet these challenges.

## **Conclusion**

In order to support nurse assistants in providing high quality care at the end of life, more focus is needed on the trajectory of older peoples' dying, on the importance of involving relatives throughout the period of care provision, and on support in encountering death and dying. There is also a need for engaged leaders of care, both registered nurses and managers, to recognize the nurse assistants and to support care provision for frail older people within the framework of palliative care philosophy over a longer period of time.

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Table 1. Nurse assistants' experiences of palliative care for older people in residential care

<b>Theme</b>	
Having to focus on doing rather than being	
<b>Categories</b>	<b>Subcategories</b>
Experiencing palliative care as a contrast to every day care	Palliative care means having a mandate to provide the help needed Palliative care means having a clear assignment in relation to relatives
Having to face death and dying	Unnatural to talk about death Having to deal with one's own emotions
Being in need of recognition and support	Gaining strength from being recognized Experiencing an invisible and opaque leadership