Challenges when caring for end-of-life patients with advanced dementia and pain: A qualitative study in Swedish nursing homes

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Abstract

Background Of Swedish people with advanced dementia, the majority dies in nursing homes. Pain is a common symptom in patients at the end-of-life, and patients with advanced dementia often experience suboptimal and inadequate pain management. Compared to cancer patients, they receive fewer palliative care interventions. Although being largely responsible for the care of these patients, few studies address the experiences of registered nurses. Therefore, this study aimed to describe nurses' experiences of caring for end-of-life patients with advanced dementia and pain.

Methods This study had a descriptive and explorative design. Individual interviews with thirteen nurses from twelve nursing homes in Sweden were qualitative and semi-structured. The content was analysed through inductive content analysis.

Results Nurses described communicative, relational and organisational challenges. A major issue was difficulties to communicate with the patient, resulting in uncertain pain assessments. Other difficulties were to separate pain from anxiety, to balance benefits and risks in morphine administration, and to create good relationships with health care personnel and relatives. Relatives could greatly influence the assessment and management of pain, both as interpreters of pain behaviour and by questioning the care given. Facilitators of good pain management were good communication and relations with health care staff and relatives, having extensive professional experience, and knowing the patient.

Conclusions This study highlights the need for nursing homes to employ specialist-trained nurses, who have the appropriate knowledge and skills to deal with the challenges in caring for end-of-life patients with dementia and pain. Additionally, there should be resources and strategies available for providing information to patients' family members and for involving them in the decisional process, as they are often unfamiliar with the multitude of considerations involved in decisions such as whether to administrative morphine or not.

Background

Dementia is a progressive, untreatable condition that involves losing your mental functioning and going through personality changes. With it follows complex needs with high levels of dependency and morbidity, especially in advanced dementia. There are about 50 million people with dementia worldwide and the number is expected to triple by 2050 (1). In Sweden today, approximately 140 000 people are living with dementia (2). Dementia incidence rises exponentially for those aged between 65 and 90 and the number doubles approximately every five years (3). As Sweden has one of Europe's fastest-growing populations of elderly, an increased public health burden because of dementia can be expected. Today, almost half of Swedish patients with advanced dementia are being cared for in a nursing home [NH] (4). Usually, physicians are not employed in the NH but visit for some hours a week. Therefore, registered nurses [from now on nurses] will have to assume major responsibility for the care, often involving
complex health problems (5). Nurses also play an active and important part in assessing and relieving patients’ pain and suffering (6).

Patients with dementia have complex needs, and as the patients gradually become more and more dependent, the need for nursing care increases (7). Additionally, they experience higher symptom burden and struggle to communicate (8, 9). For example, pain, dyspnea, tension, disorientation and depression are common symptoms or consequences that increase in patients with dementia shortly before death (10). In comparison to cancer patients, those with advanced dementia suffer from a similar symptom burden but do not receive as good symptom relief and end-of-life-care (11–13).

Studies have shown that NH patients with advanced dementia risk getting suboptimal pain relief (14, 15). Nurses can assess pain through a variety of available pain assessment tools (16), but their quality and utility have been questioned (16–18). What’s more, opioids are the first choice when using analgesic as pain relief at the end-of-life (19), but research suggests that patients with dementia respond poorly to opioid treatments and experience more harmful side effects than patients without dementia (20, 21). To summarise, pain management in end-of-life patients with dementia poses several challenges for nurses, as dementia connects with an inability to self-report, inadequate use of pain assessment tools, and other communication difficulties. These factors result in an increased risk of under-assessment, under-treatment and delayed treatment (22).

Nurses in NHs play a crucial role in pain management of these patients, but few studies elicit nurse perspectives in this context. Therefore, this study aimed to describe nurses’ experiences of caring for end-of-life patients with advanced dementia and pain.

**Methods**

Descriptive and explorative study design was used and data collected by using qualitative semi-structured interviews. This data collection method is suitable and allows participants to include more information, such as feelings, attitudes, and their understanding of the subject. (23).

**Settings and participants**

Participants were recruited from NHs in Stockholm, Sweden. Inclusion criteria were at least one-year practice as a registered nurse in an NH dementia unit and having experience of end-of-life care for patients with pain and advanced dementia.

No ethical approval is required for a non-interventional study without risks or any processing of sensitive personal data (24). After contact, sixteen out of forty-six administrative head managers at NHs randomly chosen permitted the study. Reasons for non-participation were an on-going reorganisation, high workload, or having no nurses meeting the inclusion criteria. On behalf of the researchers, the managers distributed a letter of invitation and information on the study to nurses who met the inclusion criteria.
Thirteen nurses from twelve NHs consented to participation, ten women and three men, with a wide range in work experience. All nurses included in the study signed informed consent. Eleven nurses had a Bachelor's degree in nursing, while two nurses had graduated earlier when the education was just 2-year. None had specialist training in palliative care or dementia care. For participant characteristics, see table 1.

[Insert Table 1 about here]

Data collection

Interviews were individual and conducted according to an interview guide (table 2). The guide sprung from a review of the literature and was made to suit the study aim. It consisted of semi-structured, open-ended questions, with follow-up questions for further clarification. A pilot interview to test intelligibility and suitability lead to minor adjustments. After oral and written consent, individual interviews by the first author were scheduled between February and April 2018. The interviews took place during work hours at the NHs. The digitally recorded interviews lasted between ten and thirty-two minutes, with an average of twenty-one minutes. No prior relationship existed between the nurses and researchers.

Table 2. Interview guide

Can you tell me how you assess pain in end-of-life patients with dementia?

Can you tell me how you administer pain relief to an end-of-life patient with dementia?

Can you tell me a positive experience of treating pain in an end-of-life patient with dementia?

Do you sometimes experience assessing pain to be a challenge?

Can you tell me about your experiences of pharmacological pain relief in end-of-life patients with dementia?

What do you think the prerequisites are for giving good pain relief to an end-of-life patient with dementia?

Is there something else you’d like to tell me about pain assessment and pain relief in end-of-life patients with dementia?

Data analysis

Data were analysed using inductive qualitative content analysis (25). To obtain an overall view of the data, EL read the verbatim transcriptions repeatedly. Short notes (codes) in the margins summed up the content. Next, distinct categories were formed through a search for similarities and differences among the notes. Then, a reduction of categories took place by merging similar ones and discarding those not
relevant for the study. Last, the data collected for each category was colour marked and copied into its page. Patterns between the categorised pages led to the formulation of themes.

Results

The results describe nurses’ experiences of caring for end-of-life patients with advanced dementia and pain, by the use of three themes; communicational challenges, relational challenges, and organisational challenges.

Communicational challenges: Uncertainties when assessing pain

Many nurses found it challenging to assess pain; a common cause of uncertainty was the lack of verbal and non-verbal communication caused by dementia. As one nurse expressed it: “It is difficult, because most of them you cannot ask and get a clear answer from” (Nurse 11). Nurses thought that asking the patient about her pain is the first step in pain assessment. When verbal communication was impossible, nurses instead put focus on the interpretation of pain expressions: verbal pain expressions through groaning and screams, nonverbal through anxious behaviour and body language, such as facial expression. Several nurses found distinguishing pain expressions from anxiety challenging: “It is really hard to assess pain and it is not easy to interpret if it is about pain or anxiety” (Nurse 6). The similarity of pain and anxiety expressions made nurses feel uncertain.

Another communicational challenge that caused uncertainty were if the nurses lacked an earlier relationship with the patient. That made pain assessment difficult, for example comparing current behaviours to past behaviours becomes impossible. As expressed by one nurse:

It felt tough because I didn´t know her from before...I couldn´t know if she had behaved like this before and that made it difficult. It helps so much if you have been taking care of the person for a while. (Nurse 10)

As lack of communication was the primary reason for difficulties with pain assessments, several nurses emphasized the importance of communicational skills and that professional experience develops one’s abilities:

It demands skills to be able to assess if a patient with dementia is in pain ...you need to be really good at communication to sort this out...and this is something you have to learn through practice. (Nurse 5)

Most of the nurses used the Abbey Pain Scale assessment tool. However, some of the nurses did not use any assessment tools at all, believing the existing assessment tools to be inadequate, or that no such guidelines exist at all. Instead, these nurses assessed pain by intuition. Similarly, they described that the doses of morphine were decided by an intuitive approach. This situation could make it hard to achieve a proper balance between optimal pain control and optimal safety.
Safety becomes an issue as the most commonly used pharmacological treatment is subcutaneous morphine injections. The nurses found it difficult to achieve the right balance between giving too small doses for adequate pain relief and being so generous that respiratory depression results. As one nurse expressed this challenge:

Then one is a bit careful as morphine is a problem, i.e. it affects the respiratory centre ... One does not want to sedate someone, despite having reached the end-of-life—you try to give just the required pain relief... (Nurse 6)

So, nurses tried to find the dose that makes patients peaceful and pain-free and felt satisfaction when succeeding. As one nurse described it: “It's really difficult to find a balance, to find the exact dose ... it is very positive seeing a person relax and not expressing pain” (Nurse 7). Despite worries for respiratory depression, several nurses believed it is better to administrate morphine with generosity and preferably give a bit too much rather than too little: “Well, yes, my point of view is that it is important to give something, and rather a bit much than too little” (Nurse 11).

The difficulty of distinguishing pain from anxiety expressions made several nurses adopt the strategy of combining morphine injections with midazolam injections against anxiety. As one nurse expressed it:

I noticed I had to relive both pain and anxiety and he was so tense before, and after injections of morphine and midazolam he got so relaxed, it goes hand in hand pain and anxiety...it is not unusual that we combine medication against pain and anxiety. (Nurse 8)

**Relational challenges: Relatives’ influence**

Mostly, relatives were perceived as a positive factor when caring for the dying patient, but they could sometimes negatively influence the administration of analgesics.

Several nurses viewed relatives as significant resources in pain assessment, as relatives often are familiar with patients’ earlier behaviours and can interpret their behaviour for the nurses. One nurse said that a grandchild had been “really alert when she sat beside her grandmothers´ bed; she immediately signalled to us when she saw signs of pain” (Nurse 1). Family members sometimes wished for an ongoing relationship with the health care staff, to actively influence and partake in the care.

At other times relatives could pose a challenge, for example, when the patient was administered analgesics. The relatives are often uncertain about or even afraid of morphine, and “the atmosphere in the room can change immediately when morphine injections are about to be administered” (Nurse 10). If relatives believe that their next-of-kin aren’t adequately pain relieved, nurses often comply with their wishes for more pain medication:

Relatives often want the patient to receive a lot of analgesic, of course they don’t want them to suffer, and sometimes you listen to them, and sometimes you give an injection maybe more for the sake of calming...
down relatives a little, to satisfy them, to make them feel at ease. (Nurse 9)

In some cases, relatives reportedly insisted on sending the patient to the hospital because they found the patient not adequately pain relieved. In other cases, relatives at the bedside asked the nurse to give as little morphine as possible; either because they were afraid that the drug could provoke the patient’s death, or because they feared that the patient could become addicted. Relatives’ attitudes toward morphine were often mentioned as the most complicated issue related to pain medication. This often provokes stress, or, as one nurse put it: “It’s a pressure, to be surrounded by questioning relatives” (Nurse 5). The whole process of administering morphine can be strongly facilitated if nurses communicate closely with relatives, exchange information with them, and give them good reasons for the administration of morphine, stated the nurses.

Organisational challenges

a) Time constraints

Several nurses emphasised the importance of being readily available in order to relieve the patients’ pain effectively. This can be crucial as having nurses present “can relieve pain that comes from anxiety and loneliness” (Nurse 6). If a patient instead was left alone, she could feel lonely, which could create or increase the pain. As one nurse expressed it:

Many things are important when it comes to pain, not least the psychological part. If a person feels exposed and feels like no one is there and no one cares about her, then I think she will feel more pain. (Nurse 9)

To prevent loneliness, the nurses wanted there to be health care personnel with the dying patient when relatives were not present, but sometimes the workplace did not permit additional health care personnel because of economic barriers, causing patients to dye alone and in pain. This made the nurses feel powerless and helpless: “It is miserable to know that a dying patient is alone and have nobody present ... because staff presence is insufficient” (Nurse 6). Their high workload often prevented them to step in instead:

We are so few nurses that we don’t have the time to sit and hold someone’s hand and try to comfort ... most of the time we sit down documenting [the work]. I hardly find time to be among the patients. (Nurse 7)

Time constraints were commonly described as a major barrier for nurses to be readily available to patients. This was commonly lamented: “If I could wish for something, it would be more staff and more resources” (Nurse 13).

b) Lack of competence
Another organisational challenge often mentioned was the obvious lack of professional competencies and abilities needed to manage the care. Firstly, the NHs in this study were staffed by physicians who do not spend the majority of their practice caring for the NH patients. Secondly, no nurses in this study had specialist training, although some had many years of work experience. Lastly, the nurses mentioned that they often co-operated with other health professions and found this very important as those professionals often cared more directly for the patient and therefore were better able to perceive pain. On the other hand, those professionals often lack essential knowledge or experience relating to pain management: “Lack of knowledge is one reason for it not working so well with health care personnel ... knowledge improves everything and gives good prerequisites” (Nurse 12). Some nurses experienced difficulties with deputies, who were unknown for the patient and oblivious of her earlier behaviour. This caused a risk of missing signs of pain and not reporting them to the nurses, as described: “When I entered the room, I noticed the patient was really in pain, and I questioned the health care personnel, why haven’t you said something to me?” (Nurse 9)

Discussion

This study found that nurses caring for end-of-life patients with dementia and pain are facing communicational, relational and organisational challenges.

Although pain is the most common symptom for end-of-life patients with dementia and a top priority to relieve in palliative care, nurses reported that, as dementia patients often lose their ability to communicate, pain management becomes very complex. Pain is a subjective sensation and not being able to communicate with patients makes nurses uncertain of whether there is pain and, if so, whether it is adequately managed. This corresponds to the literature, where it was found that pain assessment is difficult in patients with dementia, due to the patients’ inability to understand and answer questions (26). Even when nurses suppose that a patient has pain, they find it difficult to assess the intensity of the pain and what kind of pain it is (27).

In this study, we could see that nurses either used the Abbey Pain Scale assessment tool or did not use any such tool. Many found the Abbey Pain Scale inadequate. These findings echo other studies showing that nurses in NHs often find existing pain assessment tools inadequate (26, 28, 29). This scepticism seems warranted (16). Lichtner and colleagues (16) assessed the reliability, validity and clinical utility of 28 pain assessment tools for patients with dementia, including the Abbey Pain Scale, but could not recommend any particular pain assessment tool due to non-conclusive evidence. To carry out individual expert assessments, we thus presently need experienced and specialist-trained nurses in the NHs.

To administer morphine injections becomes a problematic task for the nurses when being uncertain about the patients’ pain status. Most challenging is finding the right balance between giving too small doses of morphine and being too generous with it, the latter which might cause respiratory depression. Many nurses said that they rather administer morphine with some generosity than risk giving too little. This attitude is in line with the study of Brorson and colleagues (27), where nurses expressed a will to
overtreat rather than undertreat pain, mindful of the risk that they may cause a hastening of death. De Witt Jansen and colleagues (30) showed that nurses in NHs often lack sufficient knowledge about the medication they were administering. This lack of knowledge represents a serious ethical and legal challenge. Again, one possible remedy for this challenging situation is better-trained nurses. A clear understanding of morphine treatment and its side effects is likely to promote nurses’ confidence when administering morphine (31).

Specialist training in palliative care can also address the need for skills in ethical deliberation. Effective pain management in end-of-life patients with dementia is often conceived as an ethical obligation and the strategies proposed are motivated with ethical reasoning. To give morphine with the intention to relieve distressing symptoms, even though there is a risk of thereby shortening the patient’s life, is often supported by “the doctrine of double effect”. This ethical principle says that “it is always wrong to do a bad act for the sake of good consequences, but that is sometimes permissible to do a good act even knowing it might have some bad consequences” (32). The application of this doctrine implies that doing something morally good (giving morphine to relieve pain) might potentially have a bad effect (shortening life), but is ethically permissible to do if the bad effect was not intended. In this way, health care professionals can use the principle to justifiably administer appropriate doses of morphine to a patient at the end-of-life, even though this may shorten the patient’s life. Used in this way, ethics training can provide conceptual tools that justify what intuitively feels right and help distinguish justified from non-justified cases of giving high dosages.

A related issue is the difficult clinical distinction between pain and anxiety. In line with previous findings (27, 33, 34), we found several nurses who experienced difficulties in distinguishing pain from anxiety expressions. Likewise, Gilmore-Bykovskyi et al., 2013 Gilmore-Bykovskyi and Bowers (26) found that nurses feel uncertain about whether behaviour changes indicate pain or are related to other causes. As nurses did not think it was possible to define the exact cause of the behaviour change, administration of analgesic became delayed. Due to such difficulties in identifying pain, several nurses in our study combined midazolam injections against anxiety with morphine injections, believing midazolam also relieved pain. This drug combination being used at the end-of-life was reported in Wilson and colleagues (31) as well. In another study, nurses stated that morphine alleviates both pain and anxiety (27). Pain and anxiety appear associated and we believe further research should be carried out to better understand the relationship between nurses’ decisions to use pain medication versus psychotropic medication when treating pain (28).

Nurses in our study often mentioned relational challenges. To know and understand the patient, nurses must build good relationships with the patients’ relatives and be able to spend some time with the patient (27, 34). Lamaheva and colleagues (35) note the importance of preparing early for a progressive decline in health and the inevitable end-of-life phase. Advanced care planning can alleviate the burden of decision-making for both relatives and nurses who attempt to make the best decision for a patient. Recurrently, the nurses in our study described relatives as a positive influence, but sometimes, mainly when nurses administered opioids at the end-of-life, relatives’ opinions could be highly challenging for
them. Then, nurses have to focus not only on the patient but also on the relatives’ comfort. They did so through conversations and by trying to be open to the relatives’ views and wishes (28). We can see a need for some on-site educational support for relatives, as that may facilitate a better co-understanding of the situation for relatives and nurses. As relatives should be included in the palliative care, being essential for understanding and learning about the patient, further research about the cooperation between relatives and nurses should be promoted.

Nurses also mentioned organisational challenges, especially in relation to good pain management. Due to economic barriers, insufficient nurse staffing meant that much-needed nurse presence was not achieved. Slettebo and colleagues (36) found that although nurses wish to do more for their patients and relatives, insufficient nurse staffing results in nurses prioritising physical needs such as pharmacological pain relief rather than psychosocial needs. The present study shows that insufficient staffing made patients lonely and could result in them dying alone and in pain. This produced a feeling of powerlessness among the nurses. Previous studies show that patients at an NH can suffer from the absence of relatives and caregivers at the end-of-life and therefore, die in pain alone. This situation is ethically burdensome for nurses (37, 38) and should be taken seriously by care management and policymakers setting the framework for care.

**Strengths and limitations**

A high workload and lack of time among nurses affected our study, as we aimed to interview several nurses from each NH. This was not possible, which resulted in two informants coming from one NH, while the other eleven nurses all came from different workplaces.

Several limitations of this study are to be considered. The aim from the beginning was to recruit a sample based on maximum variation regarding the nurses’ age, gender and work experience. However, due to poor recruitment and time pressure, all nurses who volunteered and met the inclusion criteria were included. A strategical sample would probably have provided a more varied and heterogeneous sample with participants that may have added data with wider variety (regarding age, gender and education level).

Participants were from NHs in one city, which may implicate that the results are not to be generalised to other countries and contexts. Still, we achieved saturation and good representativeness regarding age and length of work experience in NHs. However, it is noteworthy that none of the nurses were specialised in dementia care or palliative care.

Furthermore, there might be some risk of bias in that the head managers organised the recruitment. It is possible that they opted for the most suitable participants, thereby hiding some present critique, for example.
Despite the limitations, we believe that this study contributes essential knowledge of the complexity involved when caring for end-of-life patients with advanced dementia and pain.

Conclusions

This study shows that nurses face several demanding challenges when caring for end-of-life patients with advanced dementia and pain. A major issue was difficulties to communicate with the patient, resulting in uncertain pain assessments. This results in difficulties to separate pain from anxiety and to balance benefits and risks in morphine administration. Relatives could significantly influence the assessment and management of pain, both as interpreters of pain behaviours and by questioning the care given. Facilitators of good palliative care and pain management were having good relations with the other health care personnel, extensive professional experience, and enough time to care for the patient and relatives.

The many challenges might affect patient care negatively and therefore, and it is crucial to promote more research on this growing and vulnerable patient group. We also found that specialist trained nurses are sorely needed at NHs for these challenges to be met with appropriate skills and knowledge. Additionally, there should be resources and strategies available for informing and involving family members in the care as they often are unfamiliar with the considerations involved in decisions such as whether to administrative morphine or not.

Relevance To Clinical Practice

This study implies a need for specialist trained nurses in palliative care or dementia care at nursing homes in order to meet the challenges described with appropriate skills and knowledge. There is a further need for resources and strategies available at the clinic to inform about end-of-life care and sometimes to involve family members in the decision-making.

Abbreviations

NH = nursing homes

Nurses = registered nurses (RN)

Declarations

Ethical approval

No ethical approval is required for a non-interventional study without risks or any processing of sensitive personal data taking place (SFS 2003:460). The head of each nursing home gave authorisation for approaching the professionals. The study followed the Declaration of Helsinki (World Medical
Association [WMA], 2013). The informants were informed about the study, about the handling of personal data, and that personal information would be kept confidential. Written informed consent was obtained.

**Consent for publication**

Nurses consent for publication was receieved.

**Availability of data and material**

Data will be available upon request.

**Competing interests**

The authors declare that they have no competing interests.

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**Authors’ contributions**

EL and TG conceived and designed the research. EL collected the data; EL and TG analysed and interpreted it. Both contributed equally to the writing and revising of the manuscript, and approved the final manuscript.

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Tables

Table 1. Participant Characteristics
Nurses (n = 13)

| **Gender**         |       |
|--------------------|-------|
| Female             | 10    |
| Male               | 3     |

| **Age (years)**    |       |
|--------------------|-------|
| Range              | <27 to >66 years |
| <29-39 years       | 2     |
| 40-49 years        | 1     |
| 50 to >66 years    | 10    |

| **Education**      |       |
|--------------------|-------|
| Bachelor’s degree (3-year) | 11 |
| Nursing programme (2-year)   | 2    |
| Specialist nursing degree in palliative care or dementia care | 0 |

| **Working years as a nurse** |       |
|------------------------------|-------|
| Range                        | 2 to 37 years |
| Mean/median                  | 21/20  |

| **Working years in dementia ward at a nursing home** |       |
|------------------------------------------------------|-------|
| Range                                                | 1 to 15 years |
| Mean/median                                          | 10/10  |