

## RESEARCH

# Dying patients in nursing homes: nurses provide “more of everything” and are “left to deal with everything on their own”

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## **Summary**

**Background:** An increasing number of deaths take place in nursing homes. This puts a heavy burden of service delivery on nursing homes as an arena for the provision of end-of-life care and on the healthcare personnel who provide the service. We therefore need to increase our knowledge of how nurses perceive the care provided for dying patients in nursing homes.

**Objective:** The study's objective is to describe the nurses' experience of dying patients in nursing homes. The research questions explore what is required to provide optimal treatment and care at the end of life.

**Method:** Data were generated by conducting three focus group interviews with a total of twelve nurses. Qualitative content analysis was our chosen methodology.

**Results:** The nurses aim to carry out their profession to ensure that patients receive optimal symptomatic relief. They also need to look after the patients' relatives. The nurses find that the complexity of the care and treatment provided for dying patients in nursing homes calls for more of everything. In order to meet the dying patients' need for alleviating treatment and care, considerable knowledge is required, as well as special skills and attitudes. The findings show that nurses are often "left to deal with everything on their own" because the nursing home has a low staffing ratio and the personnel have inadequate nursing skills. Nurses are expected to be proficient clinicians, to show leadership and provide advice and guidance for relatives and co-workers.

**Conclusion:** According to the nurses, end-of life care in nursing homes requires "more of everything"; meanwhile, they feel they are "left to deal with everything on their own". The training of co-workers needs to take priority because the number of nursing staff is low.

In recent years, we have seen a rise in the number of patient deaths in Norway's 1,000 nursing homes, and the trend continues with approximately 48 per cent of all deaths per year (1–3). The high mortality figures put considerable demands on the nursing home as an arena for the provision of end-of-life treatment and care, and on the healthcare staff who are providing services for the dying and their relatives (2, 4). According to national guidelines (5), all nursing home wards must provide a service which meets the patients' needs for basic alleviating treatment and care, referred to as palliation.

On average, long-stay in-patients have received 6.5 diagnoses (7), and approximately 80 per cent of patients suffer from cognitive impairment (8). According to Statistics Norway, 76 per cent of patients in nursing homes are over the age of 80 (6). Many elderly people have serious chronic afflictions. There is a need for palliative treatment and care of a high professional standard due to the inherent complexities of geriatrics (5).

It is hard to obtain reliable research data from nursing homes about the end of life. One of the reasons may be a high turnover of staff, which means that study drop-out rates are high (9). Other reasons may include an insufficiently systematic approach and confusion over how to record documentation (10, 11). There is a need for more knowledge on how the needs of dying patients are looked after in nursing homes, from the patients' perspective as well as from the perspectives of relatives and healthcare personnel (2).

Nurses play a special part in the care of dying patients and their relatives because they provide round-the-clock monitoring of patients and handle complex problems associated with disease and the consequences of disease (12, 13). Consequently, we need to know more about the nurses' experiences. This study's objective is to explore the nurses' experience of dying patients in nursing homes in order to identify what is required to provide optimal treatment and care at the end of life.

## **Methodology**

The study had a qualitative, exploratory and descriptive design. We employed focus group interviews as our data collection method. The aim was to generate group dynamics by encouraging participants to share experiences and elicit different perspectives on the subject (14). Diverse experiences emerge in focus group interviews. In turn, this helps each participant see the situation in a new perspective, thus generating new understanding (15, 16).

### ***Recruitment and sample***

The first author distributed written information about the study to the health and care sector managers of three municipalities in East Norway. The invited managers from all three municipalities wished to take part. The first author was given a contact person in each local authority area; these contacts forwarded the information to the heads of their respective institutions, who in turn recruited participants. All participants signed a consent form, which was returned to the first author accompanied by contact details.

It proved challenging to recruit sufficient numbers of informants based on the selection criterion of extensive experience of end-of-life care. We excluded nurses from special units in nursing homes such as palliative units and dementia care units because staffing ratios are higher in such units than on ordinary nursing home wards (5). In the end, the sample consisted of twelve nurses from three different local authority areas (table 1). They had an average of twelve years' nursing experience, the variation ranging from two to 31 years. Six of the nurses had specialty training.

**Table 1:** Sample

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<b>Gender</b>	<b>Number of years in the nursing profession</b>	<b>EvenSpecialty training</b>
Female	14 years	No specialty training
Female	12 years	Specialty training in aging and geriatrics
Male	15years	Surgical and medical nursing
Female	31 years	Theatre nursing
Female	2 years	No specialty training
Female	10 years	Specialty training in nursing management
Male	10 years	No specialty training
Female	17 years	Specialty training in palliative care
Female	9 years	Specialty training in nursing management
Female	4 years	No specialty training
Female	8 years	No specialty training
Female	12 years	No specialty training

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### ***Data collection***

The three focus groups were made up of three, four and five nurses. The interviews were conducted at their respective places of work. The first author (moderator) conducted the interviews. The assistant moderator took notes and observed the group dynamics. The interviews were recorded on tape and then transcribed verbatim. Interview duration was between 55 and 70 minutes.

We made use of an indicative interview guide to provide a structure for our conversation. The interview guide was based on the question of how dying patients are looked after in nursing homes, as described by nurses. The guide focused on topics that had emerged from literature reviews and experiential knowledge. All three authors draw on extensive clinical experience of palliation.

### ***Analysis***

Having conducted the focus group interviews, we transferred the sound recordings to computer files and transcribed them. The transcription work can be considered part of the analysis process because the researcher establishes an overall impression of the material and its structure (17). This suggested a thematic, cross-sectional and data-led content analysis which involved all three authors.

Our analysis is inspired by Gadamer’s philosophical hermeneutics, in which understanding is a key theme. By attempting to understand the text, we give validity to its factual content. A hermeneutic perspective inspired by Gadamer (18) argues that the “wonder” of understanding emerges as a result of the participants’ shared meaning. This approach dictated an interpretive process which involved returning iteratively to the whole body of data from its constituent parts and vice versa.

The first author identified the meaning units. These units were condensed and labelled with codes in a table, one table per focus group interview. We proceeded to conduct our analysis across the interviews. We compared the codes in order to identify similarities and differences before we grouped them in sub-categories and categories (17). In order to ensure consensus and a common understanding, the meaning units were presented to each of the authors for independent coding and categorisation. We then met to discuss our way to consensus with respect to the points on which we disagreed (table 2). Our discussions facilitated interpretations on a higher level of abstraction. The results of the analysis support the synthesis as presented in figure 1.

**Table 2:** The analytic process exemplified

Meaning unit	Code	Sub-category	Category
Providing care involves showing respect and taking your time with the patient as well as the relatives, and providing symptomatic relief. If patients feel pain, give pain relief; if patients feel nauseous, give nausea relief. Preventing further discomfort, in other words. It is the last phase and it is necessary to be present and to observe the patient. It’s not just about giving morphine and then leaving, you need to be present to see if the morphine is effective.	<ul style="list-style-type: none"> <li>• Identifying symptoms</li> <li>• Assessment of symptoms</li> <li>• Symptomatic relief</li> <li>• Intervention follow-up</li> </ul>	Competence required to meet the patient’s complex needs	Roles and responsibilities in caring for dying patients in nursing homes

### ***Ethical considerations***

The study has been approved by the Norwegian Centre for Research Data (NSD) under reference number 38087. The nurses received both verbal and written information. They gave their consent to take part in the study in writing. We informed them that they were at liberty to withdraw from the study at any time without giving a reason for doing so. They were also informed that all personal details would be kept securely locked away, and that all computer files would be password protected. We emphasised that none of their statements would affect the informants’ working conditions.

In order to instil a sense of confidence and trust within the focus group, all parties involved entered into a mutual confidentiality agreement. We have complied with the ethical principles for research as set out in the Declaration of Helsinki (19).

## Results

The results showed that the complexities involved with providing care and treatment for dying patients in nursing homes call for “more of everything”, which requires considerable knowledge as well as special skills and attitudes. Moreover, the findings show that nurses are frequently “left to deal with everything on their own”, because the nursing home has a low staffing ratio and personnel are inadequately qualified. We will present the summary results in two categories with their associated sub-categories (table 3).

**Table 3.** Presentation of sub-categories and categories

Category	Sub-category
Looking after the dying patient in a nursing home	Being present: observe, assess and act
	Look after and involve relatives
	A privilege – contending with your own emotions
Roles and responsibilities in caring for dying patients in nursing homes	The competence required to meet the patient’s complex needs
	External factors

### ***Looking after dying patients in a nursing home***

The results showed that looking after dying patients in nursing homes involves patients, their relatives and nurses. The nurses focused on being present for the dying patient, which they saw as a prerequisite for providing holistic care and treatment. End-of-life care also involves the clarifications and plans that need to be made before the patient is dying. The relatives play a natural part in this process. The results showed that it can be emotionally engaging and challenging to look after dying patients. At the same time, the findings showed that the nurses considered it a privilege to be tending to the patient at the very end of life, and that that they had to contend with their own emotions and conscience in doing so.

**«The nurses considered it a privilege to be tending to the patient at the very end of life, and that that they had to contend with their own emotions and conscience in doing so.»**

### ***Being present: observe, assess and act***

The nurses referred to being present as a prerequisite for looking after the patient by making clinical observations and assessments, and by taking action as required:

“It takes more than looking in on them every now and then if you are to monitor the patients’ pain, fear and symptoms.”

The results showed that it is not always simple to assess when a patient is dying, and that nurses do not always agree:

“At times I receive reports that a patient is dying, and when I go to see them, I think ‘hmm, is he really?’ I think we have a slightly different understanding of when the end of life commences.”

### **«End-of-life care means providing more of everything.»**

Focus group member

A dying patient in a nursing home has complex needs that require close attention by a nurse, who can observe, assess and implement various alleviating measures. One nurse put it very succinctly:

“End-of-life care means providing more of everything.”

### ***Looking after and involving relatives***

The nurses often referred to the patient and their relatives as one, which highlights the fact that nurses see how important it is to include the relatives when clarifying things and making plans before the patient is dying. According to the nurses, such involvement requires targeted information, and the information often needs to be repeated. They explained that many relatives wanted to be of assistance and to do more than just sit by the bedside:

“I believe it creates a great deal of trust if they are allowed to join in. For example, I can show them how to provide mouth care, so they are able to do something when the patient is no longer taking food or drink. I think it helps them a lot, to be able to take part in what is happening.”

However, several nurses also pointed to the value of reassuring relatives that simply being with the dying is important. The nurses agreed that it was important to validate relatives for who they are and what they do. Relatives often have different needs; some require close attention and extended presence by nursing staff, while others are happy to be left on their own with only occasional visits. The nurses found that their own availability influenced the relatives' confidence with the patient, but it was necessary to make it clear that the responsibility was with the nursing staff:

“If you see that the patient is unsettled, and if you need to administer medication, you can't just administer and leave, you need to follow it up. It doesn't matter if a relative is sitting there or not, it's your job.”

### ***A privilege – contending with own emotions***

It can be emotionally engaging to look after dying patients, and one's own conscience and emotions may be affected. Several said they felt it was a privilege to be allowed to tend to patients at the very end of their lives. They also reported that it can feel overwhelming to be given that much responsibility for an individual in the very last hours and days of their lives:

“I feel something extra for them, for they are very helpless. I keep thinking that they no longer have a voice or energy to do anything at all, they are very much at our mercy. So it is a privilege, and it is a special situation; in a way, you inhabit a slightly different part of the nursing role.”

### **«The nurses reported that it can be a strain to be personally engaged when tending to the dying.»**

The nurses reported that it can be a strain to be personally engaged when tending to the dying. They described a shared wish that the dying patient should receive the very highest standard of care:

“You give all you have when you are caring for someone who is about to die. I keep going over it afterwards, in bed, and I evaluate my own performance: ‘Did I say the right things? Did I do all I could to make sure their bed was comfortable? Did my hands feel good?’ I take it very seriously.”

The nurses have different views on becoming emotionally engaged:

“I feel empathy, but when my work is done, I'm no longer involved. I have said my goodbye to the patient and the relatives. I don't think about that particular patient any longer, even if I attend their funeral afterwards, to show my respect for the patient and the family, but it doesn't affect me.”



## ***Roller og ansvar i arbeidet med døende pasienter i sykehjem***

Sykepleierne fremhevet kompetanse som en forutsetning for å føle seg trygge i egen rolle, både når det gjaldt å håndtere pasientens behov, ivareta den koordinerende funksjonen og samhandle med andre yrkesgrupper. Sykepleierne reflekterte over sin egen rolle i systemet og hva de kan påvirke. De reflekterte også over hva som administreres på et høyere nivå utenfor deres kontroll.

### ***The competence to meet the patient's complex needs***

The data showed that competence involves professional confidence and the ability to make assessments and convey information. According to our results, the nurses have highly individual perceptions of what generates confidence, for example when it comes to the administration of drugs. Some doctors prescribe “until pain relief”, some write “mg up to x 6, may be increased if necessary ...”, while others write “mg x 4” on the medication chart. Several nurses reported that they feel more confident when a maximum dose has been prescribed.

Other nurses felt more confident if they were at liberty to administer whatever dose was required to alleviate the patient's pain, so that there was no need to spend time on repeatedly contacting a doctor to increase the dose. They all agreed that clear procedures and drug prescriptions for the alleviation of troublesome symptoms are prerequisites for providing palliative care.

The nurses highlighted a number of episodes when they had been forced to negotiate to obtain a prescription for the necessary drugs:

“Some are very restrictive, almost to the point of you having to negotiate really hard to be believed regarding status. I find that really tiresome.”

### ***External factors***

The nurses highlighted organisational factors beyond their control, such as staffing ratios and professional cover:

“In hospitals there are four–five nursing colleagues and four–five doctors you can confer with. If you're unable to insert a venous cannula, an anaesthetic nurse will come and do it for you. In this place, they don't. Here you need to make the decisions and choices on your own. You need to consult a doctor, and perhaps he'll arrive in a couple of hours.”

**«Here you need to make the decisions and choices on your own. You need to consult a doctor, and perhaps he'll arrive in a couple of hours.»**

Focus group member

They expressed frustration at being pulled in different directions when there are multiple tasks, roles and responsibilities that need their attention:

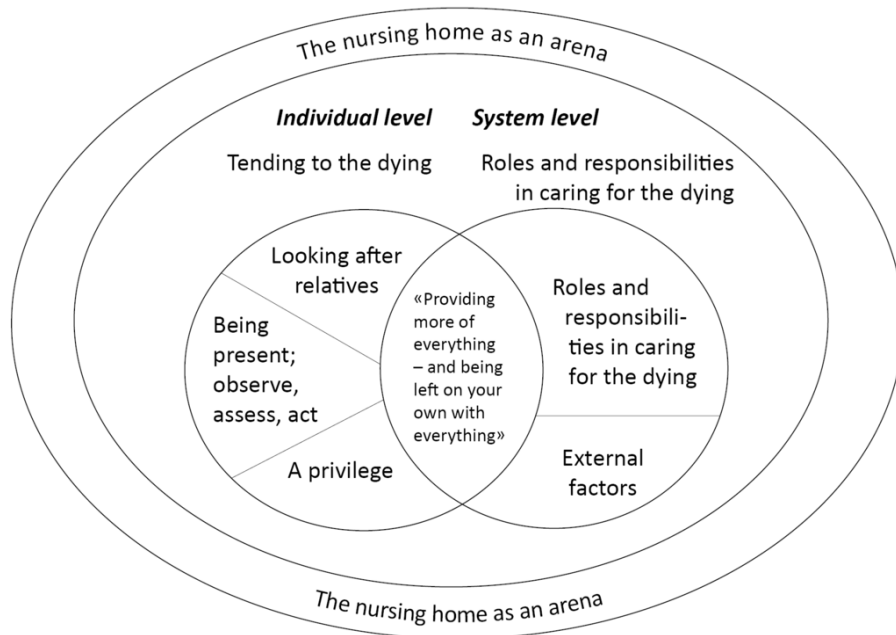
“I have been the only nurse covering 100 patients ... And two or three of them are dying ... There may be four or five relatives involved with each patient, and you need to attend to it all.”

***Providing more of everything, and being left to deal with everything on your own – a synthesis of the study’s results***

The nurses described their work with dying patients as professionally, personally and organisationally complex, as providing “more of everything “; meanwhile, they also say they are often “left to deal with everything on their own”. This means that the nurses give more focused attention to the patient’s complex needs and demonstrate greater emotional engagement; the relatives are also more involved. This complexity calls for knowledge and experience on an individual level as well as on a system level.

Figure 1 illustrates the categories that emerged from our analysis of the study’s empirical material. The findings show that the various elements illustrated in the figure mutually affect one another. For example, it is hard to provide an appropriate, holistic service (system level) without involving the individual patients and their relatives (personal level), as in accordance with the definition of palliation (21). Our analysis revealed that the nurses’ experiences with dying patients in nursing homes involve multiple processes that have mutual reciprocal effects on one another, working in dynamic interaction. These processes involve individual nurses (individual level), the interaction among colleagues, and external factors (system level).

**Figure 1.** A synthesis of the study's results



## Discussion

The study's objective was to establish what nurses consider to be required for the provision of optimal end-of-life treatment and care. The results show that nurses need to fulfil a number of functions and roles, on an individual level as well as on system level. On an individual level, the nurses feel it is essential to be able to be present for the dying, to make observations and assessments, and to take action to ease the patient's pain.

The findings show that the nurses are keen to involve and look after the patient's relatives. They also describe their care for the dying as a privilege which involves contending with their own emotions, all of which need to be processed and managed. Earlier research demonstrates that there are challenges associated with caring for dying patients in nursing homes. Gjerberg et al. (21) found, among other things, that the lack of resources and competence can give rise to ethical challenges, while Flo et al. (10) uncover an insufficiently systematic approach to caring for the dying, as well as incomplete documentation.

### ***A privilege to tend to the dying and their relatives***

The findings of our study show that it is challenging to be present when a patient is dying. The patient has complex needs that require focused attention. The nurses report that they sometimes perceive the same situation in different ways. Meanwhile, they also describe their wish for the care provided for the dying to be of the highest standard. Other studies have documented that healthcare personnel have a genuine desire to ensure that dying patients have a good death, and that nurses go out of their way to fulfil the wishes of patients and their relatives (22–24).

### **«It is challenging to be present when a patient is dying.»**

The nurses stress the significance of looking after and involving relatives, which is supported by the study conducted by Davies and Steele (25). Their study demonstrates that it may feel overwhelming, if rewarding, to attend the death-bed of a loved one. Furthermore, the study conducted by Dreyer (26) makes it clear that relatives need to be looked after. Thoresen et al. (27) also highlight the importance of being present through joint conversations in order to promote good palliation.

In our study, the job of tending to patients and their relatives is referred to as “a privilege”. The nurses describe this work as emotionally engaging. They also report that the magnitude of the responsibility can feel overwhelming. Other studies have also documented that nurses worry they are not doing enough for the dying (21, 22).

### ***Low doctor-per-patient ratios shift more responsibility on to nurses***

The results of our study show that nurses find it problematic whenever it is difficult to get hold of a doctor, and there are few doctors to call on, and when the distribution of responsibilities between doctors and nurses is blurred. The doctor-per-patient ratio in Norwegian nursing home is too low (28). There is currently one full-time equivalent doctor per 130 nursing home patients. In comparison, there is one doctor per 1.3 hospital patients (28). Knowing when to contact a doctor requires a level of competence as well as an understanding of symptomatic relief.

Our findings are supported by Marshall et al. (29), who show that healthcare personnel often find that no doctor is available, and that nurses have to make important decisions without being able to confer with competent personnel. According to Hov et al. (22), some nurses feel that their knowledge of caring for seriously ill and dying patients is ignored in their discussions with the doctor. Hov et al. reported situations that involved nurses having to negotiate to obtain prescriptions that would ease the patient’s symptoms. This highlights the need to continually confer with the doctor, which can be challenging to achieve in a nursing home.

## **Challenging for nurses to take the overall responsibility**

The study's findings showed that the nurses' coordination of work carried out by other healthcare personnel, whether skilled or unskilled, forms a part of their working day. In nursing homes, 30 per cent of staff have no formal training (30). This means that nurses have a particularly challenging function because they carry overall responsibility for the nursing service, professionally (on the individual level) and organisationally (system level). Tasks obviously need to be delegated, but according to Orvik (31) not all tasks lend themselves to delegation.

The NOVA report entitled "Underbemanning er selvforsterkende" [Understaffing is self-reinforcing] (4) points out that the low ratio of nurses to patients in nursing homes adversely affects the quality of services provided and the working environment. There is a need for competence on an individual level: tending to dying patients in a nursing home, and on a system level: roles and responsibilities in the care for dying patients in nursing homes. Our study shows that the nurses' experiences of having to provide "more of everything", and being "left to deal with everything on their own", must be taken seriously, organisationally and policywise. National surveys of nurses and their experiences, and the consequences with respect to nursing education, are important areas for future research. Moreover, the nursing home as an arena for research should be prioritised.

## **The study's strengths and weaknesses**

One of the study's strengths is that the informants are nurses with many years' experience of palliation in nursing homes, and a number of the nurses have specialty training. The focus group interviews revealed a dynamic relationship among informants, which helped to bring forth multiple perspectives on the topic.

One of the study's weaknesses is the fact that only two male nurses took part, but this gender distribution is representative of Norwegian nursing homes. The body of data is relatively small, but the richness of the data provided by the three focus group interviews was considerable. We have tried to secure the reliability of our findings by following the analytic steps. We have included quotes to demonstrate the credibility of the results (20).

## **Conclusion**

The nurses report that caring for dying patients in nursing homes requires "more of everything". Meanwhile, they also find themselves to be "left to deal with everything on their own". Nurses are expected to be proficient clinicians and show leadership, and to give advice and guidance to relatives and co-workers. They are also meant to reflect on their own practice in the light of attitudes and values. The study demonstrates how external factors such as staffing and competence levels affect the nurses' functions and responsibilities.

The nurses' clear objective is to carry out their profession to ensure that patients receive optimal symptomatic relief. This objective is achieved by nurses being proficient in providing clinical assessments and having an ability to implement relevant interventions. They also look after the needs of relatives. Interdisciplinary collaboration and training of co-workers may seem to be demanding since access to the services of a doctor is limited in nursing homes and the ratio of nurses to patients is low.

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