

# Caring for dying patients outside special palliative care settings: experiences from a nursing perspective

Birgitta Wallerstedt<sup>1</sup> RN, MSN and Birgitta Andershed<sup>2</sup> RNT, PhD

<sup>1</sup>The Advisory Team in Palliative Care, PRIVO, Vimmerby Health Care Centre, Vimmerby, Sweden and <sup>2</sup>Department of Caring Sciences, Örebro University, Örebro, Sweden, Department of Health Care Sciences, Ersta Sköndal University College, Stockholm, Sweden

---

*Scand J Caring Sci; 2007; 21; 32–40*

## Caring for dying patients outside special palliative care settings: experiences from a nursing perspective

The aim of the study was to describe nurses' experiences in caring for gravely ill and dying patients outside special palliative care settings. Tape-recorded qualitative interviews were conducted with a total of nine nurses in primary home care, community care and hospitals. The interviews were analysed according to phenomenological methodology, which resulted in the three common structures: ambition and dedication, everyday encounters, and satisfaction/dissatisfaction. In the 'everyday encounters' structure, the following key constituents emerged: responsibility, cooperation, experience and knowledge, feelings, and time and resources. The results describe the nurses' high ambitions to give dying patients and their relatives high-quality care. Despite this, they experienced

greater or lesser degrees of dissatisfaction because of insufficient cooperation, support, time and resources. They experienced satisfaction through contact with patients and relatives, functioning collegial cooperation, and the knowledge, experience and personal growth the care had given them. The results indicate that nurses need the resources such as time, improved methods of communication and cooperation as well as more support in order to give quality palliative care and achieve satisfaction with the outcome. The need for discussion about the conditions for giving palliative care outside the hospices and other special palliative care settings is also elucidated.

**Keywords:** palliative care, terminal care, hospital nurse, district nurse, community nurse, experience, nursing.

*Submitted 15 April 2005, Accepted 6 February 2006*

---

## Introduction

Care at the end of life takes place, to a varying extent, in most care forms. During recent years, it has also become increasingly common to care for gravely ill patients both in their own homes and in community care facilities. This places great and partially new demands on organizations, staff and relatives. The latest official government report in Sweden (SOU 2001:6) proposes the implementation of good end-of-life care on equal terms for all people by introducing and developing palliative care throughout the country (1).

The concept of palliative end-of-life care can be defined as active total care from a physical, mental, social and existential perspective, when an illness can no longer be cured. Through good symptom alleviation and optimized quality of life for the patient, as well as support for relatives during and after the time of illness (2), prerequisites for a

good death are created (3–5). However, in the literature there is no consensus of what a good death connotes. Several studies point out that it can be the possibility for the patient to die in a way that is consistent with his/her wishes (4, 6). Steinhäuser et al. found six major components of a good death: symptom management, clear decision-making, preparation for death, completion, contributing to others and affirmation of the whole person (7). According to Rinell-Hermansson and Ternstedt, the 6 S, that is symptom control, self-determination, social relations, self-image, synthesis and surrender, can be used as key-words in nursing documentation as well as in follow-up sessions after death with staff and relatives, creating and evaluating the quality in the dying process. These point out the importance of a great awareness of the patient's total situation in end-of-life (8).

For the nurse, the care of a gravely ill, dying patient involves an encounter with a person with different physical symptoms such as pain, dyspnoea, oedema, fatigue, constipation and nausea, among others. Anxiety, depression and confusion are examples of psychological symptoms (9–12). The experience of loss, crisis reactions and death agony are often present with emotional swings as a

---

*Correspondence to:*

Birgitta Wallerstedt, PRIVO, Vimmerby Vårdcentral, Drottninggatan 22, S-598 84 Vimmerby, Sweden.  
E-mail: birgittawa@ltkalmar.se

result (13, 14). Nursing therefore also involves an encounter with suffering that arouses feelings and the sense of a common interface (15–18). Even relatives are affected by the patient's illness. Feelings of insufficiency and uncertainty are described (19), the family balancing not only between burden and capacity (20) but also feelings of meaningfulness and hope (21, 22). Studies confirm the importance of adopting a family perspective and of relatives becoming involved in the care (15, 20, 22–24). The complexity of the care of a gravely ill person is described, as is the need for multifaceted theoretical knowledge, practical skill, emotional sensitivity and an ethical approach (25–27). The nurse's need for support, education and preparation for the encounter with patients and relatives is stressed, as well as the possibility for reflection (28–31).

Structural changes, economic restraints in care as well as organizational factors can influence staff members' possibilities of meeting the needs of patients and relatives and the possibility for contributing to a good death (32–34). Increased demands can involve doing more despite fewer resources, such as carrying out more complex care than before (32). This picture of demands can be considered in relation to the nurse's wish to give the dying patient optimal care. Taylor et al. also point out tendencies towards idealism in palliative care that can be reflected in the nurse's understanding of how care should be given. Historically, the nurse usually recognizes the patient's needs before his or her own (35). Kristjanson et al. contend that one's own expectation, as well as those of others, with respect to contributing to a good death can constitute a stress factor (5). Different types of stress can be one of the factors why nurses are quitting nursing (32, 33, 36). Setting increasingly higher objectives can also result in negative perfectionism (35).

Rasmussen points out the importance of acceptance, confidence and support in the staff group when encountering different courses of illness, as well as the possibility for clinical supervision (37). Professional support can help staff members process and integrate death experiences (5, 38). The role of humour in alleviating tension and uniting the team is also elucidated (39).

In Sweden, care at the end of life is a high-priority area where the aim is for all patients to get palliative care of equal quality in accordance with the WHO definition (1, 2). However, studies show that the healthcare system, the staff's psychosocial condition and the quality of care can be related to one another (40). The aim of the present study was to describe nurses' experiences in caring for dying patients outside special palliative care settings.

## Method

The phenomenological method was used in the study. The idea of phenomenology is based on going back to things

themselves in order to do full justice to the daily experience, the lived experience (41). According to Kvale (42), the focus of phenomenology is on clarifying both what appears and the way in which it appears, to understand the qualitative manifoldness in the experiences and make the essential meaning obvious.

## Participants

Nine nurses representing the following care forms: primary home care (district care), community care (home care and nursing home care), and hospital care (surgery, medicine and gynaecology), were included in the study. The different care forms comprise both primary care in rural areas and care at smaller hospitals in different geographical areas of Sweden. Care of patients in both curative and palliative phases were characteristic of these care forms. Advanced healthcare efforts were carried out, but no special palliative care.

The selection criteria comprised at least 3 years of professional experience (but not necessarily at the same place), and experience of caring for at least five dying patients. The managers of the respective areas of care, who had received a letter with information about the study, selected the nurses. The participants were aged 30–65 years and comprised men and women with both full-time and part-time positions. Professional experience varied between 10 and 39 years.

## Data collection

Data were collected by means of qualitative interviews. The goal was not only to describe and understand the meaning in the nurses' life-worlds, but also to engender reflection concerning experiences of caring for dying patients (41). In the interviews, the nurses were encouraged to talk spontaneously and openly about their experiences and about specific events in the care of dying patients. The interviewer posed follow-up questions aimed at attaining an in-depth understanding of the experiences. These could include questions such as 'Can you describe that a little more?' and 'Can you describe what you felt about that?' The nine interviews were all carried out in a secluded room at each nurse's place of work. The interviews were tape-recorded with the permission of the respondents, lasted 60–100 min, and were transcribed word for word by the interviewer. The study was approved by the Research Ethics Committee at the Faculty of Health Sciences in Linköping.

## Data analysis

The analytical procedure was inspired by Giorgi (43), who describes four steps. The analysis was started by reading through the text in order to get an overall impression of

each interview. The next step involved reading through each interview again in order to extract meaning units that described the nurses' experiences of care at the end of life. These units were transcribed in a number of steps, which involved concentrating the original text and revising the language (Table 1). In the fourth step, the concentrated text was formulated into a synthesis for each interview.

Finally, the contents of the nine interviews were related to one another, which resulted in three common structures: ambition and dedication, everyday encounters, and satisfaction/dissatisfaction (Fig. 1). In the 'everyday encounters' structure, the following key constituents appeared: responsibility, cooperation, experiences and knowledge, feelings, and time and resources. The nurses had many reflections concerning their experiences that could mainly be analysed in relation to the 'satisfaction/dissatisfaction' structure.

## Results

The results are reported based on the three structures: ambition and dedication, everyday encounters, and satisfaction/dissatisfaction (Fig. 1). The nurses' experiences are reported by means of descriptions of syntheses for each structure, which are then followed by examples of statements from the interviews.

### *Ambition and dedication*

The nurses had a positive attitude and were well acquainted with care in the final stage of life. They expressed high ambitions and special interest in this care form. Their ambition was to fulfill the wishes of the patient and relatives based on the needs that arose. The goal of the care was for the patient to feel as good as possible and get the best possible care. The way the patients and relatives were treated was described as very important. The main opinion of the nurses was that good knowledge was required in order to fulfil their ambitions. Caring for dying patients also demanded great dedication, which could comprise both positive and negative elements. The nurses mentioned how important it was for the final time to be focused on the unique patient. They described how flexibility and nontraditional work methods could sometimes be used to engender life quality for the patient/relatives.

And we were busy here getting her to look nice (for her wedding, despite the fact that she was dying). She had some clothes with her that she was going to wear and they were a little dirty. But we washed and ironed. Everybody was involved! That was care at a high level. And then they got married and she came back the same evening and had trouble breathing. And then she died during the night, that same day. If you're going to be in a care situation with dying people you need knowledge, you have to have it. It's

not the kind of care you do by 'instinct'. That's not the case with any care, and definitely not with this.

### *Everyday encounters*

The nurses described care in the final phase of life as everyday encounters both with patients/relatives and with staff. The key constituents that emerged in the everyday encounters were responsibility, cooperation, experience and knowledge, feelings, and time and resources.

*Responsibility.* The nurses mainly considered caring for gravely ill and dying patients to be a great responsibility. They described difficulties in caring for patients in a palliative phase at the same time, as they were caring for other patients in a curative phase. A clear area of responsibility involved the way in which patients/relatives were treated, as well as the creation of conditions that would allow the patient to experience a good death. The nurses' assessments and reports often constituted the basis for the doctors' decisions and orders. They also described how they had to assume the responsibility for the doctors becoming involved in the care of the dying. It was assumed that the nurses could act independently, but they said their responsibility did not seem so overwhelming if they could share it among themselves.

That the way we treat patients, the way I act toward the patient is of such tremendous importance and can have such lasting effects. That my actions, my words can have such a lasting effect both on relatives and on the patient. That's quite a heavy responsibility.

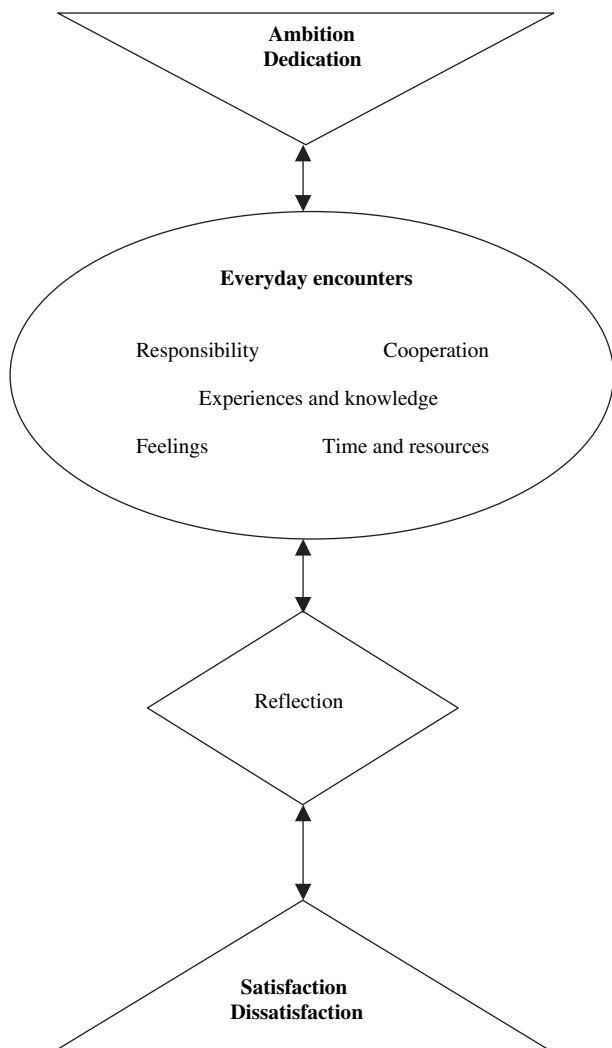
What I'm responsible for is really the nursing care. Then there's the medical care and orders and that's the doctor's responsibility. But in some way I have to be responsible that the doctor does that.

*Cooperation.* The main opinion of the nurses is that cooperation can be described as an important part of the everyday encounters. The ability to work together with the patient and relatives was considered a prerequisite for being able to attain the goal of a good death. Collegial cooperation usually worked well, with great acceptance about helping one another in the care of the gravely ill patient. On the other hand, doctors' interest in palliative care was said to vary. The nurses said that the doctors often seemed insecure when close to the dying patient, and sometimes even seemed afraid. They thought that the doctors often did things instead of talking with the patient and relatives. Fear was also experienced among home help staff, and as a result they needed support and information. Insufficient cooperation among different actors in the care chain because of matters of prestige could constitute a source of irritation.

Now and then it's really hectic. We don't have enough staff here just like in other places. I still feel that we

**Table 1** Analysis process with meaning units, structure and key constituents

Original text	Transformation 1	Transformation 2	Transformation 3	Structure: Everyday encounters Key constituent: Responsibility
S 1: On the other hand what I sometimes can feel responsible for, and it can hit me sometimes, what damned responsibility. And it's that the way we treat patients, the way I act toward the patient means so terribly much, and can have such a lasting effect both on relatives and patients. And sometimes I can feel that this responsibility is sometimes quite heavy	S says that she perceives that the way in which patients and relatives are treated involves a great deal of responsibility and that she feels this is a heavy responsibility	S says that the way one acts toward patients and relatives involves great, heavy responsibility. Being able to assist and contribute so that the gravely ill patient has a good death is perceived as a nearly superhuman responsibility	S says that great, burdensome responsibility is involved in how patients and relatives are treated, as well as in providing not only for control of the patient's symptoms but also the other dimensions. Being able to contribute to the patient's experiencing a good death was experienced as an enormous, almost superhuman responsibility	
I: Bringing about a good encounter? S 1: Yes, exactly. I'm a very spontaneous person and naturally, like everyone else, I can sometimes say things that sound, sound like one thing but are meant as something totally different. But the knowledge that you are that way, I can feel that way, and just helping someone to have a good death. Maybe you know that she's been really afraid of this. It's also an enormous responsibility, it's almost superhuman. When you think about it like that I: Not only symptom control? S 1: It's really the, the other parts that involve the actual great, heavy responsibility. That's what I think	S describes that helping a patient to experience a good death is an enormous, almost superhuman responsibility.			
	S describes that the heaviest responsibility in palliative care does not lie in symptom control, but rather in the other dimensions			



**Figure 1** The nurses experiences of caring for patients at the end of life.

give each other... We help one another! She (the nurse) has to stay in a little longer (with the patient), so I do something for her during that time, or something like that. That's how it is!

You have to keep on nagging the doctors that they should talk with the patients and talk with the relatives and maybe discontinue treatment. It's also hard to keep on, to keep on giving antibiotics right up until the last breath. There's a lot of that, treat, treat, treat.

*Experience and knowledge.* The nurses related that each encounter with patients and relatives gave them invaluable experience and knowledge both for their own benefit as well as for use in other patient situations. The everyday encounters contributed to a continuous development of their knowledge, which also increased their sense of professional security and safety and gave them the strength to accept challenges. They also described that the experiences

created greater insight and awareness about life. The following nurse described how a patient and relative helped her understand how she should act towards them:

I didn't really know how you should treat relatives. In situations when the patient was dying – what language should I use? Should I give them the facts? Should I say what I know? It was a lot, you feel your way along and they (patient and relatives) helped me. It was so natural and we had such good contact with one another. So I didn't even think about how I should act, and I was simply a nurse. In some way this helped me over the threshold – it isn't dangerous.

*Feelings.* The nurses said that everyday encounters at the end of life were often moving and evoked feelings of different kinds. They described situations that aroused ambivalent but also 'forbidden' feelings. Feelings of inadequacy and of frustration, sorrow and loss could arise when a patient died, as well as the feeling of no longer having the strength to cope. The unplanned end of a relationship with a patient could be experienced as extra burdensome. There seemed to be some risk in identifying with the patient when they felt deeply moved. They said that this special closeness and understanding could contribute to difficulties in letting go of the patient afterwards. In such situations, they were more likely to take their work home with them.

You could get totally furious at her (the patient). She could drive you completely nuts. Most of all I would have liked to tell her she was acting horribly. You can't do that – you're being destructive. I naturally couldn't do that. At the same time I thought she had many really good, strong sides to her.

There was a woman with three children – small children, and she wasn't much older than me. And of course that gets to you, naturally. You have trouble letting go of patients like that. You feel so terribly close to them. Their problems, everyday problems are exactly like your own everyday problems.

You wake up at night and go over it and go through everything...and start over again.

*Time and resources.* The nurses described how the care was often demanding during limited periods of time. Sometimes care of the dying was experienced as work in which there was only time to listen to minor problems. Greater difficulties could arise when they were responsible for many dying patients at the same time, which further limited the time for each patient. Then ordinary routines and tasks could be experienced as disruptive. Planning their work was experienced as meaningless because the plans usually could not be carried out. Working in the evening/at night, with a smaller number of nurses on duty, could involve additional stress. The nurses also experienced difficulties combining care of the dying with care of

patients receiving curative treatment in the same care unit. However, they described how a change of priorities could sometimes create more time. There could also be periods when there was time but when it was not used adequately.

You go in to the patients and say hello and wonder if there are any special problems. Then they take that up, but they don't mention anything else. They see that you don't have time... On a hectic day with a lot of patients in and out, then it's the cancer patients and the palliative patients that have to give way. Unfortunately, that's how it is.

Sometimes there are periods when you have many (dying patients). And you really don't have to have more than one (at a time), then you have your hands full. Because when you're in the middle of things with a really sick patient – you really have a whole lot! And you get involved with the family. It's nice to have a rest afterwards. And afterwards you wonder how you've had the strength!

### *Satisfaction and dissatisfaction*

The nurses' stories also contained reflections concerning what the experiences of caring for dying patients had given them, and also thoughts about the future. Many reflections touched on possible explanations and reasons why, as a nurse, they had acted in a certain way. The nurses also reflected over how they had actually had the strength to do their job. Feelings of inadequacy in caring for the dying became particularly clear when their ambition was to help but there was little possibility to carry out what they wanted to do. The nurses driving power consisted mainly in their attempt to satisfy the patient's wishes. Care at the end of life not only provided a good deal of confirmation and stimulation but was also experienced as burdensome and demanding.

*Satisfaction.* The nurses' satisfaction consisted mainly in the opportunity to give something to a gravely ill person, to fulfil special wishes and be able to care for the whole person. The fact that the care provided experience and contributed to personal growth was also felt to be satisfying. The development of palliative care, which has been underway in recent years, was also experienced as stimulating, as was the mass medial and political focus on palliative care. The nurses also described cooperation of colleagues in very positive terms.

I don't think I've ever enjoyed work as much as with my (palliative) patients. The atmosphere that's created in this work is so generous. It allows for so much. It allows such emotional swings and so... It's great! And it's still great!

*Dissatisfaction.* The constant lack of time, with little room for acute changes, was experienced as an obstacle to pro-

viding care of good quality. There was dissatisfaction concerning the way certain patients and relatives were treated and cared for. The absence of sufficient time often became a stress factor that could constitute a risk both at the organizational and the personal level. Much of the nurses' dissatisfaction originated from the organization in which palliative care was practised. Intensive contact with dying patients and relatives and many deaths one after the other within a short period of time could be stressful and result in fatigue. Despite the need, the nurses experienced insufficient support from managers and little understanding and little commitment regarding their physical and mental health. This work environment could result in gravely ill and dying patients being experienced as a burden. Varying experiences of support and clinical supervision were described. Two of the nurses had regular clinical supervision although one of them described how this was not given priority. It was found that many of the nurses were not accustomed to giving priority to their own needs.

It started right after vacations last year. How are we going to manage next summer and what happens if one of us gets sick? Sometime one of them (the managers) could ask, 'How are things? How are you feeling? Can we help?'

We've always wanted to have this clinical supervision and support. And now this past winter she (the clinical supervisor) was supposed to come. But now it's all come to nothing. And here we're also bad at giving priority to things like that. They called her (the supervisor) and cancelled it because they (the staff) didn't have time... they had something else to do. But the problem is that we're not used to making this a priority.

## **Discussion**

During the interviews and the analysis of the data, an attempt was made to be as open as possible to how the phenomenon emerged. Despite this, the pre-understanding of the interviewer may have influenced the work and thereby the results. According to the literature, the everyday understanding and scientific knowledge of the interviewer should be placed in parentheses so that the 'phenomenon' can be described in as unbiased a way as possible (41). According to Kvale, this does not mean a total absence of preconceived ideas, but instead an awareness of one's preunderstanding and a critical, analytical approach to it (42). Dahlberg et al. do not consider it possible to place all pre-understanding in parentheses, as no researcher constitutes a blank page (41).

A weakness in the studies method and design could be that the sample consisted of heterogenic levels of care. Despite the fact that the informants have different experiences of caring for dying patients requiring different levels of care, they describe similar feelings of ambition and

dedication and similar experiences in everyday encounters. They also described similar reflections and feelings about the outcome of the given care, which was a somewhat surprising result. This design can probably give a broader picture of giving palliative care than if the sample had only consisted of a homogenous level of palliative care.

The scope of the study is small, but it nevertheless describes many actors in a care chain where care is given at the end of life. Care chains constructed in a similar way – hospitals, primary home care, and community care – are found throughout Sweden and also in other countries. The function of and communication in care chains are important for the outcomes of given palliative care. There is some reason to believe that care given in the end of life would function in a similar manner in other parts of Sweden or in other countries. Areas with well-established hospice care constitute an exception. The stories of nurses working in the different areas of care in the study were not compared with one another, as that would have required a different study design. The results constitute a picture of all the nurses' experiences, irrespective of the care form.

The results show that the role and function of the nurse can be multifaceted and complex which confirms by other studies (34, 44, 45). All nurses in the study pointed out difficulties, when pressed for time, in combining care of patients in a palliative phase and those in a curative phase. On the other hand, care of healthier patients can probably give nurses positive feelings, energy and hope in a mixed work situation. A question that can be posed however is, how nurses are affected by frequently having to switch between dying patients and almost-cured patients. Studies have pointed out difficulties in assuming a number of roles at the same time. Taking part in frequent role changes can result in stress, and role conflicts have a negative influence on work satisfaction (45–47). The nurses described stress factors in the care that sometimes caused feelings of dissatisfaction, frustration and grief. Vachon report that constant confrontation with dying can also constitute a continual reminder of one's own death. The nurses could also experience grief if the patient did not have a good death. The author points out that many deaths in close succession could contribute to the nurse not having time to grieve, which could result in a decreased ability to care for gravely ill patients (46).

The results show inadequate support from managers. Studies confirm that poor leadership and limited resources can be sources of work-related stress (48, 49). It is also noteworthy that only two participants received regular clinical supervision, and that one of them sometimes had to cancel because of a lack of time. According to Travelbee, self-insight and the ability to interpret one's own and others' actions are required in order to deal with surges of emotions in patients, relatives or themselves as caregivers (50). The Swedish Government Official Report (SOU 2001:6) proposes continuous education and clinical

supervision to all staff working in palliative care (1), and this is also stressed by Jones (51). Questions of importance concern whether nurses have time to reflect over their own needs, or if those needs are not considered. What knowledge and experience are available regarding the effects of clinical supervision on nurses and their managers? By learning from experiences clinical supervision can promote palliative nurses psychological health and well-being (38). According to Jackson, 'the process of nursing practice is as important as the content of nursing practice'. She also argued the importance that nurses understand their own responses to suffering as a result of their work as healers and that nurse leaders take responsibility to create healing environments even for the staff (49).

In everyday encounters, insufficient time, resources and cooperation were found to be the main reasons for different degrees of dissatisfaction. Ramirez et al. state that care of dying patients results in work satisfaction as long as the nurse experiences that there is sufficient staffing, time and knowledge in order to perform the care in a satisfactory way (48). Cronqvist et al. point to stress factors in intensive care that can include understaffing, a heavy workload and problematic work relations. Work satisfaction is thus an important factor with respect to how stress affects the nurse (52). These descriptions could be applied to the conditions found in the present study. If demands do not correspond to the possibilities to give care of high quality, tension can be created between reality and the ideal, which can be experienced as moral stress (5, 33, 36, 45, 52).

Cooperation among colleagues was usually described as good, but relations with doctors were experienced as more demanding. In the interaction between different care institutions, prestige and territorial thinking constitute an obstacle. Studies confirm that organizational factors, communication problems and difficulties in relations with other caregivers, as well as insufficient cooperation and discipline among different care systems, are significant stress factors (34, 46). This result could also reflect a female interpretation, as the majority of those studied were women. Would the results have been different if most of the nurses had been men? Would the relation between doctors and male nurses have been different, and would this have resulted in less need for obstinacy on the part of the nurse?

Experiences of happiness and generosity in the relationship with the patient are also described. One of the nurses said that she had not experienced such stimulation and satisfaction in any previous work as she did with gravely ill patients and their relatives. Experiences and encounters in palliative care were also described as sources of increased knowledge and personal growth, results that are supported by other studies (53, 54). Maeve reported similar reflections from other nurses caring for gravely ill patients where it was important to do 'the right things' for the dying patient (17).

In the nurses' thoughts concerning the future, it was suggested that there is discord between their ambitions and reality. Tishelman et al. also point out a gap between the ideal and the reality in palliative care (34). It can also be asked whether nurses are going to continue working in an area where, despite good ambitions, intentions and interest, feelings of dissatisfaction are often the result. Can sufficient stimulation and confirmation minimize these feelings? Other studies show that work under moral stress even can result in health risks and contribute to flight from the area of care (32, 36). According to Rasmussen, meaningful care becomes good care when meaningfulness gives the nurse the satisfaction and the strength to continue providing care (37). Even Gaydos stresses that the meaning of nursing is a prominent factor whether nurses stay or not in nursing (53).

Palliative care in Sweden can generally be considered to be in a build-up phase. According to SOU 2001:6, the proposal is that palliative care should be offered on equal terms to all gravely ill/dying patients (1). This can be considered in relationship to an ageing population, to the scarcity of nurses and the large number of nurses who will be retiring in the coming years. It is probable that more and more gravely ill patients will be cared for in community facilities, and especially in the home. Can this be done in existing organizational forms for care at the end of life, and what will be the quality of care? How much of the care will fall on the family?

Research about nurses' experiences in end of life care is done earlier but mostly focused in special palliative care settings. This paper adds to the knowledge about the palliative care given in common care settings and the result indicates that nurses need resources of time, communication, cooperation and support for giving palliative care with quality and get satisfaction with the outcome. The result also elucidates the gap between nurses' ambitions for the care given in the end of life and the reality as well as the need for discussion about the conditions for giving palliative care outside special palliative care settings.

## Conclusion

In summary, the results describe the nurses' strong ambition to give the dying patient and relatives care of high quality both in hospitals, primary home care and community care. Despite this, the nurses experienced dissatisfaction to a greater or lesser degree. A lack of good cooperation, support, time and resources were reported to be the primary sources of dissatisfaction. Satisfaction was achieved through contacts with patients and relatives, functioning collegial cooperation, and through the knowledge, experience and personal growth that care had given them.

The present study shows the complexity of the nurse's function in palliative care. Further research is needed

regarding nurses' experiences of the discrepancy between their possibilities to give palliative care with quality and what they really want to do for the dying patient.

## Author contribution

Birgitta Wallerstedt was the principal author for this article, and supervision and advise was given by Birgitta Andershed.

## References

- 1 SOU 2001: 6. *Döden angår oss alla – värdig vård vid livets slut. (Death Concerns Us All – Care with Dignity at the End of Life). Huvudbetänkande från kommittén om vård i livets slutskede*. 2001, Socialdepartementet, Stockholm.
- 2 World Health Organization. *Cancer Pain Relief and Palliative Care*. 1990, World Health Organization, Geneva.
- 3 Ternstedt B-M, Andershed B, Eriksson M, Johansson I. A good death: development of a nursing model of care. *J Hospice Palliat Care* 2002; 4: 153–60.
- 4 Mak JMH, Clinton M. Promoting a good death: an agenda for outcomes research – a review of the literature. *Nurs Ethics* 1999; 6: 97–106.
- 5 Kristjanson LJ, McPhee I, Pickstock S, Wilson D, Oldham L, Martin K. Palliative care nurses' perception of good and bad deaths and care expectations: a qualitative analysis. *Int J Palliat Nurs* 2001; 7: 129–39.
- 6 Vig EK, Pearlman RA. Good and bad dying from the perspective of terminally ill men. *Arch Intern Med* 2004; 10: 977–81.
- 7 Steinhäuser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families and providers. *Ann Intern Med* 2000; 132: 825–32.
- 8 Hermansson AR, Ternstedt B-M. What do we know about the dying patient? Awareness as a means to improve palliative care. *Med Law* 2000; 19: 335–44.
- 9 Armes PJ, Addington-Hall JM. Perspectives on symptom control in patients receiving community palliative care. *Palliat Med* 2003; 17: 608–15.
- 10 Sherman DW, Matzo ML, Coyne P, Ferrell BR, Penn BK. Teaching symptom management in end-of-life care: the didactic content and teaching strategies on the end-of-life nursing education curriculum. *J Nurses Staff Dev* 2004; 20: 103–15.
- 11 Jablonski A, Wyatt GK. A model for identifying barriers to effective symptom management at the end of life. *J Hosp Palliat Nurs* 2005; 7: 23–36.
- 12 Wong FK, Liu CF, Szeto Y, Sham M, Chan T. Health problems encountered by dying patients receiving palliative home care until death. *Cancer Nurs* 2004; 27: 244–51.
- 13 Feigenberg L. *Terminalvård: en metod för psykologisk vård av döende cancerpatienter (Terminal Care: A Method for Psychological Care of Dying Cancer Patients) (in Swedish)*. 1977, Liber Läromedel, Lund.
- 14 Qvarnström U. *Patient's Reaction to Impending Death: A Clinical Study (Doctoral Dissertation)*. 1978, Stockholm University, Institute of International Education, Stockholm.



- 15 Meiers SJ, Tomlinson PS. Family-nurse co-construction of meaning: a central phenomenon of family caring. *Scand J Caring Sci* 2003; 17: 193–201.
- 16 Molander G, Parviainen T. *Så känns det att vårda döende: En kvalitativ studie av vårdpersonalens upplevelser i Danmark, Finland, Norge och Sverige (What it's Like to Care for Dying Patients: A Qualitative Study of Experiences of Care Staff in Denmark, Finland, Norway and Sweden) (in Swedish)*. 1996, Nordiska Ministerrådet, Köpenhamn.
- 17 Maeve MK. Weaving a fabric of moral meaning: how nurses live with suffering and death. *J Adv Nurs* 1998; 27: 1136–42.
- 18 Hagström B. The dying patient – a challenge to health care personnel. *Nord Med* 1998; 113: 153–5.
- 19 Brobäck G, Berterö C. How next of kin experience palliative care of relatives at home. *Eur J Cancer Care* 2003; 12: 339–46.
- 20 Proot IM, Abu-Saad HH, Crebolder HF, Goldsteen M, Luker KA, Widdershoven GA. Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scand J Caring Sci* 2003; 17: 113–21.
- 21 Kruse BG. The meaning of letting go. *J Hosp Palliat Nurs* 2004; 6: 215–22.
- 22 Millberg A. *Family members' experience of palliative home care (Medical Dissertations)*. 2003, Linköping University (No 821), Linköping.
- 23 Duhamel F, Dupuis F. Families in palliative care: exploring family and health care professional beliefs. *Int J Palliat Nurs* 2003; 9: 113–9.
- 24 Andershed B, Ternstedt B-M. Development of a theoretical framework of understanding about relatives involvement in palliative care. *J Adv Nurs* 2001; 34: 554–62.
- 25 Benner P, Tanner C, Chesla C. *Expertise in Nursing Practice: Caring, Clinical Judgement and Ethics*. 1996, Springer, New York.
- 26 Sjöstedt, E. Caring - ett relevant begrepp i omvårdnad. (Caring – a relevant concept in nursing). In *FoU-rapport 51. Reflektioner kring omvårdnad – från huvudsatser, bisatser till slutsatser. (Reflections about Nursing – From Main Clauses, Subordinate Clauses to Conclusions) (in Swedish)* (Sarvimäki A ed.), 1997, Vårdförbundet SHSTF, Stockholm.
- 27 Boston P, Towers A, Barnard B. Embracing vulnerability: risk and empathy in palliative care. *J Palliat Care* 2001; 17: 248–53.
- 28 Fisher M. Can grief be turned into growth? Staff grief in palliative care. *Prof Nurse* 1991; 7: 178–82.
- 29 White K, Coyne P, Patel U. Are nurses adequately prepared for end-of life care? *Nurs Scholarsh* 2001; 33: 147–51.
- 30 Bergstrand M. Reflektionens beskaffenhet och betydelse för sjuksköterskans omvårdnadskompetens. (The nature and importance of reflection for nursing competence). In *Reflektioner kring omvårdnad – från huvudsatser, bisatser till slutsatser (Reflections about Nursing – From Main Clauses, Subordinate Clauses to Conclusions) (in Swedish)* (Sarvimäki A ed.), 1997, Vårdförbundet SHSTF, (FoU-rapport 51), Stockholm.
- 31 Pimple C, Schmidt L, Tidwell S. Achieving excellence in end-of-life care. *Nurs Educ* 2003; 28: 40–43.
- 32 Sumner J, Townsend-Rocchiccioli J. Why are nurses leaving nursing? *Nurs Admin Q* 2003; 27: 164–71.
- 33 Corley MC. Nurse moral distress: a proposed theory and research agenda. *Nurs Ethics*, 2002; 9: 636–50.
- 34 Tishelman C, Bernhardsson B-M, Blomberg K, Börjeson S, Franklin L, Johansson E, Leveälähti H, Sahlberg-Blom E, Ternstedt B-M. Complexity in caring for patient with advanced cancer. *J Adv Nurs* 2004; 45: 420–9.
- 35 Taylor B, Bulmer B, Hill L, Luxford C, McFarlane J, Reed J, Stirling K. Exploring idealism in palliative nursing care through reflective practice and action research. *Int J Palliat Nurs* 2002; 8: 324–30.
- 36 Lützen K, Cronqvist A, Magnusson A, Andersson L. Moral stress: synthesis of a concept. *Nurs Ethics*, 2003; 10: 312–22.
- 37 Rasmussen, BH. *In Pursuit of a Meaningful Living Amidst Dying: Nursing Practice in a Hospice (Doctoral Dissertation)*. 1999, Umeå University (New Series No 592), Umeå.
- 38 Jones A. Clinical supervision in promoting a balanced delivery of palliative nursing care. *J Hosp Palliat Nurs* 2003; 3: 168–75.
- 39 Dean, RA. Occupational stress in hospice care: Causes and coping strategies. *Am J Hosp Palliat Care* 1998; 15: 151–4.
- 40 Farrington A. Strategies for reducing stress and burnout in nursing. *Br J Nurs*.1997; 6: 44–50.
- 41 Dahlberg K, Drew N, Nyström M. *Reflective Lifeworld Research*. 2001, Studentlitteratur, Lund.
- 42 Kvale S. *Inter Views. Introduction to Qualitative Research Interviewing*. 1996, Saga Pubns, California, UK.
- 43 Giorgi A. *Phenomenology and Psychological Research*. 2000, Duquesne University Press, Pittsburg.
- 44 Hopkinson JB, Hallett CE, Luker KA. Caring for dying people in hospital. *J Adv Nurs* 2003; 44: 525–33.
- 45 Wilkes L, Beale B, Hall E, Rees, E, Watts B, Denne C. Community nurses' descriptions of stress when caring in the home. *Inter J Pall Nurs* 1998; 4: 14–20.
- 46 Vachon MLS. The nurse's role: the world of palliative care nursing. In *Textbook of Palliative Nursing (Ferrel BR Coyle N eds)*, 2001, Oxford University Press, Oxford.
- 47 Cox KB. The effects of intrapersonal, intragroup and intergroup conflict on team performance effectiveness and work satisfaction. *Nurs Admin Q* 2003; 27: 153–63.
- 48 Ramirez A, Addington-Hall J, Richards M. ABC of palliative care. The carers. *BMJ* 1998; 316: 208–11.
- 49 Jackson C. Healing ourselves, healing others: third in series. *Holist Nurs Pract* 2004; 18: 199–210.
- 50 Travelbee J. *Interpersonal Aspects of Nursing*, 2nd edn. 1972, FA Davis Company, Philadelphia, PA.
- 51 Jones A. A heavy and blessed experience: a psychoanalytic study of community. Macmillan nurses and their roles in serious illness and palliative care. *J Adv Nurs* 1999; 30: 1297–303.
- 52 Cronqvist A, Theorell T, Burns T, Lützen K. Dissonant imperatives in nursing: a conceptualization of stress in intensive care in Sweden. *Intensive Crit Care Nurs* 2001; 17: 228–36.
- 53 Gaydos HL. The living end: life journeys of hospice nurses. *J Hosp Palliat Nurs* 2004; 1: 14–26.
- 54 Rosser M, King L. Transition experiences of qualified nurses moving into hospice nursing. *J Adv Nurs* 2003; 43: 206–15.