Deciphering Unwritten Rules

Patients, relatives and nurses in palliative cancer care
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Abstract


This thesis focuses on palliative cancer care in acute care hospitals and home care settings. The overall aim was to generate a grounded theory explaining the latent patterns of behavior of patients, relatives and nurses. The thesis includes one population-based study with cross-sectional design and four classic grounded theory studies.

Study I was conducted in two acute care hospitals. In this 5-year follow-up study, the proportion of hospitalized palliative cancer patients had decreased. The patients were older with more symptoms and care needs per patient. In both years, the most common symptoms were pain and deterioration and the most common cancer sites were prostate and colorectal. The results showed that associations between symptoms, care needs and cancer site were mostly weak.

In study II, striving for emotional survival emerged as the pattern of behavior through which nurses in acute care hospitals deal with their main concern, the risk of being emotionally overloaded. Striving for emotional survival involves emotional shielding, emotional processing and emotional postponing.

In study III, doing good care emerged as the pattern of behavior through which nurses in home care deal with their main concern, their desire to give good care. Doing good care involves three different caring behaviors: anticipatory caring, momentary caring and stagnated caring.

In study IV, living on hold emerged as the pattern of behavior through which patients and relatives deal with their main concern, being put on hold. Living on hold involves three modes: fighting, adjusting and surrendering.

The overall theory, deciphering unwritten rules, explains how patients, relatives and nurses are dealing with the uncertainty of how to act and behave. Deciphering unwritten rules involves figuring out, deliberating, maneuvering and evaluating.

In conclusion, this thesis demonstrates the complexities of palliative cancer care and the importance of knowledge, resources and counseling. Patients should be cared for at the right care level according to their care needs and the care focus should be on treating symptoms irrespective of the diagnosis. The palliative care approach therefore needs to be implemented in all caring contexts with dying people.

Keywords: cancer, deciphering unwritten rules, grounded theory, nursing, palliative care, patient, relative
To my lovely family Henrik, Linnea and Joel
Vi ska ses igen

Livet kan vara vackert som en sommardag
Där himlen är fri från varje moln
Men plötsligt som en blixt ifrån en himmel klar
Det känns en iskall vind
Alla har vi haft någon som vi hållit av
Som varit en del av våra liv
Och den som var vår älskade, vår bäste vän
Finns inte längre kvar

Jag har en tro som ger mig tröst och styrka
Att vi ska ses igen, när tiden tagit slut
Trots att skiljas var så svårt
Så vet jag att du lever i ett ljus
I det hemmet som vi kallar Faders hus

Vi kan inte förklara livets hemlighet
Aldrig nånsin förstå allt det som sker
Men trots dom frågor som vi har och inga svar
Gud är den som Han är
Jag har ett hopp som jag kan lita på
Jag vet, att det bär mig när jag dör
Att bortom livet finns en annan dimension
Det är min säkra tro

Jag har en tro som ger mig tröst och styrka
Att vi ska ses igen, när tiden tagit slut
Trots att skiljas var så svårt
Så vet jag att du lever i ett ljus
I det hemmet som vi kallar Faders hus

Vi måste lära oss att det liv vi fått
Är några år som snabbt försvinner bort
Men själen som vi har, den lever alltid kvar
Den kan aldrig dö bort, som den kropp vi har fått
Den får vara för evigt hos Gud

Jag har en tro som ger mig tröst och styrka
Att vi ska ses igen, när tiden tagit slut
Trots att skiljas var så svårt
Så vet jag att du lever i ett ljus
I det hemmet som vi kallar Faders hus

Anders Börjesson ©
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This thesis is based upon the following papers, which will be referred to in the text by their Roman numerals:


The papers have been reprinted with permission of the respective journals.
INTRODUCTION

A cancer diagnosis affects a person’s life situation dramatically, but with early detection and with new therapies, many patients can live with the cancer for a longer time today than would have been possible in the past [1]. Even though many patients with cancer can be cured, there are still patients who will die from the disease and it is shown that these patients have many different symptoms which may lead to suffering for both patients and relatives [2]. The goal of palliative care is to achieve the best possible quality of life for both patients and relatives [3]. The adjustment and the transition to palliative care takes time and should not be rushed. The adjustment involves shifting the care goals from curing to caring [4]. In the 1960’s, the awareness of dying among patients and relatives was mostly a closed awareness, where patients were uninformed of their impending death [5]. More recently the pendulum has shifted towards a more open awareness, especially in cancer care, where the involved know that the patient is dying and talk openly about it [6]. At the same time, the demographics of dying have changed [7]. The reduction of hospital beds increases the strain and workload for both acute care hospitals and home care services [8]. Although many patients would like to be cared for and die at home and while this approach is promoted by healthcare organizations as a cost-effective option, it can be problematic to realize [9]. In Sweden, as many as 85% of the healthy population would prefer advanced home care, provided that the standards of the service are comparable with hospital care which means, for example, a service offered on a 24/7 basis [10]. However, the availability of palliative care services varies in Sweden [11] and the prerequisites for palliative care also vary due to differing resources and caring philosophies [12]. It has been proposed that patients and relatives should receive palliative care wherever they are [13], irrespective of domicile and source of service delivery [10], meaning that the philosophy of palliative care should be spread to all contexts with dying people [14].

During the last decade there has been an increasing attention to palliative care, both on an international and a national level. The amount of research in the palliative area has increased rapidly, but the majority of the studies are conducted in advanced palliative units, advanced palliative home care and in hospices [11, 15-17]. Bearing in mind that patients and relatives should receive palliative care wherever they are [13], it is therefore of importance to gain more knowledge of their situations and of the main concerns of patients, relatives and nurses in acute care hospitals and home care contexts.
BACKGROUND

Cancer incidence, prevalence and mortality

Cancer is a worldwide problem. The World Health Organization (WHO) estimates that globally in 2008, 12.4 million new cancer cases were diagnosed and 7.6 million people died of cancer [18]. In Sweden, the number of cancer cases has continued to increase since the 1970's. This trend can be explained by an aging population but also because of an increase in some cancer types. During 2008, 51,528 persons were diagnosed with cancer: 65% of the men were 65 years or older, compared with 55% of the women [19]. At the end of 2007, the total cancer prevalence in Sweden was approximately 385,000 persons (168,000 men and 217,000 women) and at the same time, the 5-year prevalence was 164,000 persons (85,000 men and 79,000 women) [20]. The total cancer mortality in Sweden in 2007 was 22,631 persons [21].

Today many people live longer with a cancer diagnosis than in the past, as a result of early detection of the disease and the development of new therapies [22], which have also improved the care and the survival rates for cancer. At the beginning of the 1970's, the relative 5-year survival was estimated at 35% for men and 48% for women. Today, the 5-year survival is almost 70% for both men and women. Even the 10-year survival has improved and is estimated at 60% for men and 64% for women [20].

In Sweden the most common cancer for men is prostate cancer representing one third of all male cancers. The second common cancer for men is skin cancer and the third is colon cancer. For women, breast cancer is the most common at 29%, the second most common is colon cancer and the third is skin cancer [19].

The palliative philosophy of care

Palliative care was first defined by WHO in 1986 with the focus on the late palliative phase and the terminal phase of the disease. In 2002, WHO broadened their definition to include the care of patients with life-threatening illness and the need to commence palliative care earlier in the disease trajectory [3]. Palliative care is a caring philosophy which includes care of all dying people, no matter the diagnosis [3, 10]. The aim of palliative care is to relieve symptoms, supply a good quality of care and support both patients and
relatives\textsuperscript{1} [3] and it has been proposed that palliative care should be available wherever the patients are [13]. This means that patients and their relatives should receive the same standard of care, irrespective of domicile and source of service delivery [10, 13] and that the palliative care philosophy should be spread to all contexts with dying people [14].

The definition from WHO [3] describes palliative care as:

\begin{quote}

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
\end{quote}

Even though a hospital is the least preferred place for patients [23], it is the most common place for death [24]; and even if patients prefer to stay home, for various reasons, they are often admitted to hospitals during their disease trajectory [25]. Acute care hospitals have an orientation towards curative interventions [26] and the acute hospital environment can have shortcomings as a place to deliver palliative care [27], with health professionals lacking the psychosocial

\textsuperscript{1} In this thesis, the relative is referred as a close relative, meaning a family member or a friend who is close to the patient in the palliative phase.
competence to care for cancer patients [28], and where relatives at times are left alone, feeling isolated and helpless [27]. The high pace in acute care settings can hinder health professionals getting to know the patients and their relatives. The acute care philosophy is aimed primarily at curing in a “culture of quickness” which differs from the advanced palliative care units, with their different philosophy and a “culture of slowness” [12].

Patients

Receiving a cancer diagnosis requires emotional and physical adaptation to a new situation [29] and both patients and relatives must try to adjust to living with the disease [30]. If the cancer is incurable, they might feel that the healthcare system has let them down and they may confront a life crisis [31]. Psychosocial concerns, such as powerlessness and helplessness are common feelings among dying patients [32]. Uncertainty is also a common experience among everybody involved in palliative care, regardless of their role [33]. Patients are living without normal time references and a feeling that anything could happen at any time, causing frustration [32]. Maintaining independence is important [34, 35] as well as maintaining status, which means that they want to be treated as the person they have always been [34]. They want to be seen and treated as a whole person and not just a disease [36]. The willingness to participate in the care increases when patients feel trust in the professionals and the healthcare organization [37]. The professionals engaging with patients and relatives can also influence the willingness to participate as well as the possibilities for an appropriate death [38].

When trying to maintain their independence, patients are anxious about being a burden to others and they may fear being abandoned [39]. Patients oscillate between feelings and may simultaneously experience hopelessness as well as hope [40]. Hope has been described as ‘hoping for something’ which means getting cured, and ‘living in hope’, which means a reconciliation and comfort with life and death [41]. Even if during their last month of life patients assess lower quality of life in many dimensions, they can still experience happiness and satisfaction [42]. Being cared for at home provides a sense of independence and security, which increases quality of life [40]. The commitment of relatives is often seen as a precondition for home care, but a person can be cared for and die at home without having relatives nearby [43].

Palliative cancer patients have to endure various symptoms. Studies show that it is common to experience 5-11 symptoms at the same time [2, 44, 45]. Pain, dyspnoea, and nausea are all common symptoms, but the most common symptom is pain [45, 46]. Pain has been shown to be significantly associated with psychological distress [47] and having negative effects on health-related quality of life and physical health. Even if patients have several symptoms, pain can often be prevented and is therefore an unnecessary burden [48]. Asking for
the most troublesome symptom is considered important since this better reflects the patient's perspective; one third of the symptoms might be missed if not asking for the most troublesome symptom [49]. When symptoms are under control, it increases the possibilities to address patients’ concerns about the family and increases the possibility for patients to find meaning in their lives [50]. Many patients do not consider themselves to be suffering, but suffering can be explained as a multidimensional experience for those who do experience suffering, especially when it is related to physical symptoms [51]. When patients experience physical problems, they may cycle between experiencing wellness and illness. When there are new or changed physical problems, they lose wellness and experience illness instead, but with understanding of these cycles, patients can be in control of physical problems, reclaim wellness and experience well-being [52].

When care is based on safety, participation and trust, cancer patients consider the care as good [53]. Patients are often more satisfied with the received information than their relatives. They are also more satisfied with the received support than their relatives; relatives show a tendency to underestimate the support provided to patients [54]. It has been found that the emotional support to patients comes primarily from mothers and friends. Young adults with cancer have a support network bigger than just the family, but mothers still play an important role [55]. Conversations about daily activities, their families, their normal life and their hobbies are important for patients; it seems to help them to feel normal and to maintain their hope. Sometimes patients are reluctant to disclose their needs. Although they want someone to talk with, they want to choose to whom and when to talk about their difficult emotions [56].

### Relatives

The patient’s cancer diagnosis also changes life for relatives whose situation may never be the same again. An adjustment to the new situation is needed [57] and even though they need to make this adjustment, it is also important for them to live as normally as possible [33], developing new daily routines [58]. Relatives describe their grief as starting at the same time as they realized that their spouses would die. They describe this awareness almost as unbearable; that the only way to handle this was to keep on living as usual. The time perspective also changes for relatives, with time slipping or standing still [59]. Studies have shown that relatives have more difficulties to accept the situation than patients [60] and that the level of hope is lower among relatives [61]. Their perception of the patient’s pain and suffering leaves them feeling powerless and helpless [62].

Relatives have a twofold role; as caregivers and as relatives experiencing their own anxiety and physical exhaustion [57]. These different roles can also involve struggling to find treatment, being a partner, keeping the disease at a
distance, waiting for death and at the same time being experts on the patient and being a proctor [63]. Relatives may lack adequate resources and feel insufficiently prepared for their new roles [64]. The burden of the caring can lead to physical disease, emotional stress and financial crisis, and also death for the relative [65]. It can be an intense experience filled with emotions of hope, hopelessness, blame, fear and regret [66]. This situation for relatives can lead to life restrictions and increased emotional stress [67]. Even though they are emotionally overwhelmed [68], they often put their own feelings at a distance [59]: they want to be perceived as emotionally strong in front of the patient [57, 68]. Instead of sharing their emotions, they endure suffering in silence [59].

Caring for a dying person can be experienced as a burden but it can also be an opportunity to express love to the one who is sick [57, 66]; experiencing the cancer together as “companions through cancer” [68]. Through becoming actively involved in the care, relatives can reduce their own uncertainty concerning the patient’s condition [69] and may better understand the patient’s emotions. This could also be a way for relatives to handle their own feelings caused by the situation [68]. Many relatives want to participate in the care [70] and be recognized as one part of the team [57]. Being a part of the care can be relieving; relatives may feel that they have contributed to something “above” themselves [70].

Caring requires a continuous balance between the care burden and the capacity to handle the situation [71]. The well-being of the relatives is therefore crucial if the patients are to be cared for at home [72]. Since caring involves different roles and a considerable commitment, attention must be given to the needs of relatives [57, 73], but several studies have shown unsatisfied emotional support [65, 71, 74, 75]. It has been shown that relatives, not living close to the patients, are more critical of the care than relatives living closer [76]. When relatives experience different needs, they may be reluctant to disclose them to the health professionals. One reason could be that they do not think it is acceptable to talk about their own needs [72] and another reason could be that they want to preserve their independence and dignity [77]. It is therefore of great importance for health professionals to assess the relatives’ well-being and their need for emotional support [73]. The need for support and care must be recognized early and begin at the same time that the patient receives the diagnosis. If adequate information and support are given in an early phase of the patient’s treatment, the relatives will experience less needs, more trust and increased confidence in the healthcare system. They will also be better able to handle the late stages of the disease [31].
Palliative cancer care

Health professionals in oncology work closely with patients suffering life-threatening disease and where therapy at times has only a limited impact. While caring for cancer patients is challenging, it is also rewarding [78, 79]. Nurses need to balance between being close to the patients and distancing themselves [80]. Nurses often want to care for the whole person, going beyond the diagnostic concept of cancer to treat the person, not simply a diagnosis [81]. They have high ambitions and expectations to give high-quality care to dying patients and their relatives. When nurses experience good contact with patients and relatives, they feel satisfied [82]. Facing dying and death has an impact on daily work but also an impact on private life. Both professional and personal growth can be fostered by their relationship with the dying [83]. It is also shown that the nurses’ own experiences and attitudes affect the quality of the given care [84, 85]. Being motivated by a deep concern for patients and family may cause stress when resources are insufficient [86]. It can also be risky to get into deep relationships with cancer patients because the nurses may be emotionally overwhelmed and unresolved grief may negatively affect their future work capacity [87]. More knowledge of the common psychosocial concerns that patients experience could improve clinical care as well as the professionals’ sense of meaning and their satisfaction when caring for the dying person [50, 88].

Cancer care can give compassion fatigue due to communication and confrontation difficulties with dying patients and relatives. This is especially the case with ethical issues [89]. Ethical dilemmas in cancer care mainly occur in disclosure and decision making situations with different implications for nurses and physicians [90]. Physicians are responsible for the decision making while nurses have to live with these decisions [91]. Team working between nurses and physicians can thus be difficult when conflicting care goals emerge and cause frustration, impairing personal work satisfaction and the quality of care [78, 81]. It has been shown that communication around end of life issues continues to be poor between medical and nursing staff as well as between nursing staff, patients and families. This lack of communication creates unnecessary stress for everyone involved [92]. Nurses may be aware that patients and relatives are in need of emotional support, but they feel unable to give support. This may be due to their unprocessed emotions, lack of time or knowledge, etc. [93]. Emotional support is often given during the daily care. The most common ways to give emotional support are listening, touching, showing empathy, acknowledging patients’ wishes, comforting, encouraging and just being there [94].

Caring for dying may render frustration. Health professionals must care for themselves [81] with self-care strategies being essential to the enhancement of self-esteem and professional effectiveness [95]. Nurses who practice self-care strategies have an increased ability to give compassionate care without being.
emotionally overwhelmed [96]. Nurses may feel that their emotional strains are theirs to endure, getting little support from the organization in which they work. For the organization to take responsibility for the psychosocial support of the health professionals requires their acknowledgment of the stress that they encounter in a context characterized by a shortage of staff resources and competence in relation to the psychosocially demanding tasks [97].

The palliative care is a balancing act, where professionals need to balance the patient’s need for care with the resources available to give the care [98]. To give quality palliative care, nurses need resources [82]. The structural resource factors such as lack of time and training have been found to be more related to stress in palliative cancer nursing than lack of skill in caring for dying patients [79, 99]. Nurses may experience a tension between their caregiving ideals and the reality of daily work with the resultant gap hindering their giving high quality care. Examples could be limitations in time and space for staff. Nurses are aware of the ideal they want to fulfill, but the possibility to realize this is often small [100].
PROBLEMATIZING REASONING

It is proposed that palliative care philosophy should be spread to all contexts where dying patients are being cared for [10, 13, 14]. Even though the hospital is a setting where many palliative cancer patients are cared for during the disease trajectory, and where many patients die [24, 101, 102], palliative care in hospitals has been a neglected area of research [16]. It has been shown that symptoms and care needs are common in palliative cancer patients, but have primarily been studied in advanced palliative care units or hospices [15, 43, 45, 103], with only a few studies in acute care hospitals [104, 105]. Knowledge of symptom prevalence in palliative cancer patients in acute care hospitals is important for clinical practice [45, 106]. With knowledge of symptom prevalence, health professionals can focus on the prevalent symptoms anticipating problems and planning for better care. This knowledge can also help health care organizations in educating health professionals and planning services [106].

Caring for a dying person requires a continuous balance between the care burden and the capacity to handle the situation [71]. Patients should be treated as a whole person, not simply a disease [81] and patients’ and relatives’ needs should be acknowledged and not questioned or challenged [4]. Studies have shown that adequate information and support early in the disease trajectory decreases needs and increases trust and confidence throughout the dying trajectory [31, 36]. It has also been shown that professionals’ presumptions often do not correspond with the patients’ [93], and that there are mismatches between professionals, patients and relatives in terms of what is important [93, 107]. Health professionals need to know, and not just assume, what is important for patients and their relatives if they are to be able to give high quality care. It has been argued that end of life time may be taken for granted as empty and with no value. This attitude affects the given care, with the consequence that optimal resources are not offered to dying persons [108]. Nurses in palliative care can experience a tension between their caregiving ideals and the reality of their daily work. This gap can hinder their ability to give high quality care. Being aware of the ideal, but not being able to fulfill it causes frustration [100].

As mentioned earlier, there is a paucity of studies concerning nurses, patients and relatives in palliative care in acute care settings and it is high time that evidence and practice are improved in this setting. There is also a lack of empirically grounded theoretical explanations of how palliative cancer patients, relatives and nurses handle their situation in acute care and home care [11, 15]. Such understanding would be valuable if health professionals are to provide palliative care which is theoretically grounded. Thus, for health professionals to
provide high-quality palliative care in acute care hospitals and home care, more knowledge is required about what is really happening in these contexts. This thesis is aimed at explaining the latent patterns of behavior of cancer patients, relatives and nurses in palliative care within acute care hospitals and home care settings.

**AIMS**

The overall aim of the thesis was to generate a grounded theory explaining the latent patterns of behavior of cancer patients, relatives and nurses within the context of palliative care in acute care hospitals and home care settings. The aims of each of the studies were formulated as below:

I. To describe and compare symptoms, care needs and types of cancer sites in 2002 as compared to 2007, and to analyze the relationships between these factors in hospitalized palliative cancer patients.

II. To develop a grounded theory of nurses caring for palliative cancer patients in hospital care. The research question guiding the study was: What is the main concern for nurses caring for palliative cancer patients in hospital care, and how do they resolve it?

III. To develop a grounded theory of palliative home nursing care. The research question guiding the study was: What is the main concern for community nurses caring for palliative cancer patients and how do they resolve it?

IV. To develop a grounded theory of palliative cancer patients and their relatives in the context of home care. The research question guiding the study was: What is the main concern for palliative cancer patients and their relatives and how do they resolve it?
METHOD

Design and setting

This thesis includes one population-based study with cross-sectional design (Study I) and four theory generating studies (Studies II-IV and Overall Theory). The overall aim of the thesis is broad, with a focus on a research area rather than a specific research topic. Therefore, classic grounded theory was chosen as the method aims to discover the participants’ main concern and how they resolve it, and also explains problematic and relevant patterns of behavior [109, 110].

The studies were carried out in a medium-sized county serving 180 000 individuals in southern Sweden between 2002 and 2009. The county has two acute care hospitals and home care in seven rural communities. During the study period the area had no 24-hour-palliative care services. A palliative counseling team provided daytime service to the population Monday to Friday. During the study period, the team increased its staff, from three nurses (2002) to six nurses and two consulting physicians working half-time (2009). The palliative counseling team was affiliated with the oncological department. The team worked as a link between both hospitals and the community based nursing home care in supporting the health professionals. The methodological processes of the four studies are presented in detail in each of the papers (I-IV).

Study I

Questionnaire

Study I is based on the findings from a questionnaire used in acute care hospital wards to assess patients as palliative or non-palliative. The questionnaire was designed by a multi-professional panel in palliative care and consisted of the following items: eight items concerned the organization, for example clinic, ward, responsible health professional, number of hospital beds and number of inpatients; four items covered gender, year of birth, diagnosis, and place of residence of patients. The last item concerned symptoms and care needs during hospitalization and had multiple choices, where a total of 21 different symptoms and care needs were available in the list, and more than one could be chosen. There was also the possibility to write comments.

The WHO palliative care definition was used as a basis for the identification of palliative care patients and was printed on the back of the questionnaire. The questionnaire was tested for face and content validity by an expert panel of
two physicians and four nurses, focus group interviews with nurses, and finally through a pilot study, following which minor adjustments were made to the layout. The final form was distributed to the participating wards and completed by the nurses and the physicians at each unit.

**Sample and data collection**
The study was presented at information meetings in both 2002 and 2007, where discussion focused around how to assess a patient as palliative with the responsible nurses from the different wards. A palliative patient was defined as a patient whose disease was not responsive to curative treatment and where the prognosis was limited.

During 2002 and 2007, one-day-inventories were done in the hospital wards. On a specific day each month the responsible nurse, together with the physicians, assessed which of the patients were palliative cancer patients and filled in the questionnaire. In 2002, 10 one-day-inventories were done in 10 wards: one oncology ward (20 beds), four surgical wards (104 beds) and five medical wards (119 beds). In all, 82 one-day-inventories were analyzed (data missing 18%). In 2007, 12 one-day-inventories were done in 12 wards: one oncology ward (17 beds), four surgical wards (89 beds) and seven medical wards (153 beds). In all 142 one-day-inventories were analyzed (data missing 1.4%). Both in 2002 and 2007, one reminder call or one e-mail reminder was done. In total, 1 352 patients were assessed and registered in 2002 and 2 972 patients in 2007.

**Statistical analyses**
Analyses of differences between 2002 and 2007 were performed using Student’s t-test (age) and the chi-square test (nominal variables). Multiple logistic regression analyses (backward stepwise, likelihood ratio) were done to analyze associations between each symptom and care need and cancer sites. The purpose with multiple logistic regression analyses is to describe associations between exposure or explanatory variables and a dichotomous outcome [111]. Through backward stepwise regression, elimination of non-significant variables is done until all those remaining variables in the model are significantly associated with the outcome [112]. Logistic regression analyses provide an estimate of the relative risk as odds ratio (OR) and compute the 95% confidence interval (95% CI). Prior to these analyses, bivariate associations between each symptom and care need with different cancer sites were assessed. Cancer sites that were associated with the respective symptom and care need were included in the logistic regression model if the p-value was ≤ 0.20. All analyses were performed controlling for age. The Nagelkerke R-square statistics were then calculated in order to evaluate the strength of the associations between symptoms and care needs with type of cancer site.
Data from 2002 and 2007 were used for general comparisons, but in order to focus on the current situation, only data from 2007 were used in the regression analyses, as associations are dependent on changes/improvements in therapy, and such changes between 2002 and 2007 cannot be ruled out. P-values <0.05 were regarded as statistically significant. The computer based statistical program SPSS, version 16.1 (SPSS Inc, Chicago, Ill) was used for all analyses.

Classic Grounded Theory Methodology (Studies II-IV and Overall Theory)

In the literature, grounded theory is used as a common label for very different research methodologies and there exist numerous interpretations and remodeled versions of the original, or classic, methodology [113]. While this can be confusing for the novice researcher, the choice of methodology should depend on its fit to the researcher’s purpose and skills, or the contextual purpose [114]. This thesis is written according to classic grounded theory methodology, with the perspective rooted in the work of Glaser and Strauss [110] and Glaser’s subsequent work [109, 113, 115-122].

Historical development

Grounded theory was discovered by Barney Glaser and Anselm Strauss in the mid-1960s in their research on dying people [5]. Classic grounded theory derived from a mix of the authors’ backgrounds. Barney Glaser studied quantitative and qualitative math under Paul Lazarsfeld at Columbia University. He also did studies of ‘explication de texte’ at the University of Paris and studied theory construction under Robert Merton. Anselm Strauss studied symbolic interactionism under Herbert Blumer at the University of Chicago [110, 113]. When Glaser had received his PhD from Columbia University in 1961, he went to University of California San Francisco. There he joined Strauss in the research study on dying in hospitals. It was through this study on dying patients, that grounded theory methodology was elaborated. To show how the dying study was done, Glaser and Strauss then wrote the groundbreaking work, “The Discovery of Grounded Theory” [110]. After its publication, Glaser continued to elaborate the methodology and wrote several subsequent books on to the methodology and its use [109, 113, 115-122].

Theoretical foundations

Glaser resists all attempts at labeling grounded theory as an "ism" and claims that grounded theory is free of ties to any theory of science, because grounded theories are just hypotheses of interrelationships between a set of categories and does not deal with philosophical conceptions of what is “truth” [113, 118]. Classic grounded theory is as “issues free as research can get – conceptually abstract of issues and subject to modification by constant comparison” (p. 116)
Andrews [123] suggests that the ontology and epistemology of grounded theory are not very clear and therefore it is difficult to evaluate to what extent different influences have affected the methodology. Nathaniel [124] considers grounded theory as a natural product of the post-positivist movement and symbolic interactionism; this since Strauss was a student of Blumer, who is considered by many to be the founder of symbolic interactionism. Many scholars attribute grounded theory to symbolic interactionism [124], but Glaser identifies symbolic interactionism as just one of many theoretical codes that have to earn their way into the theory [119]. Glaser has explained several times that symbolic interactionism is not the foundational theoretical perspective of classic grounded theory; that grounded theory “is a general inductive method possessed by no discipline or theoretical perspective or data type” (p. 141) and that “the quest for an ontology and epistemology for justifying grounded theory is not necessary”; that grounded theory is a “paradigm for discovery of what is going on in any particular arena” (p. 145) [119].

Grounded theory has been positioned as positivist, pragmatist, non-empiricist, interpretivist, constructivist and realist by different authors, but Holton [125] claims that grounded theory is a general methodology, occupying its own distinct paradigm on the research landscape. She does not suggest that classic grounded theory is a superior methodology; it is simply a different methodology. It has its own principles and procedures for what constitutes valid research and is therefore a distinct paradigm. Classic grounded theory methodology does not fit within established research paradigms; since it is a general methodology, “classic grounded theory transcends the specific boundaries of established paradigms to accommodate any type of data sourced and expressed through any epistemological lens” (p. 268). Classic grounded theory uses all kinds of data and “accommodates a range of epistemological and ontological perspectives without having to espouse any one perspective; in essence, the methodology is epistemologically and ontologically neutral” (p. 268) [125].

**Classic grounded theory as a general methodology**

As a general methodology, classic grounded theory stands alone as a conceptual method for generating abstract conceptual theory [118]. Grounded theory uses all kinds of data, both quantitative and qualitative, and therefore transcends descriptive methods and their associated problems of accuracy, interpretation and constructionism [126]. It is a different methodology but does not claim to be a better method than others; it is just one among many methods.

Classic grounded theory conceptualizes patterns of behavior in which people are engaged [109, 113]. Glaser explains that the goal for grounded theory “is to generate a theory that accounts for a pattern of behavior which is relevant and significant for those involved. The goal is not voluminous description, not clever verification” (p. 93) [109]. It is a conceptual method, not a descriptive method. In grounded theory, it is behaviors, not people, that are categorized [116]. Grounded theory attests that people have multiple and variable
perspectives and that the researcher’s purpose is to raise these perspectives to an abstract level of conceptualization, to be able to see the underlying or latent pattern [127]. Grounded theory allows categories and their properties to emerge from data and to be integrated into hypotheses that later result in a theory. The theory is an integrated set of conceptual probability statements that explain the behavior that accounts for the processing or resolving of a main concern or problem for the participants [117]. Thus, the aim for the researcher is to develop a theory about how people continually process or resolve their main concern. This is done by discovering their latent pattern of behavior and conceptualizing it. The individuals in the substantive field may be aware of their own behavior but not the behaviors of others and it is also unlikely that the individuals can see the overall pattern of behavior [113]. Since the focus is a generated abstraction of the doings of the individuals and since concepts are generated from much data, the member checking associated with qualitative methods is unnecessary in classic grounded theory [116].

The goal for classic grounded theory is not accurate description; the goal is instead conceptualization of patterns of behavior carefully discovered by constant comparing of data that are theoretically sampled for conceptual saturation of interchangeable indices [109]. The foundation of classic grounded theory development is therefore the conceptualization of data and the core process is coding. The conceptual abstraction of data and its reintegration as theory takes place through coding [116, 126].

The decision to use classic grounded theory is a full package decision and the researcher has to be aware that generating grounded theory takes time. As a delayed action phenomenon [113], the process can be confusing to the novice researcher. The ability to generate concepts from the data and relate them in a theory demands theoretical sensitivity; it requires an analytic temperament and a level of competence that not everyone has. Personal analytic temperament means maintaining analytic distance from data, tolerating chaos and trusting in conceptual emergence. Analytic competence means developing theoretical insight and the ability to conceptualize data [125].

**Conceptualization versus description**

It is important to understand the distinction between conceptualization and description to be able to understand classic grounded theory methodology [125]. According to Glaser, classic grounded theory stands alone as a conceptualization method [117]; he points out that conceptualization is the core process of grounded theory [116, 126] and that many researchers lack knowledge and competence in conceptualization [127].

For generating a grounded theory, the two most important properties of conceptualization are that concepts are abstract of time, place, and people, and that concepts have enduring grab [126]. “One of the most important aspects of conceptualization is that concepts last forever, whereas descriptions are tied to time and people and are only of value within a concrete setting” (p. 82) [128].
Conceptualization has tremendous grab with endurance and power that overwhelms the power of description. Glaser claims that description “is stale dated soon after the research, whereas conception goes on forever” [129]. He does not mean that description is bad or wrong; it is just different properties and uses [126]. Glaser [116] draws the distinction between abstract conceptualization where the theory must be grounded empirically in the data yet transcend the data to form a theory and conceptual description which, while also grounded in data, fails to provide a conceptually integrated theory.

Sometimes researchers get confused as to whether a grounded theory describes a unit or conceptualizes a process within it [116]. A grounded theory must give a conceptually abstract explanation of a latent pattern of behavior and it must explain, not just describe, what is happening. It is the abstraction to a conceptual level that makes it possible to theoretically explain rather than describe the behaviors [117]. By putting focus on concepts and abstraction, the researcher is free from qualitative research’s concern with accuracy and interpretation of multiple perspectives [127]. Proofs are not the point in grounded theory and the illustrations that might be given in a theory are not examples intended to prove that the theory is correct. While all the concepts are grounded, the theory is still just suggestions since the theory is an integrated set of hypotheses and not findings. Grounded theories are not concerned with accurate evidence on a descriptive level, but on a conceptual level [109]. “Quantitative research and QDA (qualitative data analysis) provide description of aggregates and in-depth cases respectively whereas grounded theory provides a conceptual overview with grounded interpretations, explanation, impacts, underlying causes and so forth” (p. 118) [117]. Grounded theory is not superior, but rather complementary to other methodologies. Accuracy is an issue in qualitative methodology, but since grounded theory deals with abstract patterns and has a conceptual nature, accuracy is not an issue and the theory is easily modified if new data comes the researcher’s way [116].

A grounded theorist is not interested in the group or the unit per se, but is interested in collecting data on categories for the generation of properties and hypotheses. The emphasis in grounded theory is to type behavior and not people. The emphasis is on behavioral patterns [113]. The main concern is not a description of the “voice” of the participants; it is rather a generated abstraction from both the participants’ doings and their meanings [126] and a “conceptualization of it based on a theoretical coding and conceptual saturation of interchangeable indices” (p. 103) [116]. In the case of QDA, the goal is full conceptual description, but grounded theory’s concern is abstract conceptualization. Holton [125] explains that “grounded theory is not about the accuracy of descriptive units, nor is it an act of interpreting meaning as ascribed by the participants in a study; rather, it is an act of conceptual abstraction” (p. 272).
**General implications**
QDA is focused on description of time, place and people and therefore has to contend with problems of accuracy, interpretation and construction, when trying to produce “what is”. Grounded theory on the other hand, generates conceptual hypotheses that can be applied to any relevant time, place and people with emergent fit. New data can through constant comparison, modify the theory’s explanation of behaviors, not people [126]. Generalizing behavior is easier than generalizing units, because behavior patterns transcend the borders of units [114]. A grounded theory doesn’t describe a unit; it conceptualizes a process within the unit [116]. Grounded theory analysis “produces a substantive, conceptual theory with general implications, not descriptive findings” [118]. It transcends the substantive area studied with general implications. The generalizing is “never a factual transfer, such as in description, it is just multiple integrated hypotheses modified to fit where applied” (p. 90) [116].

**The criteria for evaluating grounded theory**
A grounded theory should be judged by fit, workability, relevance and modifiability [113].

- **Fit** is an aspect of validity and depicts how the concepts match the incidents they represent. The emergence of conceptual codes and categories has to come from data and not from the use of preconceived codes and categories from already existent theories.
- **Work** refers to the ability of the theory to explain and interpret behaviour with much variation and to predict future behaviour.
- **Relevance** means that the concepts relate to what is really going on and how it is continually processed or resolved. Relevance also refers to the significance of the theory for the participants in the substantive area; the intended audience of the theory should judge its relevance.
- **Modifiability** refers to the theory’s ability to be modified by comparing new relevant data to existing data. Modifiability is therefore a living quality of grounded theory that ensures the theory’s continuing relevance and value to the area from which it has emerged.

A grounded theory should be judged according to these principles, but a grounded theory is never right or wrong; the theory only has more or less fit, workability, relevance and modifiability [113]. Grounded theory is good as far
as it goes in explaining what is going on in an area [130]. Glaser [113] also considers grounded theory’s process of constant comparison (of incidents to incidents, of incidents to emergent concepts and of concepts to concepts for emergent theoretical integration) to be the theory’s own constant verification; continually modifying the emergent theory by constant comparison.

**Studies II-IV**

**Data sources**

In classic grounded theory, “all is data” (p. 8) [113] and therefore formal and informal interviews, observation and literature were used as data in Studies II-IV. The sample size in the studies was based on theoretical sampling and saturation, rather than the representativeness of a sample since this is not an issue in grounded theory [113]. Theoretical sampling guided where to collect more data in order to refine and elaborate emergent categories and later on with a specific focus on categories related to the core category in the emerging theory. “Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges” (p. 36) [109]. Theoretical saturation occurs when no new properties emerge; rather, the same properties continue to emerge when coding and analyzing the new data [109].

In study II, 16 nurses were interviewed in oncology and surgical wards in acute care hospital wards. All were women, and half of them had more than 10 years of working experience as nurses. In addition, a secondary analysis was undertaken of previously conducted interviews in palliative care [98]. The purpose of the secondary analysis was to compare data and refine and delimit the coding to variables related to the core concept.

In study III, 33 nurses working in community care were interviewed; 30 of them had more than 10 years of working experience as nurses. All the nurses were women. Secondary analysis was done for 11 formal interviews and 3 focus group interviews with community nurses, surgeons and general practitioners [98] as well as 16 nurses in an acute care hospital (Study II). Documents from a training course for community nurses and documents from the palliative counseling team were also analyzed according to “all is data” [113]. Also field notes and memos from informal interviews and participant observations at conferences and seminars were also analyzed and compared with the formal interviews.

In study IV, 25 interviews were done with palliative cancer patients and their relatives. The patients had various cancer diagnoses in different stages and with different prognoses, but all were in the palliative phase. Relatives in the study were the patients’ partners except for two interviews where the patients’
daughters were interviewed. Secondary analysis was undertaken of previously collected interviews from earlier unpublished studies with the most comprehensive interviews with patients and relatives chosen for analysis. Also in this study, field notes and memos from informal interviews and participant observations at cancer care conferences were coded and analyzed.

Data collection

In grounded theory methodology, data collection and data analysis are not separate processes; rather, they are conducted concurrently [113]. In coding and analysis of the data, the researcher continues to focus on the following questions: What is the main concern being faced by the participants, and what accounts for the continual resolving of this concern? [109]

The major data source for studies II-IV was interviews. The interviews were generally informal, open-ended conversations [110]. Theoretical sampling guided the interviews meaning that while interviewing, new ideas emerged of what to ask next and later on. These ideas guided further data collection, a central property of theoretical sampling [109, 113]. Analyzing the data currently with subsequent interviewing enabled the researcher to further refine, elaborate and saturate the emerging categories [109].

Even though classic grounded theory does not recommend tape-recorded interviews [113], most of the interviews in study II and some of the interviews in study III were tape-recorded to comply with nursing faculty requirements. With all interviews, even those tape-recorded, field notes were taken during and directly after; the field notes were expanded and used as data for analysis.

Since the researcher has worked with cancer patients at a surgical ward, in line with grounded theory, the researcher’s experience and preconceived thoughts were written down and used as additional data. The literature review was not undertaken until the substantive theory was formulated, and in accordance with classic grounded theory, the literature was treated as another data source in the constant comparative process [113].

Study II

The interviews with the nurses were carried out by the researcher between 2001 and 2003. Interviews lasted between 35 and 70 minutes, with the length of interviews reduced as more specific questions emerged during analysis to direct further theoretical sampling. All interviews began with the invitation, “Tell me what it is like to care for palliative cancer patients” and later on when the core category had emerged during the analysis, more specific questions were asked; for example, “How do you handle difficult situations?” and “What kind of support do you get?” As in study I, although most of the interviews were tape-recorded and transcribed, field notes were taken during the interviews as the basis for data analysis.
Study III
The interviews with nurses in the community were conducted between 2004 and 2006. Each interview lasted between 45 and 90 minutes, with shorter interviews by the end of the study, due to the delimiting properties of grounded theory. Field notes were taken during all interviews; the first ten interviews were also tape-recorded and later transcribed. The interviews began with: “Tell me what it is like to care for palliative cancer patients”. Subsequent theoretical sampling questions included: “Tell me about a difficult caring situation”, “How do you handle difficult situations?” and “Tell me about a caring situation that went well”.

Study IV
The interviews with patients and relatives were conducted between 2006 and 2008; either interviewing them together or separately. The interviews were conducted in the patients’ homes since this environment seemed more relaxed for patients and relatives. All of the patients had experiences of being hospitalized while being in the palliative phase. Interviews lasted between 60 and 180 minutes. Given the delimiting properties of grounded theory, interviews should have been shorter towards the end of the study, but the patients and relatives wanted to share all their experiences and therefore it was difficult to conclude the interviews prematurely. The interviews began with open questions, allowing responses to emerge without any direction from preconceived questions. Thus, the interviews resembled open conversations rather than strict formal interviews. Both patients and relatives were asked to tell about the disease trajectory and their situation.

Data analysis
Throughout the analytic process, conceptual memos were written to capture emergent theorizing at any time and place, often in the shape of text and figures to capture creative ideas. Memos are the “theorizing write-up of ideas about substantive codes and their theoretically coded relationships as they emerge during coding, collecting and analyzing data and during memoing” (p. 177) [113]. The importance of memo-writing could be explained as follows: your mind is not the memory – your memos are your memory. Memoing is seen as foundational in classic grounded theory; without memos there could be no grounded theory. Eventually memos on memos are written and over time, a rich memo bank is established about the emerging theory.

The analytic process starts with the open coding of data as the basis for concept generation. The data in the form of field notes are coded line by line directly after each interview. It is the articulated incidents in the data that are analyzed and coded in grounded theory. Coding means “fracturing the data, then conceptually grouping it into codes that then become the theory which explains what is happening in the data” (p. 55) [109]. During this open coding,
one asks a set of questions of the data: What is this data a study of? What category does this incident indicate? What is actually happening in the data? What is the participants’ main concern? How do they continually resolve this concern? The purpose of these questions is to keep the analyst theoretically sensitive and to avoid description when analyzing, collecting, and coding data [113]. It should be emphasized that the conceptualization process focuses on properties that repeat themselves across the majority of the data, and not on single incidents within the data.

The initial open codes are then compared with each other followed by comparing newly generated concepts to new open codes and then concepts to other concepts; through this process eventually the core concept emerges. The core category is central in grounded theory and explains the behavior of the participants in processing or resolving their main concern. The theory is generated around a core category, which can be any kind of theoretical code such as dimensions, a process, a typology, conditions, or consequences. “Without a core category, an effort of grounded theory will drift in relevance and workability. Since a core category accounts for most of the variation in a pattern of behavior, it has several important functions for generating grounded theory: integration, density, saturation, completeness and delimiting focus” (p. 75) [115].

When the core concept had emerged, the selective coding process begins. Selectively sampling new data is done with the core category in mind. This means that further data collection and coding is delimited to the categories related to the core concept. The categories which are not in relationship with the core concept are delimited. As described earlier, secondary analysis of previously collected data was employed to saturate the core category and related concepts. All data used for secondary analysis was related to the behavior of the participants in palliative care and was constantly compared with the formal interview data. Additional interviews were conducted as necessary to saturate the emergent core concept and related categories. When these subsequent interviews and field notes did not seem to make any further contribution to the emerging theory, the emergent theory was deemed theoretically saturated and data collection ceased [109].

Theoretical coding re-integrates the previously fractured and now conceptualized data. In theoretical coding, relationships between categories and the core concept emerge through the hand sorting of memos. During this sorting stage, additional memos are written to capture ideas on the emergent theory and on what theoretical codes may organize the relationships between the core category and related concepts. There are many theoretical coding families. The basic social process is one of the most common theoretical codes but a grounded theory is not always a basic social process [119]. In study II, the theoretical codes of dimensions and strategies emerged during the analysis and the theory is built around these codes. In studies III and IV, the theoretical code of typology emerged during analysis and the theories are therefore presented as typologies. Once the appropriate theoretical code or codes have emerged through the
sorting of memos, the memos are written up in this sorted order as the last stage of the grounded theory process. As this stage indicates, the elements of time, place and individuals have been left behind with the final theory written as conceptually abstract [109, 113].

During several grounded theory troubleshooting seminars with Dr. Barney Glaser (Grounded Theory Institute), the researcher received assistance with the conceptualization of core categories and the emergent theories. The researcher also received advice around the theories through discussions with supervisors and through e-mail contacts with other grounded theorists.

Studies II-IV were later used to generate a new grounded theory unifying the three studies and explaining the latent patterns of behavior among patients, relatives and nurses in palliative settings (Overall Theory). Analysis was done on the memos and the theories from the three different studies. New memos were written throughout the subsequent analysis and concepts and incidents were generated through constant comparison. The memos were then hand sorted and the new theory Deciphering Unwritten Rules written up.

**Ethical considerations**

Research in the area of palliative cancer care raises questions about ethical issues. The patients and their relatives are in a vulnerable situation; some even question whether such research should be done. Wilkie [131] suggests that research in palliative care should be done, if following the directives of the Declaration of Helsinki [132]. Strang [133] also argues that research in palliative care is ethically defensible. He suggests that not researching this area would be unethical because health professionals need to know what the care means to the patients and relatives in order to provide good care [133]. The studies in this thesis were performed in accordance with the Declaration of Helsinki [132].

Since study I did not involve any identifiable patient data, the study was considered as part of normal clinical improvement procedure by Swedish law and praxis and an approval by The Regional Ethics Committee was thus not necessary. Ethical approval was granted by the operations managers and the heads of the departments at both hospitals. Written information was sent out to the heads of the wards and information meetings were held for the responsible nurses on the wards. At the information meetings, the purpose of the study was discussed and explanation given for how to assess a patient as palliative.

The Regional Ethics Committee of Lund University, Sweden, approved study II (LU 721-01) and studies III-IV (LU 680-3). The studies were also approved by those responsible for the departments at the hospitals and those responsible for home care in the municipalities involved. The researcher was not involved in the recruitment of the participants in any of the studies and was not involved in the care of the patients in study IV. Written informed consent was obtained from the participants before the interviews and in the invitation
letter, they were informed about the aim of the study, their right to voluntary and free participation, and an explanation of the confidentiality. Also verbal information was given before the interview started and the participants were again assured confidentiality. After each interview, the researcher made certain that the participants were doing well, and assessed possible needs for emotional support.

Methodological considerations

In this thesis both statistical methods (Study I) and classic grounded theory methodology (Studies II-IV and Overall Theory) were used. This design mix of statistical analyses and a theory generating method was considered as a suitable design for exploring the overall aim of the thesis. Study I was a population-based study which provided information on symptoms, care needs and diagnosis of palliative cancer patients during hospitalization, but also on how the situation had changed over a 5-year interval. Study I provided information on the medical and healthcare context as well as the organizational context, thereby increasing the trustworthiness of the thesis results. Studies II-IV present explanations of the main concerns of patients, relatives and nurses and of the behaviors that continually process or resolve those concerns. The emergent nature of classic grounded theory methodology enables the discovery of their main concerns, which is unlikely with methods focusing on predefined problems and questions. Grounded theory has been shown appropriate for nursing research [134]. A particular strength with this thesis is that patients, relatives and nurses were included offering different perspectives. Although each study was undertaken as a separate investigation, the earlier study results affected the subsequent study results through the analytic process. The separate studies were then unified in an overall theory, Deciphering Unwritten Rules, although further research is needed to saturate and fully develop this theory, its consequences and the impacts of its different strategies.

Study I

Study I employed the same design in both years of research, with the same questionnaire and with responsible nurses at each ward. It is important to have a reliable instrument and the questionnaire used in this study was designed by an expert panel and then tested in a pilot study, followed by some minor corrections. An important strength of this study is the low data missing in both years. One limitation of the study is that the assessment of symptoms and care needs was done by the responsible nurses and physicians at the wards and not by the patients themselves, so there might be a number of unrecognized symptoms in the study. Earlier studies have shown that patients generally are the best raters of their quality of life [135, 136], but when assessing symptom distress it has been shown that on average, patients and proxies provided similar
reports [136]. It should also be emphasized that the aim of this study was not to have full coverage of symptoms and care needs, rather an assessment of patients’ symptoms and their care needs during hospitalization. Another limitation is that the reasons for admission and the length of the hospital stays are unknown. This means that some symptoms and care needs might have appeared in the hospital, maybe as a complication of a treatment or as a consequence of lack of treatment.

Assessing a patient as palliative may be subjective, but to minimize the risk of assessing patients differently, information meetings were held with discussions about how to assess and define a patient as palliative according to WHO’s definition of palliative care. Also, it was generally the same nurse who assessed the patients at each one-day-inventory at the wards which increases the reliability of the assessment.

The healthcare organization in the county was stable during the study, so the decreased number of palliative patients could not be explained by organizational changes. Even though more medical wards were included in the study in 2007, this did not affect the total number of palliative cancer patients and the decrease was instead seen at the oncology ward.

The multiple logistic regression models showed wide confidence intervals even though significant associations between symptoms and care needs with cancer sites were obtained. To evaluate the strength of these associations, Nagelkerke R-square analyses were calculated. These analyses showed relatively low values; only two models had a Nagelkerke R-square over 0.3. This means that none of the final models were exhaustive. The low values indicate that most of the symptoms and care needs in hospitalized palliative cancer patients are not associated with their cancer diagnosis; on the contrary, symptoms and care needs seem to be similar for many cancer diagnoses.

External validity refers to what extent the results can be generalized to other populations beyond the one investigated [137]. While not completely generalizable, the results in study I could be compared with other studies in similar contexts. Given that the study was population-based, with low data missing, most of the palliative cancer patients during hospitalization were probably included in this study. Also taking into consideration that the diagnosis panorama in the study seems comparable to the situation in Sweden, the results regarding the associations between symptoms and care needs with cancer site might be generalized to a certain extent, but it should be emphasized that there is a need for larger studies to verify these results.

Studies II-IV and Overall Theory
One must bear in mind that grounded theory is not about description; it is about explaining what happens and that this is done as follows: seeing a pattern, naming it and studying a core concept. Conceptualization is central in grounded theory but naming a concept with grab can be difficult when the language is not one’s mother tongue. However, the opportunity to participate in
several international grounded theory seminars with Dr. Barney Glaser where the emerging theories were discussed offered the researcher considerable help in naming categories. Discussions about the naming of categories were also held with supervisors and the English text editor.

From the beginning, the focus of these studies was on a research area of interest and not a research problem. When using grounded theory, the researcher does not know what is relevant and cannot have specific research questions. The methodology itself focuses the problem through constant comparison; forcing of preconceived ideas is avoided. Instead, it is important to be open to what emerges. The following example illustrates this openness. When the researcher had written the theory of nurses in acute care hospitals in study II and then started the interviews with nurses in the community in study III, the researcher had ideas and intentions of expanding the theory of Striving for Emotional Survival, but what emerged was a totally different main concern for the nurses in the communities and therefore another grounded theory, which was called Doing Good Care. The researcher could have chosen to force the data and try to expand the first theory anyway, but it would have been difficult to find new data to compare since the nurses in the community did not experience the emotional burden as their main concern. Of course, they also experienced difficult emotions occasionally, but this was not their primary concern. So in the theory Doing Good Care, there are some concepts and strategies that are similar to those in the first theory in relation to how to handle the risk of being emotionally overwhelmed.

Being open to what emerges can be affected by one’s personal experiences in the research area. There have been discussions about doing qualitative research in your own field and how this affects the results [138]. Glaser argues that it may be easier to do research in unknown areas, but doing research in your own area creates a special motivation which is also important. Personal knowledge and experience of a research area is not a hindrance in grounded theory as “the researcher can interview himself and do field notes, like he was interviewing someone else. Then he adds these notes to the other notes of research” (p.120) [113]. This was followed, so the researcher’s experience and preconceived thoughts were written down and used as data. During the analytic process, things emerged that would never have been possible to logically think up; this could be considered as one assurance against preconception.

Theoretical sampling was used as much as possible in studies II-IV, but using theoretical sampling can be difficult when interviewing dying patients and when ethical permission about the participants is needed. But since “all is data” the researcher also used casual conversations or unplanned conversations as data for constant comparison. When it is difficult to find new participants or when concepts need further refining, secondary analysis is another possibility. Secondary analysis is common in qualitative analysis methods where the purpose is description [139], but in grounded theory, secondary analysis is used to compare incidents and behaviors in the secondary data with the emerging concepts
for the purpose of refining the concepts rather than comparing the participants and their descriptions [109]. Therefore, the contexts of these interviews are often not of importance since the purpose is conceptualization and not description.

In study IV the researcher generally interviewed patients and relatives together. The researcher informed the patients that the interviews could be done separately or together with the relatives. It was then up to the patients to decide what they wanted and in all cases, they wanted the relative to be present during their interview. In one case, the patient was too ill to participate, so the interview was done only with the relative. It is uncommon in research to interview patients and relatives together. When interviewing, there is an interaction between the interviewer and the interviewed [140] and when interviewing patients and relatives together, there is also an interaction between them, but since the interviews were more like conversations about their situation rather than formal interviews with a structured interview guide, both patients and relatives seemed relaxed and comfortable with the situation.

During most of the interviews, field notes were taken instead of taping. This made the interviews more like conversations and while field noting, spontaneous pauses allowed the participants to think and continue talking thus hindering forced questions. The purpose with grounded theory is not full description and therefore transcribed interviews are not needed. The theories presented in studies II-IV do not claim to represent the participants’ entire being or doing. The participants are, of course, also engaged in other patterns of behavior which need to be further explored. The presented theories can always be modified through comparison with new relevant data.

A grounded theory is not the “truth”; it is simply a set of integrated hypotheses [109] for explaining what is going on in an area [130]. Using the constant comparative method is verification in itself, since the constant comparison verifies the concepts and patterns [109, 113]. When evaluating a grounded theory, it should be judged by its fit, relevance, workability and modifiability [113]. As such a grounded theory is never right or wrong, it just has more or less fit, relevance, workability and modifiability. Fit describes how closely concepts fit with the incidents they represent. A relevant study evokes grab and deals with the real concern for the participants. Workability means that the theory explains how that concern is resolved and modifiability means that a grounded theory is always modifiable through constant comparison with new relevant data. The relevance and workability of the study’s emergent theories was confirmed when presenting the theories to caregivers and researchers in palliative care. The literature reviews which were done in connection with each study also indicated fair relevance, workability and modifiability of the theories. It should also be mentioned that since a grounded theory is an integrated set of conceptual hypotheses, the theories presented in this thesis could be tested in empirical studies.
Given its abstract conceptual nature, grounded theory’s concepts last forever, in contrast to descriptions which are tied to time and people, with value in a concrete context [109, 141]. With this in mind, the presented theories (Studies II-IV and Overall Theory) might well be expanded to other areas to contribute a general understanding of how people deal with different situations in different contexts. This means that the theories (Studies II-IV and Overall Theory) have general implications that apply beyond palliative cancer care and which could be further developed through emergent fit to the new areas.
SUMMARY OF FINDINGS

This thesis is based on five studies which explore the situation of cancer patients, relatives and nurses within the context of palliative care in acute care hospitals and in home care settings. Study I was the foundation for the subsequent four studies. This first study provided a picture of the situation for palliative cancer patients in the county where the subsequent studies were conducted. Studies II and III address the perspective of nurses and study IV the perspective of palliative cancer patients and their relatives. The overall theory unifies studies II-IV, explaining the latent patterns of behavior of patients, relatives and nurses in palliative cancer care.

Symptoms, care needs and diagnosis in palliative cancer patients in acute care hospitals (Study I)

In 2002, 1 352 patients were registered of which 192 were assessed as being palliative cancer patients. In 2007, 2 972 patients were registered with 328 assessed as being palliative cancer patients. There was a decrease in the total proportion of palliative cancer patients (14% vs. 11%, p<0.01).

Symptoms and care needs
The three most common symptoms and care needs in 2002 were pain 39%, deterioration 27% and nausea 17%, compared with pain 44%, deterioration 44% and infections 25% in 2007 (Table I). The mean number of symptoms and care needs for each patient increased between the two observed years (1.6 in 2002 vs. 2.6 in 2007, p<0.001).

Cancer sites
In 2002, the three most common cancer sites were prostate 18%, colorectal 15% and lung 12% and in 2007, prostate 13%, colorectal 13%, lung and hematological malignancies 12% (Table II). The only statistically significant change between the two observed years was the increased proportion of patients with hematological malignancies.

Relationships between symptoms and care needs with cancer site
Gender related cancers were excluded in the overall model (Table III) because they strongly influenced and overshadowed certain associations. Separate models were performed for men and women (Table IV). Pain was associated with
prostate cancer in men, while pain did not associate with any specific cancer site in women.

In the overall model, deterioration was weakly associated with colorectal cancer and infection with hematological malignancies, whereas pain was not associated with a specific cancer site. A higher occurrence of infections and a higher need for blood transfusions and infusion were seen in patients with hematological malignancies. Patients with stomach and esophagus cancers had more nausea, nutritional problems and need for infusions. Abdominal surgery and infusions were associated with patients with unknown primaries (Table III). The associations in the gender-specific model were similar to the overall model, but had some differences (Table IV). In men, pain and diagnostic procedures were associated with prostate cancer and deterioration was higher for colorectal cancer as well as for pancreatic and lung cancer. In women, colorectal and gynecological cancers were associated with abdominal surgery, but no cancer site was associated with the common symptoms of pain and deterioration.

Table I. Prevalence of symptoms and care needs in palliative cancer patients during hospitalization

<table>
<thead>
<tr>
<th>Symptoms/care needs</th>
<th>2002</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All</td>
<td>Men</td>
</tr>
<tr>
<td></td>
<td>(n=192)</td>
<td>(n=107)</td>
</tr>
<tr>
<td>Abdominal surgery</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Deterioration</td>
<td>27</td>
<td>30</td>
</tr>
<tr>
<td>Diagnostic procedure</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Infection</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Infusion</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Nausea</td>
<td>17</td>
<td>22</td>
</tr>
<tr>
<td>Nutrition</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>Pain</td>
<td>39</td>
<td>41</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Social issues</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Surgical stenting</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>

# = gender not given in five patients, a = significant difference between the years for all, ♂ = significant difference between the years for male, ♀ = significant difference between the years for female, * p<0.05, ** p<0.01, *** p<0.001
Table II. Prevalence of cancer sites in palliative cancer patients

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All</td>
<td>Men</td>
<td>Women</td>
<td>All</td>
</tr>
<tr>
<td></td>
<td>(n=192)</td>
<td>(n=107)</td>
<td>(n=80)</td>
<td>(n=328)</td>
</tr>
<tr>
<td>Breast</td>
<td>4</td>
<td>-</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>Colorectal</td>
<td>15</td>
<td>15</td>
<td>15</td>
<td>13</td>
</tr>
<tr>
<td>Gynaecological</td>
<td>10</td>
<td>-</td>
<td>21</td>
<td>6</td>
</tr>
<tr>
<td>Haematological</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>12 a**</td>
</tr>
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<td>Lung</td>
<td>12</td>
<td>15</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Pancreas</td>
<td>10</td>
<td>12</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Prostate</td>
<td>18</td>
<td>31</td>
<td>-</td>
<td>13</td>
</tr>
<tr>
<td>Stomach/oesophagus</td>
<td>5</td>
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<td>Unknown primary</td>
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<td>1</td>
<td>11</td>
<td>6</td>
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<td>Urological</td>
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<td>13</td>
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<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>2</td>
<td>12</td>
<td>10</td>
</tr>
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</table>

# = gender not given in five patients, a = significant difference between the years for all, ² = significant difference between the years for male, ³ = significant difference between the years for female, * p<0.05, ** p<0.01, *** p<0.001

Table III. Relationships between symptoms, care needs and cancer sites

<table>
<thead>
<tr>
<th>Symptoms/care needs</th>
<th>Cancer site</th>
<th>p</th>
<th>OR</th>
<th>95% CI</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdominal surgery</td>
<td>Colorectal</td>
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<td>7.2</td>
<td>2.3-22</td>
<td>.18</td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
<td>.007</td>
<td>7.8</td>
<td>1.8-34</td>
<td></td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>Haematological</td>
<td>&lt;.001</td>
<td>14</td>
<td>6.7-31</td>
<td>.27</td>
</tr>
<tr>
<td>Deterioration</td>
<td>Colorectal</td>
<td>.035</td>
<td>2.1</td>
<td>1.0-4.1</td>
<td>.06</td>
</tr>
<tr>
<td>Diagnostic procedure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infection</td>
<td>Haematological</td>
<td>&lt;.001</td>
<td>10</td>
<td>5.0-22</td>
<td>.19</td>
</tr>
<tr>
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<td>2.7</td>
<td>1.1-6.4</td>
<td>.07</td>
</tr>
<tr>
<td></td>
<td>Stomach/oesophagus</td>
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<td>4.7</td>
<td>1.6-14</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
<td>.032</td>
<td>3.4</td>
<td>1.1-10</td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td>Stomach/oesophagus</td>
<td>.012</td>
<td>3.8</td>
<td>1.3-11</td>
<td>.13</td>
</tr>
<tr>
<td>Nutrition</td>
<td>Stomach/oesophagus</td>
<td>.001</td>
<td>15</td>
<td>3.1-68</td>
<td>.22</td>
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<tr>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiotherapy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social issues</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgical stent</td>
<td>Pancreas</td>
<td>.001</td>
<td>4.9</td>
<td>1.9-13</td>
<td>.08</td>
</tr>
</tbody>
</table>

α = gender specific cancer sites not included, p = p-value, OR = Odds Ratios, CI = Confidence Interval, R² = Nagelkerke R-square
Table IV. Relationships between symptoms, care needs and cancer sites for men and women

<table>
<thead>
<tr>
<th>Symptoms/care needs</th>
<th>Cancer site</th>
<th>p</th>
<th>OR</th>
<th>95% CI</th>
<th>R²</th>
<th>Cancer site</th>
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<th>OR</th>
<th>95% CI</th>
<th>R²</th>
</tr>
</thead>
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<td>Abdominal surgery</td>
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<td>3.2-422</td>
<td>.26</td>
<td>Colorectal</td>
<td>.002</td>
<td>17</td>
<td>2.9-95</td>
<td>.28</td>
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<td>25</td>
<td>8.0-70</td>
<td>.35</td>
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<td>3.6-42</td>
<td>.24</td>
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<tr>
<td></td>
<td>Stomach/oesophagus</td>
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<td>8.3</td>
<td>1.8-40</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deterioration</td>
<td>Colorectal</td>
<td>.047</td>
<td>2.0</td>
<td>1.0-3.9</td>
<td>.16</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pancreas</td>
<td>.003</td>
<td>9.4</td>
<td>2.2-41</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lung</td>
<td>.002</td>
<td>4.4</td>
<td>1.7-11</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnostic procedure</td>
<td>Prostate</td>
<td>.043</td>
<td>2.2</td>
<td>1.0-4.9</td>
<td>.08</td>
<td>Unknown primary</td>
<td>.013</td>
<td>4.4</td>
<td>1.4-14</td>
<td>.11</td>
</tr>
<tr>
<td>Infusion</td>
<td>Haematological</td>
<td>&lt;.001</td>
<td>13</td>
<td>4.8-36</td>
<td>.24</td>
<td>Haematological</td>
<td>&lt;.001</td>
<td>7.8</td>
<td>2.5-25</td>
<td>.19</td>
</tr>
<tr>
<td></td>
<td>Stomach/oesophagus</td>
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<td></td>
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<td>.19</td>
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<td>Stomach/oesophagus</td>
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<td>19</td>
<td>3.2-111</td>
<td>.37</td>
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<td>Prostate</td>
<td>.007</td>
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<td>1.3-5.9</td>
<td>.14</td>
<td></td>
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<td></td>
</tr>
<tr>
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<td>Breast</td>
<td>.017</td>
<td>5.1</td>
<td>1.3-20</td>
<td>.22</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Lung</td>
<td>.003</td>
<td>8.8</td>
<td>1.8-37</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stomach/oesophagus</td>
<td>.009</td>
<td>10</td>
<td>1.8-58</td>
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</tr>
<tr>
<td>Social issues</td>
<td>Breast</td>
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<td>.09</td>
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</tr>
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<td>Pancreas</td>
<td>.004</td>
<td>6.9</td>
<td>1.9-26</td>
<td>.13</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

p = p-value, OR = Odds Ratios, CI = Confidence Interval, R² = Nagelkerke R-square
Striving for Emotional Survival (Study II)

The worry of being emotionally overloaded emerged as the main concern for nurses caring for palliative cancer patients in acute care hospitals. The caring could be experienced as valuable and supportive, but also as stressful and with a high emotional pressure most of the time. The risk of being emotionally overwhelmed could be affected by factors such as their emotional competence, experience, knowledge, attitudes and values, but it could also be affected by external factors such as time, external resources, and colleagues’ attitudes and values. Striving for Emotional Survival emerged in the analysis as the pattern of behavior through which nurses try to maintain their emotional health; it involves three main strategies: emotional shielding, emotional processing, and emotional postponing.

**Emotional shielding**

Emotional shielding protects from emotional overload and consists of protective attitudes toward emotionally difficult situations and events. Emotional shielding includes professional shielding and cold shielding. In professional shielding, nurses use their professional role as a sound emotional protection whereby the emotions are controlled, protecting nurses from becoming emotionally overwhelmed. Professional shielding is done through the strategies of shifting between professional and private life, balancing intimacy, showing empathy and finishing work by prioritizing time. In cold shielding, nurses are hiding behind their profession, as an emotional shield; mentally distancing themselves from emotional threats while caring. Cold shielding may cause a cold distance between nurses and patients and relatives, thereby reducing the quality of care.

**Emotional processing**

Emotional processing helps nurses to learn more about their capabilities and how to set boundaries; it increases emotional competence and strengthens their professional shield. Emotional processing can be done through the following strategies: chatting, confirmation seeking, self-reflecting, and ruminating. Chatting is done shortly after the difficult event when nurses cannot wait for professional counseling. This is done either by ventilating, where nurses express their feelings and later process their emotions, or by letting go, where they use chatting as a way to process the difficult emotions completely. Through confirmation seeking, nurses seek professional and personal feedback and confirmation; through self-reflecting, they process the emotions upon returning home, when relaxing or exercising and while socializing with relatives and friends. Ruminating means pondering emotions; this takes extra energy and could affect both work and the family situation.
**Emotional postponing**

Emotional postponing means that emotions are postponed instead of processed and this could be caused by a lack of emotional competence, time, or energy. Emotional postponing could be done by *storing*, which means that emotions are consciously stored for later processing, or by *stashing*, which means that emotions are unreflectively buried with no deliberate intention to process them later.

**Emotional competence and time**

Emotional competence explains how well emotions are handled and refers to emotional skills for handling emotionally charged situations. Emotional competence depends on personality, but can be improved by working experiences. Having emotional competence facilitates understanding of the emergent emotions and the consequences of unprocessed emotions. Nurses with high emotional competence often have good emotional health and are in control of their thoughts, feelings and behaviors. A low or high degree of emotional competence in relation to external factors such as time, gives different patterns of emotional survival (Figure 1).

**Figure I. Relationships between emotional competence and time**
Doing Good Care (Study III)

The genuine desire to ‘do good’ emerged as the main concern for nurses caring for palliative cancer patients in home care. This includes a responsibility towards the patients and their relatives; when nurses fail in doing good, they also feel that they have let the patient down which may lead to frustration and a sense of powerlessness. Several factors influence their desire for doing good such as emotional competence, knowledge, feedback, resources, access to physicians, and time. Knowing what is best for the patient, but not being able to do it may cause ethical stress and feelings of guilt. The emergent theory, Doing Good Care, involves three different caring behaviors through which nurses handle this desire for doing good: anticipatory caring, momentary caring and stagnated caring. Depending on the circumstances, nurses can hover between these three caring types with different emotional survival strategies being used in each type.

Anticipatory caring
Anticipatory caring emerged as the optimal way of caring for everyone involved. This means doing best or even better than necessary. Anticipatory caring is done through foreseeing trajectories, creating trust, collaborating, and prioritizing. Foreseeing trajectories means that nurses are predicting what might happen then being one step ahead by planning and organizing on the basis of what can be predicted. Creating trust means promoting safety by cultivating relationships with patients and relatives; this safety can make it possible for patients to stay at home. Collaborating with colleagues is essential to discuss and assess the needs of patients and relatives and to be one step ahead. Prioritizing means postponing tasks that can wait and giving first priority to dying patients.

The desire for doing good or even better than necessary is emotionally demanding and professional shielding is used as a protection towards the arising emotions. There is a risk of losing the professional shield and getting too close in relationships with the patients. The emotional survival strategies of emotional processing through self-reflecting and confirmation seeking are also commonly used while giving anticipatory care (Study II).

Momentary caring
Momentary caring means doing best momentarily and doing as good as possible in every situation. Momentary caring can have the anticipatory thinking but lack the resources to render anticipatory care. Momentary caring involves temporary solutioning where nurses are momentarily prioritizing, which means that they are prioritizing without any future planning and they are doing as well as they can under the circumstances by using temporary solutions. In temporary solutioning, nurses are also sporadically collaborating, which means that colla-
boration is done when necessary. This limited collaboration may lead to decreased understanding and communication between the persons involved.

When giving momentary care, nurses are also using emotional survival strategies such as professional shielding and emotional processing and, in particular, confirmation seeking and chatting. But when nurses experience lack of resources, time and emotional competence, they can also use emotional survival strategies such as ruminating and emotional postponing (Study II).

**Stagnated caring**

Stagnated caring means doing what is expected of them, and even if they are driven by a desire for doing good, they cannot see any reason for changing their way of caring and they are totally satisfied with it. Stagnated care could be a consequence of decreased recognition when giving momentary care, resulting in a sense of resigning and giving up. Another reason for stagnated caring could be low emotional competence and a fear of death. Stagnated caring behavior involves avoiding changes and resigning. Avoiding changes means that nurses avoid changes in order to protect themselves. Changes and challenges require more effort than nurses can handle and produce an impending attitude of suspicion and distrust towards, for example, new techniques. The suspicion and distrust decreases the willingness to collaborate and involve other people. Resigning is common when there is a lack of recognition or adequate resources, leading to frustration and decreased energy. Resigning makes it difficult to create trust and predict what might happen.

Cold shielding is a common emotional survival strategy when giving momentary care and it leads to a cold distance towards patients and relatives. In such circumstances, nurses are affected by the belief that they do not have the responsibility of life and death. This results in a false sense of protection and a routine manner of care. Here, postponing emotions is common since nurses often lack the emotional competence or the energy to process them.
Living on Hold (Study IV)

Being put on hold emerged as the main concern for palliative cancer patients and their relatives. Being put on hold means that their normal existence is falling apart; their normality is breaking down and with it a loss of control. Living on Hold consists of three mode behaviors through which patients and relatives handle being put on hold; fighting mode, adjusting mode and surrendering mode. Mode being depends on, for example, age, personality, diagnosis and prognosis, social network, earlier experience of crisis, continuity of care and professional competence. During the disease trajectory, there may be triggers that start a reconciling process that can lead to mode shifts, so the modes are not fixed and no mode is better than another.

Reconciling process
The reconciling process is the connecting link between the different modes. Regardless of the mode, patients and relatives evaluate their lives and their current situation, but also the past and the near future. Mode shifting can happen anytime during the trajectory through the reconciling process. Mode shifting triggers such as receiving bad news, dependency experience, and feelings of uncertainty can trigger the reconciling process and lead to a change of behavioral mode. The patient and the relatives often valuate life differently which may lead to different behavioral modes. Depending on their different moods, fast mode shifting may happen during a short period of time which could be energy draining for all involved.

Fighting mode
In the fighting mode, patients and relatives are striving to renormalize their lives and no change in their lives is desired. Through renormalizing, they want to return to normal, managing self and keeping track as before. Potential powers are discovered and unrealized innate powers may emerge when needed. Rebelling means protecting and fighting the whole situation, but also fighting the disease. Through blaming, patients and relatives seek reasons or causes for the disease, finding something or someone to blame. In the fighting mode, they appreciate foreseeing, since this gives them full control over life, even if it is put on hold. Since they are hyper-sensitive, they are scrutinizing everything around them.

Adjusting mode
Patients and relatives in the adjusting mode are adjusting to a new normality and to new routines. Even though they are adjusting, they do not let the disease take over or control their lives. Adjusting to a life on hold involves moment living, which means a total presence here and now with a planning for daily life but not the future; disease diminishing, which means not letting the disease af-
fect their lives, is done through re-routing where new routines are created. Adjusting also involves *facading*, which means keeping an emotional facade and staying emotionally strong.

**Surrendering mode**
There are two reasons for being in the surrendering mode: resigning, which means giving up, and accepting, which means submitting their lives to a higher power. In surrendering mode, a life on hold is handled through *total trusting*, where they are living in a complete trust that everything is going to be alright and they have full trust in others to make decisions. Through *releasing control*, they are letting go and submitting control to the health professionals as they do not want any participation in the care.

**Feasible mode shifting and possible outcomes**
Patients and relatives can be either in the same or in different mode simultaneously; this mode synchronicity may lead to problems within the family but also in contacts with health professionals (Figure II).

<table>
<thead>
<tr>
<th>Relative</th>
<th>Fighting</th>
<th>Adjusting</th>
<th>Surrendering</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fighting</td>
<td>Ok within the family</td>
<td>Risk for conflicts</td>
<td>Risk for conflicts</td>
</tr>
<tr>
<td>Adjusting</td>
<td>Risk for conflicts</td>
<td>Ok within the family</td>
<td>Risk for conflicts</td>
</tr>
<tr>
<td>Surrendering</td>
<td>Risk for conflicts</td>
<td>Vicarious fighting</td>
<td>Ok within the family</td>
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*Figure II. Possible outcomes of being in different modes for patient and relative*
Deciphering Unwritten Rules (Overall Theory)

The uncertainty of how to behave in different contexts emerged as the main concern for nurses, patients and relatives in palliative cancer care. Uncertainty as to the appropriate or correct way to act and behave is common to all involved. Not knowing how to act or behave so as to feel safe in a situation may feel like struggling against a faceless, invisible giant. Living with this uncertainty can be exhaustive, creating an emotional fear of being unsafe. There is, therefore, a need to construct certainty which means creating certainty in an uncertain situation. Handling the uncertainty of how to act and behave therefore requires constantly deciphering unwritten rules. Deciphering means finding out what the rules mean and trying to interpret them in their actual situation, which can be done consciously but most of the time it happens unconsciously.

Although nobody talks openly about it, there exist unspoken expectations and unwritten rules of how to behave in the different contexts. These contexts may entail different kinds of atmosphere. It can be difficult to pinpoint exactly what makes the difference, but one possible explanation may be that unwritten rules may create these special atmospheres. Unwritten rules can be about which values and attitudes individuals expect to have confirmed or accepted. Everybody understands that there are invisible rules to follow but it can be difficult to get knowledge about them since they are continually changing and thus the rules will differ from situation to situation. Health professionals may signal to patients and relatives, wittingly or unwittingly, how they are supposed to behave and what problems are important from the professionals’ perspective. This influences the interaction regarding what issues they are allowed to talk about or not. One example of deciphering unwritten rules can be how to deal with sensitive issues. There are unwritten rules regarding how to deal with sensitive issues depending on the persons involved and the actual context. There can be unwritten rules such as: “Don’t talk about the problem”, “Act like nothing has happened”, “Don’t say things to upset the ill person”, “Don’t talk about your feelings and absolutely do not show your feelings in the open”, “Open feelings leads to conflict”. Deciphered unwritten rules of how to behave could actually lead to decreased safety instead of increased safety for those involved. This insecurity can be regarded as “walking on eggshells” when the individual does not know how to act. The complexity increases when, for example, patients are cared for in different contexts with totally different unwritten rules. With fast changes, patients do not have the energy to decipher the unwritten rules, and they may surrender with the attitude “do whatever you want to do with me; you know what is best for me”.

For nurses, there are also unwritten rules regarding workplace etiquette, which means that nurses are supposed to have certain values or behave in a certain way. There can be an unspoken rule like: “Good is not good enough” in re-
relationship to other professions. This means that as a nurse, you might need to show yourself better than expected and do better than good enough to be confirmed by other professions.

Deciphering unwritten rules is done by all involved in the care and is necessary for deciding if the rules are to be followed or not. Not everyone has the ability to decipher unwritten rules and since many patients and relatives are hypersensitive, they can become insecure as to how to interpret the unwritten rules. Also, if patients, relatives and nurses disclose their ignorance of how to act by showing vulnerability and insecurity, they may lose their façade, leading to feelings of failure. Through façading, they pretend to follow the rules, but instead they collect clues of how to decipher the unwritten rules by observing how others behave and copying their behavior.

How patients, relatives and nurses decipher unwritten rules depends on their personality and experiences. For nurses, it also depends on their caring behavior, i.e. anticipatory caring, momentary caring or stagnated caring (Study III) and how they process emotions while caring for palliative cancer patients (Study II). For patients and relatives, it also depends on their mode being while living a life on hold; fighting, adjusting or surrendering (Study IV). Even though all involved use the deciphering process, some of the strategies are more or less common among the involved. Therefore, some examples are highlighted under the strategies, but it should be emphasized that the involved can use all the strategies in the process. Deciphering unwritten rules is a continuous process which involves figuring out, deliberating, maneuvering and evaluating.

**Figuring out**

Figuring out unwritten rules needs to be done when entering a new context, meeting new people, when being in a new situation or when experiencing new symptoms. Figuring out the unwritten rules can be experienced as an unattainable goal. Although the rules are unwritten, the persons involved in the care have a tacit awareness of the existing rules, but since this shared awareness is not communicated verbally, unwritten rules may be taken for granted and therefore easily missed by someone new to the context. Ruminating over how to act and behave can paralyze the involved persons and decrease the possibility of figuring out the unwritten rules. Figuring out can be done in an active way or in a passive way.

**Figuring out in an active way**

Patients, relatives and nurses figure out the rules in an active way through moment capturing and constantly questioning. Moment capturing means every opportunity is taken to figure out the unspoken rules. Constantly questioning the care is a way to handle the insecurity of not knowing the unwritten rules. Through questioning, they get attention from the people around them which may lead to a disclosure of the unwritten rules.
The purpose of deciphering unwritten rules is important when figuring out the rules in an active way. For example, patients and relatives in the fighting mode may experience insecurity when lacking information and support but with knowledge of the unwritten rules, they can find out how to act to receive what they need. The genuine desire of doing good helps nurses engaged in anticipatory caring to figure out which unwritten rules are useful to get what they want, both at a personal level but also when giving palliative care.

**Figuring out in a passive way**
Nurses engaged in stagnated caring behavior and patients and relatives in adjusting and surrendering mode often use the passive way, which can be done through *passing over* or *strategic incompetence acting*.

Passing over means letting other people figure out the rules. Nurses engaged in stagnated caring behavior and patients and relatives in the surrendering mode may not have the emotional sensitivity to figure out the rules by themselves. Instead, they let those around them take that responsibility and then copy and follow their acting. Passing over is easier for patients and relatives than for nurses, although it is possible to pass over during a short period of time without impacting the care.

Strategic incompetence acting is a way to get what the involved want; even though they might have the competence to figure out the rules in an active way, it is more convenient to be passive. Being in the adjusting mode for patients and relatives, leads to insecurity of not knowing how to act and since they do not want to show their vulnerability through any involvement from outside the family, they act incompetent to figure out the rules. From a professional perspective, patients and relatives seem to deny the situation, which can be difficult for professionals to handle. Nurses also act strategically incompetent to receive help in disclosing unwritten rules in order to get what they need from the situation.

**Deliberating**
After figuring out the unwritten rules, patients, relatives and nurses deliberate as to how these rules might affect their situation and how they will act in relation to these rules. They carefully consider which rules to apply to receive the best outcome from their point of view and there can be different reasons for this deliberating. Patients and relatives might deliberate how to act to get the treatment they want or receive the “right” care for the moment, deliberating which actions to prioritize to get what they want out of the situation.

An inability to deliberate could be caused by lack of energy, knowledge or low motivation, but insecurity, personality and low emotional competence also affect how the involved deliberate how to deal with the rules. Being in the fighting mode motivates, for example, patients and relatives to deliberate the rules in their favor since knowing the rules and how to handle them increases
their safety. On the other hand, patients and relatives in the surrendering mode are not active in deliberating which rules to apply; they just follow the people around them and hope for the best. Strategic incompetence acting can also be used when deliberating the optimal way of dealing with the rules.

Deliberating which rules to apply or not can be affected by dual protection in a family. Dual protection means a relational safety: “I will be okay if you will be okay”. Deliberating can also be affected by patients’ posthumous caring, which means protecting by taking care of what will happen to the relatives after the patient’s death. This includes financial and practical issues to secure the family's future. Patients therefore deliberate which rules to apply to be able to reach their goals.

Before deciding which rules to apply, they may test the rules to find out if they have deciphered them correctly and if the rules are good to follow or not. Nurses in momentary caring are often testing newly deciphered rules to see the consequences in the specific moment since they are moment-prioritizing.

**Maneuvering**

After deliberating, patients, relatives and nurses maneuver the rules by either following rules, ignoring rules, denying rules, rebelling against rules, rule bending, rule breaking or rule making.

**Following rules**

The decision to follow unwritten rules may depend on the positive benefits of acting by the rules. Some rules might be good to follow from a personal perspective while other rules may not be so good, but the outcomes are more important than the rules themselves so sometimes patients, relatives or nurses feel forced to follow the unwritten rules to be able to get what they want out of the situation.

Although the rules may give the expected outcome, there is a risk of losing one’s own values and attitudes when complying with new rules. Having emotional competence facilitates deciding which rule to apply in the right moment or situation. By façading, patients, relatives and nurses maintain the image of knowing and following rules, even though they have not figured out the meaning of the rules.

There is a constant emotional fear of breaking rules and of the consequences of rule breaking. This fear might increase among patients and relatives who are hypersensitive and want to do everything as expected.

**Ignoring rules**

Ignoring rules is used as an emotional protection. Pretending that the rules do not affect them, patients, relatives and nurses can live as usual for as long as possible. Ignoring rules is common among nurses in stagnated caring behavior, since they do not want any changes. Patients or relatives, who have been disap-
pointed in earlier situations, may ignore rules to protect themselves from being emotionally hurt again.

**Denying rules**
Denying rules may be caused by problems with deliberating the rules. Since those involved do not understand the meaning of the rules, it is easier to deny them than to try and decipher the meaning of the rules. Patients and relatives in the adjusting mode may seem to deny unwritten rules since they do not act as expected, even though they often suffer in silence. Nurses in both momentary and stagnated caring behaviors may deny rules when they experience new situations and have to learn several things at the same time.

**Rebelling against rules**
If the unwritten rules do not fall in line with personal values, an individual may rebel against the rules. Patients and relatives in the adjusting mode may choose to rebel against the rules rather than ignore them. Rules regarding how to act towards the end of life might be upsetting for patients and relatives. When they do not accept that death is inevitable, they may rebel against these rules. When nurses use anticipatory caring, they may rebel against rules which do not go in line with their values and the goals of palliative care. Since they want to be one step ahead, there might be unwritten rules hindering this approach. Rebelling against rules may lead to rule bending and later on to rule breaking to get what they want out of the situation. Also, nurses in stagnated caring may rebel against the rules; this is often due to incompetence and lack of knowledge as to how to maneuver new rules. In such cases, it is more convenient to follow ingrained rules.

There can also be a rebelling against working etiquette rules for nurses. One provocative unwritten rule could be: “Nursing is a mission in life and you must be a ‘Nightingale sister’ and sacrifice yourself if you want to work here”. This unwritten rule can be upsetting and nurses openly rebel against this unwritten rule through rule breaking which then leads to rule making.

**Rule bending**
As mentioned, rebelling against rules might lead to rule bending. Sometimes the rules are bent as much as possible to get what is wanted without breaking the rules. There might also be ways around the rules and by bending the rules, they can indirectly follow the rules but in a somewhat devious way.

By sweetening up nurses, patients and relatives bend the rules to get more attention and receive wanted recognition and the expected care. While recognizing that sweetening up nurses may not be the best way to maneuver the rules, they see it as necessary to receive the outcomes they want.
Rule breaking
Even though there is unconscious rule breaking, there is also conscious rule breaking for a specific purpose. Rule breaking can be a consequence of rule bending where they have tried to follow the rules by bending them, but they have realized that it is impossible to continue bending. Both nurses in anticipatory caring and stagnated caring use this strategy, but for different reasons. Nurses in anticipatory caring are rule breaking with the intention of making new rules, while nurses in stagnated caring are rule breaking because they do not have the emotional competence to decipher the rules. For both patients and relatives as well as for nurses, rule breaking may lead to rule making, where new rules are created in order to receive expected outcomes or to give good quality care.

Rule making
Rule making and rule inventing may occur when situations are affected by a lot of changes. Unwritten rules change just like written rules but with unwritten rules, it is unknown who made them and therefore there is no one to blame for the rules. Rule making can threaten to change the atmosphere of a workplace since new rules at first increase the uncertainty until everybody has deciphered the new rules. Nurses in anticipatory caring might create new rules or rewrite old ones so that they fit their intentions and ambitions with the care. These new rules may lead to frustration for other nurses and if they do not have the ability or the energy to decipher these new rules, they may resign to stagnated caring where they ignore the new rules or they may even change workplace in order to find an emotionally safe workplace with rules they can maneuver.

Patients and nurses in the fighting mode may create new rules if they cannot decipher the existing rules, or if they do not receive the expected outcomes. New situations with new rules may also trigger the reconciling process, which means evaluating their lives on hold with a possible change of mode being for patients and relatives.

Evaluating
Patients, relatives and nurses are continually evaluating, for the most part unconsciously, their maneuvering of unwritten rules and the consequences. Even though those involved may be unaware of the unwritten rules, these rules underpin how they act and make sense of the situation. Although some rules seem irrelevant from an outside perspective, these rules help in navigating the situation. Unwritten rules also help those involved to find their place and to feel safe in the context, even though it was not their decision to be there and they just did not have any other option.

When evaluating the maneuvering of rules, they might discover that the maneuver strategy did not deliver the outcomes they expected, and they might therefore deliberate to change the maneuvering of the rules. If nurses in stag-
nated caring have ignored rules in order to avoid changes later discover that this strategy does not protect them emotionally, they may have to figure out the rules to find a way to maneuver them in order to survive emotionally.

When a situation changes or something unexpected happens, patients, relatives or nurses may need to decipher the new unwritten rules and the deciphering process then starts again. This process is often continuous since there always seem to be new unwritten rules to decipher, triggered by new symptoms or changed symptom burden, health professionals’ acting, new routines, change of hospital ward for patients or new organization, etc.
**DISCUSSION**

To give high quality palliative care, health professionals need to know what is important for those involved in different contexts. The aim of this thesis was therefore to generate a grounded theory explaining the latent patterns of behavior of patients, relatives and nurses in palliative cancer care in acute care hospitals and in home care settings.

**Symptoms and care needs in palliative cancer care**

The results from study I show that patients with cancer in a palliative phase are common in acute care settings, even though the total number had slightly decreased in our 5-year repeated population-based study. Although the total proportion of hospitalized palliative cancer patients was low compared to a similar Swedish study [104], this share could have decreased with advanced palliative home care availability. It has been shown that palliative care teams can improve cancer patients’ symptoms [142] and that palliative home care can reduce the need for hospitalization for the patients if the care is provided by trained personnel [143]. Even though many patients would have the advantage of palliative home care, there will always be patients who need to be hospitalized for periods of time. It is therefore of great importance to integrate a palliative care approach into acute care settings [26].

Compared to other studies, the number of symptoms per patient in study I was low, but a probable reason for this difference could be that only symptoms and care needs considered relevant for the actual hospitalization were recorded and not the total symptom occurrence. However, the results are in line with a similar study of patients referred to a hospital or an outpatient clinic where three symptoms per patient were recorded [45]. Although it has to be emphasized that the symptoms and care needs in study I were not necessarily the reasons for hospital admission, they were symptoms and care needs assessed during hospitalization.

It was found that patients and relatives were hypersensitive to what happens and that this hypersensitivity may be energy draining (Study IV). Health professionals need to be aware of the patients’ and relatives’ hypersensitivity and the possible triggers which could have a negative impact on their hypersensitivity. New or changed symptoms could trigger a reconciling process for patients and relatives (Study IV) and it is therefore important to assess and treat new symptoms. The patients’ pain affects more than just the patients themselves. It has been shown that relatives’ perceptions of the patients’ suffering, for example pain, were connected with their own experiences of powerlessness and helplessness [62]. To make it possible to reclaim wellness, patients need to
both understand their physical problems and be able to control them [52]. It is easier for patients to keep their psychosocial integrity and find meaning in life when physical suffering is under control [50]. It was found that due to the risk of being emotionally overloaded, nurses are often good at treating symptoms and doing practical things, but may avoid the emotional needs of the patients (Studies II-III). This avoiding could be caused by a lack of emotional competence and could be compared with seeing the diagnosis but not the whole person behind the diagnosis [144]. This goes in line with the theory Doing Good Care (Study III) which suggests that nurses with a stagnated caring behavior have difficulties handling emotions and revert to doing only what is expected of them. One consequence of this stagnated caring behavior could be a non-optimized quality of care for the patients and relatives.

In study I, pain and deterioration were the most common symptoms in hospitalized patients in both years. Previous studies have shown that pain is the most common symptom among palliative cancer patients [45, 46, 145]. When present, pain is a symptom almost impossible to neglect and can overshadow other symptoms [145]. Hence, other needs of the patient may appear when pain is under control [103]. Pain negatively affects quality of life and is more common towards the end of life. Since pain can often be prevented, it is an unnecessary burden for many patients [48]. It has been shown that one third of patient symptoms could be missed if health professionals do not ask patients for their most troublesome symptoms [49]. In study I, symptoms assessments were done by health professionals and, as such, the symptom burden could therefore be under-assessed. Yet again, the aim was to investigate symptoms and care needs in relation to patient hospitalization, not the complete symptom burden.

Study I showed that medical interventions, such as diagnostic procedures, radiotherapy and surgical stenting, had increased during the 5-year interval. One important question is what caused this increase but it cannot be answered based on the study design. Without argument, medical interventions may be necessary for patients, and are sometime lifesaving, but health professionals need awareness of the conceivable consequences before starting interventions. Previous research has shown that both diagnostic and therapeutic medical interventions can cause suffering and that even so-called routine procedures may be traumatic for seriously ill patients [26]. There could be a dominance of medicine in palliation and it is sometimes difficult for the patients to differentiate between previous cure-oriented treatment and current treatment for palliation. The patients cling to the hope that the treatment will cure and postpone the thoughts of death [146]. The intention of palliative care is not to maximize care but to optimize it [147]. It has been shown that physicians may be inclined to aggressively treat for little benefit rather than providing supportive care. Through this behavior, physicians avoid the painful confrontation with bad news but they do this with the perception that patients seem to avoid information and leave decision-making to their physicians. While thinking they are
helping the patient, the dilemma remains [148]. This perception of the patient’s wishes aligns with the theory Living on Hold (Study IV) where patients and relatives in the surrendering mode want to surrender decision-making to health professionals who are the experts. It is therefore important for professionals to have sensitivity for the mode beings of patients and relatives if they are to give information at the right level and to give individual support.

Weak associations were found between symptoms and care needs with cancer sites in the hospitalized palliative cancer patients (Study I). This fact supports the idea that focus should be shifted from diagnosis to symptoms in palliative care since many symptoms seem common for several cancer types as the end approaches [106]. The current disease-focused approach should be transformed to a patient-centered philosophy, which requires coordination across disciplines and specialties, and access to palliative care teams [149]. This supports the fact that many palliative cancer patients could be treated in palliative care units or at home by advanced palliative care teams instead of being treated for symptoms at his or her “home clinic” in acute care settings.

Emotional burden in palliative cancer nursing

Many health professionals in acute care settings have chosen their workplace to be able to care for people needing help for surgical or medical conditions; not to care for dying people. Shifting between patients with both curable and incurable cancers as well as non-cancer patients can result in severe emotional strain when working in acute care settings (Study II). Previous research has shown that nurses may experience a tension between caregiving ideals and the reality of their work, for example, lack of time. Knowing the ideal and how to fulfill it but being unable to do so causes frustration [100]. This is comparable with the theory Doing Good Care (Study III) where nurses are giving momentary caring. They might know what to do but do not have the resources to complete the procedures which could lead to giving over to stagnated caring. Earlier studies have suggested that the stress involved in palliative cancer nursing is most likely related to structural resources such as lack of time and training rather than lack of skills [79, 99], but it has been shown that health professionals in acute care settings feel a lack of psychosocial competence to care for cancer patients [28]. The theory Striving for Emotional Survival suggests that tending too many patients at the same time may lead to unfinished work and when experiencing difficult deaths or multiple death situations may increase the risk of being emotionally overloaded (Study II). In contrast to nurses in acute care settings, nurses in home care settings usually care for only a few patients at a time. Even though it has been found that community nurses may experience difficulties in communicating with dying patients and their relatives [150], it is often legitimate in home care to take extra time and even ask for more resources [151].
Even though the risk of being emotionally overloaded emerged as the main concern for nurses caring for palliative cancer patients in the acute care setting (Study II), this risk also existed for nurses in the home care context but it was not their main concern (Study III). The risk of being emotionally overloaded varies depending on factors such as knowledge, attitudes, time and emotional competence (Study II). This supports earlier findings that resources such as time, communication methods, cooperation and support are needed not only to give quality palliative care but also for health professionals to achieve satisfaction with the given care [82].

To survive emotionally while caring for palliative cancer patients, nurses protect themselves through, for example, professional shielding which involves balancing distance and involvement in relationships. This balancing act as well as the balance between work and private life is facilitated by a nurse’s experience and knowledge (Study II), which is in line with an earlier grounded theory of balancing [98]. Another strategy to protect from emotional overload is emotional postponing which can be compared to strategies such as denying emotions thereby decreasing sensitivity to patients’ emotions [152]. To be sensitive and to be able to meet the needs of patients and relatives, nurses must first process their own emotions concerning dying [153]. If nurses do not have the emotional competence or the time to process emotions, they may revert to the emotional protection of cold shielding (Study II). This strategy may be a possible cause for nurses’ use of stagnated caring behavior. Stagnated caring may lead to avoiding uncomfortable and difficult conversations with patients and their relatives (Study III). Examples of stagnated caring include ignoring cues given by patients, failing to respond to bells and only approaching patients for necessary treatments [154]. Unfortunately, given the scarcity of psychosocial support in many organizations, nurses are often left on their own to endure emotional strains [81]. Lack of psychosocial support may lead to decreased quality of care and the emotional strains may also lead to change of workplace [78]. The importance of psychosocial support for nurses offered by healthcare organizations should be emphasized.

Complexities in palliative cancer care

Palliative care has received increased attention and research over the past decade. Yet, there is room for improvement in the perception of palliative care among both health professionals and the general population. The results of study I and the grounded theories (Studies II-IV and Overall Theory) offered in this thesis demonstrate the complexities of palliative cancer care; complexities that are often not recognized by those involved in the care settings. This lack of awareness or ignorance may negatively affect the care given.

Increased awareness of the definitions and terminology used in palliative care is also important. Although health professionals often assume that they
share the same terms with the same purpose, it has been shown that there is a lack of clarity with regard to the definitions and terminology used in palliative care [155]. There is an urgent need for a consensus around this issue if we want to improve palliative care and give high quality care to patients and relatives. Palliative care is not only a public health issue; it is also a human rights issue and palliative care needs to be a priority. National and local guidelines are needed on palliative care and treatment and on the organization of such services as basal and specialized palliative care.

In the overall theory, Deciphering Unwritten Rules, the main concern for everyone involved in palliative care is struggling with how to act and behave. Unspoken expectations as described earlier [68, 156] affect those involved in different ways. The uncertainty of how to act and behave affects how health professionals give care but also how patients and relatives experience the care. Furthermore, patients are cared for in different caring contexts during the disease trajectory and they and their relatives meet professionals with different caring behaviors. Since every caring context has its own unwritten rules, they constantly need to figure out how to act and behave. Families may experience “reinventing the wheel” when they have to struggle with the same issues as many other families (such as administrative and logistical needs), but without any knowledge of how to handle them [157]. Making everyday choices may appear uncomplicated on the surface, but the uncertainty and the unpredictability in palliative care may increase the complexity of such decision-making [158]. Increased communication and information at the appropriate levels can assist all those involved in figuring out these unwritten rules. Asking instead of assuming what patients and relatives find important is crucial. If professionals do not ask about needs or preferences, patient care and interventions are professional-centered rather than patient-centered [93].

There can be mismatches and clashes when professionals have different caring behaviors, i.e. the anticipatory, momentary or stagnated caring (Study III). The situation can be even more complex when professionals with different caring behaviors meet patients and relatives who are handling their lives being put on hold through different modes, i.e. the fighting, adjusting or surrendering mode (Study IV). As an example, if professionals are using anticipatory caring and the family is in the adjusting mode, using façading and moment-living, the family may not act or behave as if they have understood the information about the seriousness of the situation and the potential for a terminal outcome for the patient. They live on as usual, confusing the professionals who continuously give information over and over again and try to make the family understand the situation. This leads to frustration for all involved; the professionals may feel that they are not giving the “right care” and are letting the family down. The family, on the other hand, may feel disrespected and tread upon. Professionals’ assumptions of what seems to be the best may actually be in conflict with a patient’s wishes [100]. Patients and relatives in different behavior modes can cause different perceptions for health professionals. The way the situation is
perceived may not present a full or accurate picture. For instance, patients and relatives in the surrendering mode are often perceived as positive by professionals who then decide what seems to be best for the patients. The patients and relatives are then seen as good patients and good relatives since they follow all the directives where, in fact, patients and relatives who are in the surrendering mode might be the ones who are the most in need of support and encouragement. It has been argued that the professionals’ behavior can influence not only the participation of patients and relatives in the care but also the patient’s potential for an appropriate death [38]. Mismatched perceptions may affect the relationships among those involved as well as impact on the quality of care [107]. With this in mind, it is important to assess the need for support, both of patients and of relatives. When they are in different modes, they apparently have different needs; an awareness and knowledge of the different modes may facilitate caregiving and support at the right level for each person in the family.

Individualized care has been highlighted earlier [50, 61, 159], but it has also been shown that there is a risk of focusing on care related issues rather than focusing on the concerns of those involved [58]. This becomes even more complicated when relatives believe that the patient’s needs are the most important and therefore do not want to share their own needs [160]. Death and dying are also deeply personal issues and therefore rarely discussed with professionals [161]. Palliative home care can only be defended on an ethical basis if the relatives are in the situation voluntarily and if they receive individual support during the whole caring period [57]. Relatives need support as well as the patient; sometimes even more than the patient, depending on their mode behavior (Study IV). Therefore it is especially important to also assess their well-being and their need for support [73]. A cancer diagnosis not only affects the ill person, but also their partner’s life, causing increased healthcare costs and also an increase in psychiatric diseases among the partners [162]. So high quality palliative care can not only positively affect the experience of patients and relatives’ experiences, but may also be cost-effective for the healthcare system in general.

**Need of a palliative care approach in all caring contexts**

The fact that more and more people want to be cared for and also die in their own homes [11, 101] will affect home care services, which need to involve more palliative care [8]. To meet this demand in the future, home care may need to change and input from the palliative care philosophy and resources will be needed to ensure high quality in palliative home care. Close collaboration with physicians is necessary to be able to give anticipatory care (Study III). Close links, especially between oncology services and palliative care, can optimize the care of palliative cancer patients [163]. Increased knowledge of palliative care is also important, for nobody can practice what they do not know [149].
With well functioning palliative home care, many referrals to hospitals can be avoided. It has been shown that patients were more likely to seek admission to hospital if they were insecure or lacked confidence in their support network at home [101], and patients were also admitted to hospital if the informal caregivers received inadequate resources [164]. It has also been shown that patients were admitted to hospital because of inadequate practical help at home [101] and inadequate management of symptoms [164], but it has been found that admissions could be averted if palliative medication kits were used. These kits turned out to be a simple and effective way of anticipating and controlling symptoms for dying patients in the community and could also extend the time that patients could be cared for at home [165]. Therefore, knowledge of how to assess and manage symptoms is important if patients are to be cared for and die at home [150].

Patients and relatives struggle with uncertainty and their feelings of interrupted normality; this may affect their feelings of safety and security in being cared for in their homes (Study IV). Previous research has found that their safety can be increased when nurses are perceived as being sensitive, competent and professional when giving care [166]. Feeling trust in the professionals and the healthcare organization may also decrease their vulnerability [71] and increase their willingness to participate in the care [37].

Although many patients may prefer to die at home and home care is regarded as a cost-effective option, it may not be a reality for all patients [9]. It should be emphasized that home death is not a measure of a good death and not all palliative cancer patients should be cared for at home. Rather, patients should be cared for at the right organizational level depending on their own wishes and needs, not depending on resources or the most cost-effective option. Therefore, there may be a need to critically evaluate the existing models of care, at the department and hospital levels and also at hospital and community levels. Perhaps there is a need for new national organizational structures. How the care organization is structured and its caring approach will affect the care and the relationships with patients and relatives. Organizational structures can promote or hinder reaching care goals. To promote good palliative care, the palliative care approach needs to be introduced early in the disease trajectory and adjusted and implemented in all caring contexts wherever patients are. It is suggested that adopting this palliative approach could reduce the experience of dissatisfaction for many people involved [167]. Implementing a palliative care approach into all caring contexts requires education and training for the people involved as well as further research to establish what constitutes successful palliative care in different contexts.
CONCLUSIONS

- Many palliative cancer patients are still cared for in acute care hospitals, although the total number had decreased during a 5-year interval (Study I).

- Pain and deterioration were the most common symptoms among the patients during hospitalization but relatively few symptoms and care needs were associated with specific cancer sites (Study I).

- The constant risk of emotional overload is a major concern for hospital nurses caring for palliative cancer patients. Striving for emotional survival emerged as an overall strategy by which nurses manage their concern, affecting both their professional and everyday lives (Study II).

- Emotional competence, a property of striving for emotional survival, explains more or less adequate ways of dealing with emotional overload (Study II).

- Doing good care is a pattern of behavior through which nurses in the community deal with their main concern, their desire for doing good. When they fail in doing good, nurses experience a feeling of letting the patient down, which leads to frustration and a sense of powerlessness (Study III).

- Nurses use different caring behaviors to handle their “do-good-desire”. Although anticipatory caring is the optimal way, momentary caring is the most common behavior. Stagnated caring is less common and may lead to serious consequences for everybody involved (Study III).

- Patients and relatives in palliative care must live on hold when their normality is disrupted. They handle this through being in either fighting, adjusting or surrendering modes (Study IV).

- Mode synchronicity can vary for patients and relatives, causing problems and conflicts within the family but also with health professionals. Awareness of the actual mode being facilitates palliative caregiving (Study IV).
• Patients, relatives and nurses in palliative cancer care are continually deciphering unwritten rules as to how to act and behave. How they deal with these unwritten rules affects not only their experiences but also the quality of care (Overall Theory).

• Including palliative care early in the course of incurable cancer is crucial and will facilitate better management of the complexity of palliative cancer care for all involved.
CLINICAL AND RESEARCH IMPLICATIONS

The findings in this thesis on palliative cancer care can be useful in both clinical practice and research by contributing new knowledge on behavioral patterns of patients, relatives and nurses.

- Relatively few symptoms and care needs were associated with specific cancer sites among hospitalized palliative cancer patients and this indicates that the care focus should be on treating symptoms irrespective of the diagnosis in palliative cancer care. Larger studies are needed to verify our findings on few associations between symptoms and cancer sites. Research about symptoms cluster, i.e. how symptoms relate to each other, is also needed.

- It is of utmost importance to elucidate the situation for hospitalized palliative cancer patients and the reasons for their admission. Although certain admissions are necessary, there are probably also unnecessary admissions. Patients should be cared for at the right care level according to their care needs. To attain this goal, healthcare organizations may need to reorganize their care structures.

- To give high quality individual palliative care, health professionals need awareness of patients’ and relatives’ actual modes so that they can support their individual needs. Further research is needed to explore more about the reconciling process, its antecedents and consequences so as to increase knowledge of how best to give support and provide individual care.

- Healthcare organizations must recognize the importance of giving education in palliative care and offering counseling to health professionals to minimize the risk of being emotionally overloaded.

- There is also a need to develop and test educational programs and other interventions based on the theories presented in this thesis.
• These theories may well fit other substantive areas, after some modification, thereby contributing an understanding of how people are surviving emotionally, doing good care, living on hold and deciphering unwritten rules in different situations and contexts.

• Further research on the overall theory of deciphering unwritten rules is needed to find out how to facilitate the deciphering for everybody involved in palliative cancer care.

• A palliative care approach needs to be implemented in all caring contexts with dying people. Further research is needed to investigate how a palliative care approach can best be implemented and how it affects care in different settings.

• Although palliative care has received increased attention in the last decade, the awareness of palliative care and its goals still need to be increased among health professionals and the general public.
Att tyda oskrivna regler - patienter, närstående och sjuksköterskor i palliativ cancervård

Bakgrund

Under de senaste åren har intresset för palliativ vård ökat. Forskning har främst genomförts i avancerad palliativ hemsjukvård, på palliativa enheter och hospice. Forskning i akutsjukvård och hemsjukvård har hittills varit begränsad, trots att många cancerpatienter får palliativ vård även inom dessa vårdformer.

Syfte
Det övergripande syftet med avhandlingsarbetet var att utveckla en grundad teori som förklarar hur patienter, närstående och sjuksköterskor hanterar det som är den gemensamma huvudangelägenheten inom palliativ cancervård inom akutsjukvård och hemsjukvård.

Metod
Symtom, vårdbehov och cancerdiagnos hos palliativa patienter inom akutsjukvården (Studie I)

Syftet i denna studie var att beskriva och jämföra symtom, vårdbehov och cancerdiagnoser hos palliativa patienter som vårdades på olika avdelningar inom akutsjukvården år 2002 och 2007 samt att analysera vilka samband som fanns mellan dessa faktorer.


Det totala antalet palliativa cancerpatienter hade minskat under denna femårsperiod (14% vs 11%, p<0,01). Patienterna var äldre 2007 (74 vs 70 år, p<0,001) och hade fler symtom och större vårdbehov per patient (2.6 vs 1.6, p<0,001). Både under 2002 och 2007 var smärta (39% vs 44%, NS) och avtackling (27% vs 44%, p<0,001) de vanligaste symtomen. De vanligaste cancerdiagnoserna var prostatacancer och tjocktarm/ändtarmscancer.

Sambanden mellan symtom, vårdbehov och cancerdiagnoser var mestadels svaga dvs. flertalet symtom och vårdbehov kunde inte med säkerhet relateras till en specifik cancerdiagnos. Smärta kunde inte sättas i samband med någon cancerdiagnos när analysen gjordes på män och kvinnor tillsammans, exkl. könspecifika cancerdiagnoser. Vid analys av smärta hos enbart män, konstaterades ett samband mellan smärta och prostatacancer. Vid analys av smärta hos kvinnor, upptäcktes därremot inget samband med någon specifik cancerdiagnos, detta gällde även avtackling. Bland män var därremot avtackling relaterat till tjocktarm/ändtarmscancer, bukspottskörtelscancer och lungcancer.

Strävan att överleva emotionellt vid vård av patienter i palliativt skede (Studie II)

Syftet i denna studie var att utveckla en grundad teori om sjuksköterskor som vårdar palliativa cancerpatienter inom akutsjukvården. Forskningsfrågan som låg till grund för studien var följande: Vad är mest angeläget för sjuksköterskor och hur hanterar de detta?

Intervjuer med 16 sjuksköterskor på onkolog- och kirurgavdelningar vid ett akutvårdssjukhus genomfördes under åren 2001 t.o.m. 2003. Sekundäranalys av tidigare genomförda intervjuer inom palliativ vård användes även som data, eftersom ”allt är data” enligt forskningsmetoden grundad teori.

Strävan att överleva emotionellt framträdde som det beteendemönster genom vilket sjuksköterskorna hanterade den överhängande risken att bli emotionellt överbelastade vid vård av döende cancerpatienter. Denna risk kunde påverkas av flera faktorer, såsom sjuksköterskornas emotionella kompetens, erfarenhet,
kunskap, attityder och värderingar. Även externa faktorer såsom tid, resurser och kollegors värderingar och attityder kunde påverka risken att bli emotionellt överbelastad.

Strävan att överleva emotionellt involverar följande strategier: *att skapa emotionellt skydd, att bearbeta emotionellt samt att senarelägga den emotionella bearbetningen*. Sjuksköterskor kan skydda sig emotionellt genom att skapa ett *professionellt skydd*. De bearbetar då de känslor som uppstår i vårdandet och utvecklar strategier för att behålla den emotionella kontrollen. Sjuksköterskor kan även använda sig av *vitrocksdistansering*, vilket innebär att de gömmer sig bakom sin yrkesroll. De distanserar sig själva från det emotionella hot som kan uppstå genom deras arbete och kan av patienter och närstående uppfattas som kalla och oberörda.

Det finns flera strategier för emotionell bearbetning, såsom *att småprata, söka bekräftelse, reflektera och grubbla*. Vilka strategier sjuksköterskor använder beror på den situation de befinner sig i, både när det gäller arbete och privatliv. Genom emotionell bearbetning kan sjuksköterskor öka sin emotionella kompetens, få förståelse för vad de klarar av och lära sig att sätta gränser.

Brist på emotionell kompetens, tid, energi och/eller resurser leder för det mesta till att sjuksköterskor senarelägger den emotionella bearbetningen. Detta kan ske antingen genom att de *lagrar* sina känslor och bearbetar dem vid ett senare tillfälle eller genom att de *stoppar undan* känslorna och försöker gömma och glömma dem, vilket leder till vitrocksdistansering om känslorna förblir obehandade.

**Att vårda utifrån önskan att göra gott (Studie III)**

Syftet i denna studie var att utveckla en grundad teori om sjuksköterskor som vårdar palliativa cancerpatienter i hemmet. Forskningsfrågan som låg till grund för studien var följande: Vad är mest angeläget för sjuksköterskorna och hur hanterar de detta?

Intervjuer genomfördes med 33 sjuksköterskor i sju olika kommuner under åren 2004 t.o.m. 2006. Även i denna studie genomfördes sekundäranalys av tidigare gjorda intervjuer samt av intervjuerna från studie II. Även data från informella intervjuer, information från deltagande vid cancervårdskonferenser och grundad teoriseminarier analyserades, allt enligt grundad teori metoden.

Genom beteendemönstret ”*Att vårda utifrån önskan att göra gott*” hanterar sjuksköterskorna sin önskan att erbjuda en god vård. Denna genuina önskan att göra gott är drivkraften i vårdandet och sjuksköterskornas huvudangelägenhet. Vårdandet tar tid och de känner ett ansvar gentemot både patienter och närstående. När sjuksköterskor upplever att de inte klarar av att ge en god vård, känner de att de sviker patienterna, vilket kan leda till frustration och maktlöshet. Misslyckandet att ge en god vård kan bero på resursbrist, såsom tidsbrist, kunskapsbrist, begränsad tillgänglighet till läkare, brist på feedback samt avsaknad av framförhållning men det kan även orsakas av brist på emotionell kompetens hos sjuksköterskorna.
Att vårda utifrån önskan att göra gott innefattar tre olika vårdssätt: framförhållningsvård, tillfällighetsvård och stagneringsvård. Sjuksköterskor kan växla mellan vårdssätten beroende på vilken situation de befinner sig i, både när det gäller arbetet och privatlivet.

Det optimala vårdssättet för patienter, närstående och sjuksköterskor är framförhållningsvård, där sjuksköterskor gör sitt allra bästa och ibland även bättre än vad som är nödvändigt. Framförhållningsvård innebär att förutse vad som kan tänkas hända och att vara ett steg före genom att planera och organisera vad som kan förutsetes. Även genom att skapa tillit, att samarbeta och att prioritera kan en framförhållningsvård ges. För att ge framförhållningsvård krävs resurser men även kompetens i palliativ vård.

Tillfällighetsvård innebär att sjuksköterskor gör så gott de kan just i den situation de befinner sig. De använder sig av de resurser som finns tillgängliga för att kunna erbjuda en god vård. Tillfällighetsvård involverar strategin tillfällig problemlösnings genom att tillämpa tillfällig prioritering och sporadiskt samarbete.


**Att leva i väntan (Studie IV)**

Syftet i denna delstudie var att utveckla en grundad teori om palliativa cancerpatienter som vårdades i hemmet samt om deras närstående. Forskningsfrågan som låg till grund för studien var följande: Vad är mest angeläget för patienter och deras närstående och hur hanterar de detta?

Intervjuer genomfördes med 25 patienter och närstående under åren 2006 t.o.m. 2008. Sekundäranalys genomfördes av de intervjuer med patienter och närstående som genomförts vid tidigare studier. Även data från informella intervjuer och information från deltagande i cancervårdskonferenser användes vid analysen.

Genom beteendemönstret "Att leva i väntan" hanterar patienter och närstående huvudangelägenheten, att vara satt att vänta. Att vara satt att vänta innebär att det normala bryts och att kontrollen förloras, vilket leder till upplevelse av osäkerhet och maktlöshet.

Att vara kämpande innebär att patienter och närstående strävar efter att återskapa det normala livet, vilket medför strategier såsom att åternormalisera, revoltera, anklaga, förutse och ransaka. Att vara anpassande innebär att patienter och närstående försöker lära sig att leva ett liv i väntan genom att anpassa sig till en ny normalitet och nya rutiner, vilket innefattar att leva i nuet, att förminska sjukdomen och att skapa en fasad. Att vara överlämnande innebär att ha fullständig tillit och att våga släppa kontrollen. Patienter och närstående som tillämpar detta förhållningssätt har antingen resignerat efter att ha försökt att kämpa eller anpassat sig, eller så har de helt enkelt accepterat sin livssituation och överlämnar sig åt ödett eller Gud.

Att tyda oskrivna regler (Den övergripande teorin)

Den övergripande teorin utgår från avhandlingens övergripande syfte: att utveckla en grundad teori om patienter, närstående och sjuksköterskor i palliativ cancervård inom akut- och hemsjukvård. Data från de olika studierna användes för jämförelse och analys enligt metoden grundad teori. Att tyda oskrivna regler framträdde som det beteendemönster genom vilket patienter, närstående och sjuksköterskor hanterar ovissheten om hur de ska agera och bete sig. Det finns uttalade förväntningar och oskrivna regler om hur de bör bete sig och vilka värderingar och attityder som de bör ha för att bli accepterade och bekräftade, men det finns ingen som talar öppet om dessa oskrivna regler. Hur patienter, närstående och sjuksköterskor hanterar denna ovisshet och hur de sedan tyder de oskrivna reglerna påverkas av patienters och närståendes förhållningssätt (studie IV) och sjuksköterskornas vårdssätt (studie III) samt hur de hanterar den överhängande risken att bli emotionellt överbelastade (studie II). Att tyda de oskrivna reglerna är något som sker kontinuerligt, eftersom situationer och människor är föränderliga. Att tyda reglerna sker genom en ständig pågående process som innefattar att klura ut reglerna, att överlägga, att manövrera och att utvärdera. I manövrersningsfasen, kan de antingen följa reglerna, ignorera dem, förneka, revoltera, tänja på reglerna, bryta mot reglerna eller skapa nya regler.

Slutsats

Avhandlingens resultat bekräftar redan befintlig kunskap, samtidigt som teorinerna tillför ny insikt. Att relativt få symtom och vårdbehov var associerade med specifika cancerdiagnoser bland inneliggande patienter indikerar att fokus i palliativ cancervård bör ligga på att behandla symtom oavsett cancerdiagnos. Dessutom bör patienters behov avgöras inom vilken vårdform de ska vårdas, men för att uppnå detta mål kan hälso- och sjukvårdsorganisationen behöva omstruktureras.

Resultaten belyser även komplexiteten i palliativ vård: när sjuksköterskor med olika vårdssätt möter patienter och närstående med olika förhållningssätt. Personalen behöver medvetenhet om patienters och närståendes förhållnings-
sätt för att kunna bedöma och möta deras behov och därigenom ge en individuell palliativ vård. Palliativa cancerpatienter vårdas inom många olika vårdformer. För att kunna erbjuda en god vård behöver det palliativa vårdande perspektivet implementeras inom alla vårdformer. Även om palliativ vård har fått ökad uppmärksamhet under de senaste åren, behövs det fortfarande en ökad medvetenhet om denna vård och dess mål bland personal men även bland befolkningen i stort.
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