



Mittuniversitetet
MID SWEDEN UNIVERSITY

Thesis for the degree of Doctor of Philosophy, Östersund 2012

EXISTENTIAL ISSUES IN SURGICAL CARE

Nurses' experiences and attitudes in caring for patients with cancer

Camilla Udo

Supervisors:
Ella Danielson
Christina Melin-Johansson
Bertil Axelsson
Ingela Heno

Department of Health Sciences
Mid Sweden University, SE-831 25 Östersund, Sweden

ISSN 1652-893X,
Mid Sweden University Doctoral Thesis 136
ISBN 978-91-87103-42-1

Akademisk avhandling som med tillstånd av Mittuniversitetet i Östersund framläggs till offentlig granskning för avläggande av filosofie doktorsexamen torsdag, 13 december, 2012 klockan 10.15 i sal F234, Mittuniversitetet Östersund. Seminariet kommer att hållas på svenska.

EXISTENTIAL ISSUES IN SURGICAL CARE
Nurses' experiences and attitudes in caring for patients with cancer

Camilla Udo

© Camilla Udo, 2012

Department of Health Sciences
Mid Sweden University, SE-831 25 Östersund
Sweden

Telephone: +46 (0)771-975 000

Book cover: ©Lena Olai, 2012. All rights reserved.

All previously published papers have been reproduced with permission from the publisher.

Printed by Kopieringen Mid Sweden University, Sundsvall, Sweden, 2012

ABSTRACT

The overall aim of this thesis was to explore surgical nurses' experiences of being confronted with patients' existential issues when caring for patients with cancer, and to examine whether an educational intervention may support nurses in addressing existential needs when caring for patients with cancer. Previously recorded discussions from supervision sessions with eight healthcare professionals were analysed (I), written descriptions of critical incidents were collected from 10 nurses, and interviews with open questions were conducted (II). An educational intervention on existential issues was pilot tested and is presented in Studies III and IV. The intervention was the basis of a pilot study with the purpose of testing whether the whole design of the educational intervention, including measurements instruments, is appropriate. In Study III and IV interviews with 11 nurses were conducted and 42 nurses were included in the quantitative measurements of four questionnaires, which were distributed and collected. Data was analysed using qualitative secondary analysis (I), hermeneutical analysis (II), and mixed methods using qualitative content analysis and statistical analyses (III-IV). Results in all studies show that existential issues are part of caring at surgical wards. However, although the nurses were aware of them, they found it difficult to acknowledge these issues owing to for example insecurity (I-III), a strict medical focus (II) and/or lacking strategies (I-III) for communicating on these issues. Modest results from the pilot study are reported and suggest beneficial influences of a support in communication on existential issues (III). The results indicate that the educational intervention may enhance nurses' understanding for the patient's situation (IV), help them deal with own insecurity and powerlessness in communication (III), and increase the value of caring for severely ill and dying patients (III) in addition to reducing work-related stress (IV). An outcome of all the studies in this thesis was that surgical nurses consider it crucial to have time and opportunity to reflect on caring situations together with colleagues. In addition, descriptions in Studies III and IV show the value of relating reflection to a theory or philosophy in order for attitudes to be brought to awareness and for new strategies to be developed.

Keywords: cancer care, educational intervention, existential, nurses, surgical care

SVENSK SAMMANFATTNING

Det övergripande syftet med denna avhandling var att undersöka kirurgsjuusköterskors och undersköterskors erfarenheter och upplevelser av existentiella frågor vid vård av patienter med cancer, samt att undersöka om en utbildningsintervention med existentiella frågor kan vara ett stöd för kirurgsjuusköterskor och undersköterskor att bemöta existentiella frågor. Tidigare inspelade diskussioner från handledningssessioner med åtta vårdpersonal analyserades (I), skriftliga "kritiska händelser" från 10 sjuusköterskor och undersköterskor samlades in och intervjuer med öppna frågor genomfördes (II). Trots att syftet var att testa design och upplägg av en utbildningsintervention, samt att se om mätinstrumenten var möjliga att använda, presenteras ändå resultat som antyder att utbildningen kan ha potential att utgöra stöd för sjuusköterskor och undersköterskor att nå en djupare förståelse och ökad säkerhet i kommunikation om existentiella frågor (III-IV). Intervjuer med 11 sjuusköterskor och undersköterskor genomfördes i studierna III och IV och 42 sjuusköterskor och undersköterskor var inkluderade att besvara fyra olika enkäter. Insamlad data analyserades med kvalitativ sekundär analys (I), hermeneutisk analys (II), och kombinerad metod med kvalitativ innehållsanalys och statistiska analyser (III-IV). Resultat i samtliga delstudier visar att existentiella frågor är närvarande vid de kirurgiska vårdavdelningarna. Dock fann sjuusköterskorna och undersköterskorna det svårt bemöta dessa frågor på grund av bl.a. osäkerhet i kommunikation, ett snävt medicinskt fokus och bristande strategier. Resultat i denna avhandling antyder att utbildningsinterventionen kan utgöra ett stöd i kommunikationen gällande existentiella frågor, att positivt influera det upplevda värdet av att ta hand om svårt sjuka och döende patienter liksom minska arbetsrelaterad stress. De kvalitativa resultaten i samtliga delstudier visar att det är avgörande för kirurgsjuusköterskor och undersköterskor att få tid och möjlighet att tillsammans med kollegor reflektera över vårdandet. Delstudie III och IV visar värdet av att i reflektion i grupp och individuellt också relatera till en teori eller filosofi i en utbildning, för att nå ökad medvetenhet gällande attityder och utveckla strategier. **Nyckelord:** Cancervård, existentiell, intervention, kirurgisk vård, sjuusköterskor, undersköterskor, utbildning

CONTENTS

ABSTRACT	iv
SVENSK SAMMANFATTNING	v
LIST OF PAPERS	x
1. INTRODUCTION	1
1.1. RESEARCH POSITION AND PRE-UNDERSTANDING	1
1.2. THE ONTOLOGICAL FOUNDATION	2
1.3. THE EPISTEMOLOGICAL FOUNDATION	2
2. BACKGROUND	4
2.1. NURSING IN SURGICAL CARE	5
2.2. COMMUNICATION IN NURSING	6
3. THEORETICAL FRAMEWORK	8
3.1. CARING	8
3.2. EXISTENTIAL FOUNDATION	9
3.2.1. <i>Meaning</i>	11
3.2.2. <i>Freedom</i>	11
3.2.3. <i>Existential isolation</i>	12
3.2.4. <i>Death</i>	12
3.2.5. <i>Caring in limit situations</i>	13
4. RATIONALE FOR THE THESIS	14
5. AIMS	15

5.1. OVERARCHING AIM	15
5.2. SPECIFIC AIMS	15
6. METHODOLOGY	16
6.1. DESIGN	16
6.2. THE EDUCATIONAL INTERVENTION ON EXISTENTIAL ISSUES	18
6.3. SETTING AND PARTICIPANTS	20
6.3.1. <i>Study I</i>	20
6.3.2. <i>Study II</i>	20
6.3.3. <i>Studies III and IV</i>	20
6.4. SELECTION PROCEDURES	21
6.4.1. <i>Study I</i>	21
6.4.2. <i>Study II</i>	21
6.4.3. <i>Studies III and IV</i>	21
6.5. METHODS OF DATA COLLECTION	22
6.5.1. <i>Group discussions in supervision sessions</i>	22
6.5.2. <i>Critical Incident Technique</i>	22
6.5.3. <i>Interviews</i>	23
6.5.4. <i>Questionnaires</i>	23
6.6. METHODS FOR DATA ANALYSES	24
6.6.1. <i>Qualitative secondary analysis</i>	24
6.6.2. <i>Hermeneutical analysis</i>	25

6.6.3. <i>Qualitative content analysis</i>	26
6.6.4. <i>Statistical analyses</i>	27
6.7. ETHICAL CONSIDERATIONS	28
7. RESULTS	29
7.1. COMPONENTS OBSTRUCTING OR SUPPORTING NURSES TO ACKNOWLEDGE PATIENTS' EXISTENTIAL ISSUES	29
7.1.1. <i>Medical-oriented care hindering existential dialogues</i>	29
7.1.2. <i>Lack of strategies</i>	30
7.1.3. <i>Work environmental and organizational constraints</i>	30
7.1.4. <i>Reflection and valuable support from colleagues in caring</i>	31
7.2. INCREASED AWARENESS AND CONFIDENCE WHEN ENCOUNTERING PATIENTS WITH EXISTENTIAL ISSUES	31
7.2.1. <i>The process of nurses' caring</i>	31
7.2.2. <i>The process of nurses' communication</i>	33
7.2.3. <i>The process of nurses' reflections</i>	33
8. DISCUSSION	35
8.1. CURE ORIENTATION IN A CARE SITUATION	36
8.2. AFFIRMING LIFE WHEN CARING FOR PATIENTS DYING OF CANCER	37
8.3. THE RESPONSIBILITY TO COMMUNICATE ON EXISTENTIAL ISSUES OR THE FREEDOM NOT TO	39
8.4. HUMANISTIC NURSING IN SURGICAL CANCER CARE	41
9. METHODOLOGICAL CONSIDERATIONS	43

9.1. RATIONALE FOR CONDUCTING A PILOT STUDY	43
9.2. VALIDITY AND RELIABILITY	43
9.3. TRUSTWORTHINESS	45
10. CONCLUSIONS	47
11. IMPLICATIONS AND RECOMMENDATIONS FOR FURTHER RESEARCH	48
12. POPULÄRVETENSKAPLIG SAMMANFATTNING (SUMMARY IN SWEDISH)	49
13. ACKNOWLEDGEMENTS	54
14. REFERENCES	56

LIST OF PAPERS

- I. Udo C., Melin-Johansson C. & Danielson E. (2011) Existential issues among health care staff in surgical cancer care – discussions in supervision sessions. *European Journal of Oncology Nursing* **15**, 447-453.
- II. Udo C., Danielson E. & Melin-Johansson C. (2012) Existential issues among nurses in surgical care – a hermeneutical study of critical incidents. *Journal of Advanced Nursing* doi: 10.1111/j.1365-2648.2012.06032.x.
- III. Udo C., Melin-Johansson C., Henoeh I., Axelsson B. & Danielson E. Surgical nurses' attitudes toward caring for patients dying of cancer – A pilot study of an educational intervention on existential issues. (*Submitted*)
- IV. Udo C., Danielson E., Henoeh I. & Melin-Johansson C. Surgical nurses' work-related stress when caring for severely ill and dying patients with cancer after participating in an educational intervention on existential issues. (*Submitted*)

1. INTRODUCTION

The focus of this thesis is existential aspects of caring for patients in different phases of cancer in surgical care from nurses' perspectives.

In Sweden, 55 342 persons were diagnosed with cancer during 2010. Cancer disease is a common cause of death in the country and an estimated one-third of Swedes will be afflicted with cancer at some point during their lives (The Swedish National Board of Health and Welfare 2011). Although many die in palliative care settings, some die on a surgical ward. In the surgical care context, nurses interact daily in various situations with patients with different needs. Aside from the obvious physical and medical needs, patients also express needs relating to emotional and/or existential aspects of the new and often unexpected life situation (Strang & Strang 2002; Grumann & Spiegel 2003; Sand & Strang 2006; Mok, Lau, Lam, Chan, Ng et al. 2010). Existential issues arise in critical situations (such as a life-threatening illness) where a previously envisioned future and one's basic security come under threat. They may encompass meaning, loneliness, death and freedom and are common to all people, regardless of culture or religion (Yalom 1980). Nurses caring for these patients are drawn in to their existential issues, thoughts and reactions, and handle various reactions among patients who know that life may soon end. They may encounter questions such as "Why me?", a common question following on the heels of severe illness (Winterling, Wasteson, Sidenvall, Sidenvall, Glimelius et al. 2006; Lavoie, Blondeau & De Koninck 2008). Therefore, as a threat to existence, medical problems are also existential problems involving suffering and issues of life and death (Torjuul, Nordam & Soerlie 2005). This may pose a challenge for nurses who often have no training or strategies to address patients' existential needs (Molzahn & Shields 2008; Browall, Melin-Johansson, Strang, Danielson & Henoch 2010).

1.1. Research position and pre-understanding

As a trained social worker and a PhD student in nursing my perspective is largely an outside perspective. However, my professional experience from working as a social worker within cancer care and palliative home care, both in surgical and in oncology contexts, contributes to some inside perspective. Although I have always been deeply interested in existential issues, the experience of encountering fellow humans in earth-shattering life situations strengthened the awareness of how truly important such encounters can be. The awareness awakened a deeper interest in how encounters and authentic dialogues can be achieved between professionals working in clinical settings, on the one hand, and the patients and their families, on the other. Listening to and engaging in dialogue with patients and their loved ones has made me realize that existential issues are indeed human, and are often triggered in severe life-threatening situations, such as

being diagnosed with a disease like cancer. When working in these settings I have always had the beneficial opportunity to participate in regular supervision sessions, where one of my supervisors was a trained existential therapist. This perspective on human encounters brought a philosophical perspective into the medical context, and the collected experiences inspired me to learn more about existential philosophy and psychology. They also deepened my interest in how health care professionals' everyday encounters with patients in caring situations, may be supported.

1.2. The ontological foundation

A basic ontological foundation of this thesis is the assumption that humans are not determined, but, that they are influenced by their past, present and future. According to continental existential philosophy, all situations contain some degrees of freedom and constraints, while the perceived world is in constant process of change and transformation. People find themselves in life situations with varying degrees of freedom, where different aspects, such as practical, physical, emotional and perceived boundaries, affect freedom (Kierkegaard 1844/1980). Sartre (1946/1948), inspired by Heidegger (1927/1962) and other philosophers, argued that existence precedes essence in the sense that there can be no essence without existence. We are born into the world and therefore we exist, however the essence of existence is unique, largely created in situations and encounters, within varying degrees of freedom. Thus we are to some extent co-creators in forming who and what we are, constantly moving in some direction (cf. Heidegger on intentionality) and aiming at something when in the process of forming the essence of our existence (Kierkegaard 1844/1980; Jaspers 1970). Already Descartes (1641/1996), followed by Kierkegaard (1844/1980) and others, claimed that we perceive the world subjectively, thus creating unique possibilities and limitations, as well as attitudes. In other words, our interpretation of the world is individual and multiple interpretations of the same situation are possible based on the assumption that we are all unique with a unique context and experience (Gadamer 1960/1989). Existential dimensions are always present in human life, though often dormant until something happens and we are forced to confront our latent and "forgotten" thoughts.

1.3. The epistemological foundation

As humans, we are constantly in a process of interpreting the world and therefore our understanding of the world changes along with situations and context (Gadamer 1960/1989). The epistemological basis of this thesis is the perception that knowledge is largely empirical, based on experience, observation

and interpretation of the daily interaction with others (Berger & Luckmann 1966). This thesis is based on the belief that enhancing knowledge is more about processes than about tangible structures. In addition, knowledge is closely linked to our view of the world (Burr 2003). The perspective on knowledge in the present thesis is largely based in the Aristotelian perspective of knowledge and the different ways of “knowing”: episteme, techne and phronesis (Ackrill 1981). Being a nurse involves all three dimensions of knowing. The constant process of enhancing knowledge involves interpretation and understanding of explanatory theories such as scientific knowledge (episteme). In addition the practical skills seen in daily routine care (techne) are of course needed from the nurse; however, without assimilation with a deeper intuitive practical wisdom (phronesis) derived from reflection and awareness, episteme and techne may be useless. In the medical context today, episteme and techne are the basis, and phronesis is sometimes forgotten owing to the high degree of specialization and medicalization, amongst other reasons (Svenaesus 1999).

2. BACKGROUND

While working on this thesis, systematic searches were undertaken using Medical Subject Headings (MeSH) terms and text/key words in the databases of PubMed, Medline, CINAHL, PsychInfo, and the Cochrane Library and Social Sciences Citation Index. Examples of terms and key words used are: advanced disease, attitudes, cancer, Critical Incident Technique, death, dying, end of life, existential, health care professionals, health care staff, intervention studies, mixed methods, moral stress, nurses, personnel, qualitative analysis, secondary analysis, spiritual, surgical care, work-related stress. These words were differently combined with one another and sometimes truncated.

Several educational intervention studies have been published with the aim to improve health care professionals' (mainly nurses' and oncologists') communication in cancer care from a more general point of view, i.e. not focusing on existential issues (see e.g., Razavi, Delvaux, Marchal, Bredart, Farvacques et al. 1993; Hainsworth 1996; Fallowfield, Jenkins, Farewell, Saul, Duffy et al. 2002; Wilkinson, Leliopoulou, Gambles & Roberts 2003; Arranz, Ulla, Ramos, del Rincón & López-Fando 2005). For example, Jenkins and Fallowfield (2002) conducted 3-day residential communication training workshop for physicians containing cognitive, experiential and behavioural components (including video-taped consultations, group discussions, etc.) with increased focused responding and asking of more open questions. Similar to Jenkins and Fallowfield's (2002) communication course, workshops for oncologists in Italy, conducted over a period of 5 years, were evaluated by Lenzi, Baile, Costantini, Grassi and Parker (2011) showing improvements in communication, such as giving difficult information. Wilkinson, Perry, Blanchard and Linsell (2008) trained nurses in communication in a course similar to that in Jenkins and Fallowfield (2002), which showed an impact on nurses' improved ability to communicate.

However, the studies mentioned above evaluate communication in general. Intervention studies on how to support nurses' communication on existential issues are still few. Some studies focus on patients and existential issues. They identify important components for psycho-social well-being, such as perceived meaning, purpose and hope (Breitbart 2002; Richer & Ezer 2002; Lin & Bauer-Wu 2003; Breitbart, Gibson, Poppito & Berg 2004; Chochinov, Krisjanson, Hack, Hassard, McClement et al. 2006; Lethborg, Aranda, Bloch & Kissane 2006). There are also descriptive studies focusing on how nurses perceive existential issues and how existential support is prioritised (Strang, Strang & Ternstedt 2001; Browall et al. 2010), and on nurses' stress and coping ability needing to deal with existential issues (Ekedahl & Wengström 2007). Henoeh and Danielson (2009) report that there is a gap in knowledge about how patients' existential well-being may best be supported by nurses and other health care professionals in everyday practice.

One of the few intervention studies that I found concerned meaning-focused interventions for palliative care nurses aimed at improving their sense of work-related meaning and quality of life to better manage the stress associated with caring for the dying (Fillion, Duval, Dumont, Gagnon, Tremblay et al. 2009). The authors based the intervention on Viktor Frankl's logo therapy (1987). The intervention included four weekly meetings. It showed no effects on general job satisfaction or quality of life, but did improve nurses' perceived benefits of working in palliative care. In another intervention study regarding nurses' attitudes towards caring for patients feeling meaninglessness, Morita, Murata, Kishi, Miyashita, Yamaguchi et al. (2009) describe an educational intervention for nurses in different settings consisting of lectures on theory, communication and reflection. The intervention was shown to have affected nurses' confidence during patient encounters, as well as improving their attitudes towards helping patients who were experiencing meaninglessness. Frommelt (1991, 2003) has shown that training in communication may influence nurses' attitudes towards patients at the end of life, and contribute to better care for the patients in addition to supporting more productive communication with patients. Iranmanesh, Savenstedt and Abbaszadeh (2008) propose that education about death may contribute to changes in attitudes in how nurses handle death and dying, and improve the quality of interaction with and consequently the care of dying patients. Other studies, likewise suggest that there is a connection between attitudes and ways of caring (Dunn, Otten & Stephens 2005; Rolland & Kalman 2007; Lange, Thom & Kline 2008; Braun, Gordon & Uziely 2010). Education and training, where reflection leads to a change in attitudes and increased awareness, seems to have the potential to affect communication on death, and caring for dying patients.

According to Polit and Beck (2012) nursing research implies developing systematic knowledge about the nursing profession including both practice and administration, as well as education and other matters important to nursing. Burns and Grove (2005), reporting from a more clinical focus, explain nursing research as something that validates or refines already existing knowledge or generates new influences on nursing practice. In this thesis, research has been inspired by the responsibility and inter-relational concerns that, according to Paterson and Zderad (1976), are important in nursing research. This thesis is based on the conviction that nursing builds on important practical knowledge, and nurses are especially successful when they integrate episteme, techne and phronesis in their daily work.

2.1. Nursing in surgical care

Since one of the main treatments for cancer is surgery (The Swedish National Board of Health and Welfare 2011) most patients with a cancer diagnosis have contact with a surgical ward. In Sweden, surgical wards are often medically specialized, for example in gastro-intestinal diseases, breast cancer etc. Many

newly graduated nurses take up their first employment at a surgical ward (Hallin & Danielson 2007, 2008; Jangland, Larsson & Gunningberg 2011). Being new in the profession may imply challenges, as newly graduated nurses sometimes lack experience in handling the complex and shifting situations that often occur in surgical care. In addition, patients stay in hospital for a shorter time compared with previously (Jangland et al. 2011). This implies high demands on the nurse to meet and care for many new patients with different needs. On a surgical ward, this includes both newly diagnosed and dying patients. Surgical nurses have expressed difficulties in finding a balance between providing curative care and giving palliative care (James, Andershed, Gustavsson & Ternstedt 2010). In this context, quick decisions are needed when there are many patients to attend to, with a variety of diseases (often including cancer disease); different professionals are working together to do what is regarded best for the patient. The complex situations in surgical care involve a need for communication with both other professionals and the patients, and also require skills in handling, and knowledge about, the technical equipment. The constant development of technology in modern surgery has contributed to the possibility to prolong life (Hansson 2007) and although the benefits of technical advancement and new knowledge cannot be overemphasized, new dilemmas and difficulties arise with this increased knowledge. Nurses in the surgical care context face diverse ethical dilemmas, sometimes due to the advancement of prominent treatments (Torjuul, Nordam & Soerlie 2005). Despite the emphasis in surgery on technical advancement, nursing is still a discipline based on a human interaction (Benner, Hooper-Kyriakidis & Stannard 1999) where nurses can make a difference for the patient (Hawley & Jensen 2007; McGrath 2008).

2.2. Communication in nursing

Communication is a basic strategy in interaction and caring. Fallowfield, Saul and Gilligan (2001) found that communication problems between patients and nurses not only have negative effects on patient care, but also create stress for the nurses. Ödöling, Norberg and Danielson (2002) report that nurses at a surgical ward perceive the patients' and relatives' needs for proper and continuous information about their situation, but find it hard to communicate this. When surgical nurses move from patient to patient, caring for a variety of patients in different phases of a disease (Johansson & Lindahl 2011), multi-faceted interaction with patients is one of the key elements because nurses meet with patients and families in various situations and stages of illness (Arranz et al. 2005). For example, patients under care and/or treatment for cancer often have existential issues and a desire to discuss them (Landmark, Strandmark & Wahl 2001; Strang et al. 2001; Henoch, Bergman, Gustafsson, Gaston-Johansson & Danielson 2007; Sand, Strang & Milberg 2008). If these needs are ignored, adjustment to the new situation become more

difficult and the patient's quality of life may be negatively affected (Laubmeier, Zakowski & Bair 2004; Vachon 2008). If, however, issues such as meaning are recognized and supported patients can better cope with their disease and treatment (Landmark et al. 2001; Mazzotti, Mazzuca, Sebastiani, Scoppola & Marchetti 2011). Since nurses often feel they are unprepared to meet with patients facing the end of life (Frommelt 1991; Strang et al. 2001; Delgado 2007) and seriously ill patients often refrain from discussing their existential thoughts with nurses because they feel that nurses do not acknowledge this need (Westman, Bergenmar & Andersson 2006), many patients are dissatisfied with their emotional and existential support, even if they are satisfied with their medical and physical care (De Vogel-Voogt, Van Der Heide, Van Leeuwen, Visser, Van Der Rijt et al. 2007). Although sometimes patients need professional counselling from a social worker or therapist, it would usually suffice for a nurse to pause and acknowledge that they recognize the patient's difficult existential situation (Houtepen & Hendrikx 2003; Chochinov et al. 2006). Nurses and other health care professionals need to create a climate of legitimacy and acceptance in which patients can raise existential questions so they can prepare for any treatments and/or changes that accompany the disease (Richer & Ezer 2002). Fallowfield et al. (2001) emphasize the importance of communication skills for nurses to support patients, and argue that communication is the essence of nursing.

As previously mentioned, few studies focus on existential issues in a surgical context. International clinical intervention studies with a focus on existential issues from a nursing perspective are few and little research on existential education and training for nurses in clinical practice has been carried out. We have found no Swedish educational intervention studies associated with surgical care and focusing on existential issues.

3. THEORETICAL FRAMEWORK

Christianity has had a strong influence across Europe for many centuries (Halman & Riis 2003). The Nordic countries, including Sweden, however, are now to a great extent secularized and the belief in a traditional God as a source of meaning has diminished. Nevertheless, Christianity retains an influence over the majority of people in Sweden in the form of traditions such as Easter and Christmas celebrations (Halman & Riis 2003). According to Stark and Bainbridge (1985), secularization stimulates religious innovation which does not necessarily include religious or spiritual dimensions, but may be purely existential. The existential fundamentals pertain to humanity in general, irrespective of culture or religion, and address humanity's "ultimate concerns" which include issues such as meaning, freedom, existential loneliness, and death (Yalom 1980). The "ultimate concerns" are concerns of human existence, in which physical aspects are crucial since we humans inevitably exist within the reality of the physical world, with which we are forced to cope. When we address existential issues we may challenge basic assumptions, beliefs about life and its conditions that we as humans believe to be true without questioning them (Yalom 1980). Serious illnesses such as cancer activate our "ultimate concerns" and have the potential to shake the foundation of our core beliefs.

3.1. Caring

When discussing nursing, the concept of caring cannot and should not be avoided. According to many, caring is the essence of nursing (Morse, Solberg, Neander, Bottorff & Johnson 1990; Wilkin & Slevin 2004; Rhodes, Morris & Lazenby 2011). In the often stressful and technical context of surgical care, the concept of caring is perhaps especially important to highlight so it does not get lost in the fast-paced work environment. Caring may be seen as the ethical aspect of nursing (Watson 1985), where involvement and connectedness are in focus (Benner 1984). In the present thesis it is regarded as the more phronesis-based side of nursing, and concerns the "personal touch" in which nursing is provided. In this sense, caring is relational, depending on the nurse's presence, understanding for the Other and awareness of the situation. From an existential perspective, both the nurse and the patient are unique individuals (cf. Buber 1970) with unique experiences. Both individually interpret the caring situation (cf. Gadamer 1960/1989). It is, however, important to remember that the nurse-patient relationship is asymmetric as the nurse is present by choice as a professional while the patient is there involuntarily. This power balance may imply a complex situation where a caring relationship can only be achieved if the nurse feels empathic understanding. Even if the purpose of the nurse-patient encounter is

often shared many times it is not, and consequently awareness is needed. Although caring is not unique to nursing, the caring aspect of nursing is essential when supporting another human physically and medically. Wilkin (2003) describes a caring relationship as the relationship between a nurse and a patient moving towards a common goal. To achieve this, also in a sometimes obstructive and stressful work environment, authenticity in the human encounters is needed. According to existential philosophers such as Kierkegaard (1844/1980), being authentic involves choosing one's own way to act, and taking responsibility for it. Similarly, Levinas (1979/1987) describes an ethical philosophy with a focus on relationships. The response to the Other is, according to Levinas, an inevitable responsibility derived, not from ethical guidelines, but from seeing and apprehending the Other's face there and then. In contrast to Buber (1970), whose philosophy also concerns human relationships, Levinas (1979/1987) claims that the "total otherness" of the Other can never be entirely extinguished, which Buber (1970) seems to think can occur in an authentic I-Thou dialogue. In terms of existential philosophy e.g. Kierkegaard (1844/1980), Levinas (1979/1987) Buber (1970), nurses' responsibility as humans for how they respond to the patient cannot be erased.

Caring is still the core in nursing according to Watson (1985), even when curing is not possible. In line with this, Paterson and Zderad (1976) claim that caring for patients who are living under the substantial threat of death inevitably involves preserving the dignity for patients who are experiencing awakened existential issues. When caring is integrated in nursing, and episteme and techne are permeated with phronesis, humanistic nursing is implied, based on a caring interaction where the patient's as well as the nurse's way of being in a situation influences the outcome of the caring situation (Paterson & Zderad, 1976). The holistic perspective in the philosophy of palliative care is another important aspect when discussing caring also within a surgical care context because cancer care also in settings other than the palliative setting involves caring for dying patients. Palliative care in the Western world today is much based on the modern hospice movement. Its founder Cicely Saunders (1978), when writing about "total pain", include not only physical pain but also psychological, social and spiritual pain, which opened up a broadened and deepened view of caring. In the hospice movement, death is regarded as a natural part of life where alleviation is seen as important and possible even if cure is not.

3.2. Existential foundation

The meaning of being human and the human conditions has always been contemplated on by people (Tomer, Eliason & Wong 2008). Questions concerning what it is to be human and how we live our lives are also dealt with in existential philosophy where the human condition is explored with basis in actual real life

(May 1983). In existential philosophy an effort is made to grasp reality through exploring humans and human issues derived from real life situations. Existential issues concern the fundamental human condition and the basic choices surrounding us all, regardless of culture or religion, to which we are forced to relate to (Yalom 1980). Humans are viewed more as human *becoming* than as human *being*, which emphasizes that existence is a constant process rather than a condition that has been achieved and reached once and for all (cf. Kierkegaard 1844/1980; Jaspers 1970; Yalom 1980). The ability to reflect on large and, often, complex questions from everyday situations is common for existential philosophers. Kierkegaard (1844/1980), Jaspers (1970) and many others who have contemplated on human existence have found that the fact that we exist inevitably forces us to relate to certain unavoidable existential conditions which often concern themes such as angst, freedom, choice, meaning, loneliness and death. Existential philosophers such as e.g. Kierkegaard (1844/1980) and Jaspers (1970) saw the ontological tension of angst, when faced with the possibility of nothingness, as an opportunity to become more self-reflective and authentic (cf. Heidegger 1927/1962).

Within the context and for the purpose of this thesis, existential issues concern those inevitable parts of being human that are rooted in the individual's existence (Yalom 1980, 2009). Yalom claims that although there are many sources of despair, there is also always the possible despair of the inevitable confrontation with the "givens" of existence (Yalom 2009). When using the term "givens of existence", Yalom refers to these as based in what Tillich calls "ultimate concerns", and although the ultimate concerns, or existential issues, are individual there are some basic concerns that are particularly prominent for all humans: existential isolation, meaning, death and freedom (Tillich 1952; Yalom 1980, 2009). How we address these issues is highly individual. Some people find strength through spirituality, belief in a higher power, and sometimes, but not always, through a religious community. As human beings we are all forced to deal with these existential issues with or without a higher power or religious belief. Yalom (1980), strongly inspired by May uses an existential approach both in individual and group therapies. Through his work with patients with cancer he is familiar with the existential threat that the disease constitutes (Yalom 2000, 2005). Partially influenced by the cognitive behavioural approach (sometimes stressing the need for diagnosis), he does not always enter into deep discussions of paradoxes and the complexities of the ultimate concerns. Rather, he describes these as evoking anxiety, which leads to different defence mechanisms. This perspective may be regarded as more of a medical perspective than an existential one, where the latter focuses on exploring, understanding and handling the anxiety derived from the ultimate concerns rather than trying to remove them (Van Deurzen 1988, 2010). Strang (2002) further clarified "existential" as a concept by placing it in relation to the neighbouring concepts of spirituality and religion. Religion is a social manifestation in which

rituals are expressions of the religious dimension that spirituality does not necessarily encompass, even if spirituality assumes belief in some form of higher power. Existential issues may be encompassed in a higher power, but this is not obligatory. Meaning, freedom, death, and existential isolation are basic existential aspects of life which may generate anxiety and inner conflict when one is confronted with them (Yalom 1980). These concepts are central to this thesis and are therefore presented separately below.

3.2.1. Meaning

In contrast to the past, when people in Christian Western Europe (including Sweden) had religious guidelines governing meaning, we now find ourselves in a secular society in which no obvious purpose in life is shared. Instead, we are expected to find our own individual subjective meaning in life to avoid being caught in a sense of meaninglessness. Yalom (1980, 2009) argues that to achieve true meaning, engagement is needed. From a philosophical existential perspective, humans are caught in the constant dilemma of seeking meaning in a world without objective meaning (Sartre 1946/1948; Yalom 1980; Van Deurzen 1988), and the only way to avoid meaninglessness is through engagement (Yalom 1980; May 1983). The concept of meaning was also contemplated by Frankl (1963) who developed a therapy, logotherapy, aimed at helping people find meaning in their lives in order to fight the vacuum (meaninglessness), the general sense of which, according to Frankl, has increased. According to philosophers such as Kierkegaard (1844/1980) and Jaspers (1970), our lives are bearers of meaning and we are inevitably co-creators through our choices, pre-conditions and historicity. Like most other existential philosophers, Kierkegaard (1844/1980) argued, that humankind is always, inevitably attributing a meaning to everything; Kierkegaard added that the individual is free to choose what meaning they attribute to their surroundings and situations. This has also been suggested by Travelbee (1971), who claims that human beings are always motivated to create meaning in situations in life and that as a nurse, it is important to be aware of this. The nurse may then be able to support the patient into finding meaning in the vulnerable situation they are in. Our choices in life show what we consider to be meaningful, and as humans we cannot avoid the question of meaning (Kierkegaard 1844/1980).

3.2.2. Freedom

Freedom is a complex multi-dimensional concept and entails the opportunity to choose, which it requires individuals to do (where not choosing also entails a choice). Kierkegaard's philosophy regarding freedom concerned the deeply human and serious choices in life, including responsibility (Kierkegaard 1844/1980). Since

choosing one thing always means that something else is “unchosen”, choice also generate a sense of guilt (Kierkegaard 1844/1980). Therefore, freedom is connected to both responsibility and guilt. The reverse side of freedom may be a sense of groundlessness and lack of coherence (Yalom 1980). Therefore, these issues are also connected to freedom.

3.2.3. Existential isolation

Existential isolation is completely different from social loneliness. Existential isolation has its base in the uniqueness of existence and does not mean being socially alone (Yalom 1980). It is characterized by the vulnerability of our existence – we enter life alone and we leave it alone, even if loved ones may accompany us almost to the end (Yalom 1980). When for example being diagnosed with a cancer disease, even though a life companion or perhaps a close friend is present holding our hand and being supportive, this is merely supportive. Our utter existential loneliness is based on the uniqueness as a human (Jaspers 1970). For instance, although cancer is one of the most common diseases in the world, when the disease strikes, being diagnosed with cancer is still a unique situation and it is the unique individual who is forced to cope.

3.2.4. Death

Although we are all aware that we must all die at some point, we are unaccustomed to speak about death and to face death and dying (Ternstedt 1998). In Sweden and elsewhere in Western Europe, the view of death has changed from it being a natural part of life to it becoming almost invisible and often being denied in today’s society (Wikström 1999). As already mentioned, Christianity, which previously provided rituals for dealing with death, has today yielded to a more secular society in Sweden (Halman & Riis 2003) and there now seems to be an absence of societal and personal rituals to deal with issues and feelings arising from the close encounter with death (Ternstedt 1998). The attitudes of people towards death are influenced by today’s secular society (Halman & Riis 2003) in which God and the church no longer present a strategy for dealing with death. The result is a more individual approach to death since a natural forum in which it can be discussed is not readily available. In existential philosophy and psychology, death is a recurring concern and is central to existential issues. All existential philosophers address death: Jaspers (1970) describes the encounter with or threat of death as a limit situation in which the individual can reach a truer and deeper sense of life through the devastating despair that initially occurs (provided the individual does not succumb to hopelessness and despair). Yalom (1980) sees life

and death as two sides of the same coin where, as Jaspers also states, death can enrich life: How would endless life be, without death as a limit?

3.2.5. Caring in limit situations

Influenced by Nietzsche (1883/1961) and others, philosophers Kierkegaard (1844/1980) and Jaspers (1970) based their contemplation and asking of philosophical questions on personal experiences. Jaspers (1970), like Kierkegaard (1844/1980), claimed that as humans we are always in situations which most of the time can be influenced to some extent. However, there are situations that cannot be altered or avoided, only faced and endured; the so called limit situations (Jaspers, 1970). These are unavoidable, *existenz*-opening situations that are impossible to escape or change, but to which we can only relate (Jaspers, 1970). The unchangeable situations, such as being diagnosed with a severe disease, differ from the usual everyday situations, which we often enter with an unreflective self (cf. Jaspers' "existence"). Limit situations, i.e. when being close to death, are life-shattering as they remind us of the boundaries of our existence. Patients with cancer are sometimes caught in these situations, and it is in these situations that surgical nurses sometimes encounter patients. According to Jaspers (1970), it is in such situations that humans' authentic self is revealed. Jaspers states that all limit situations are associated with suffering, but they can also generate inner strength. Jaspers outlines four types of reactions to suffering: resignation, escapism, heroism (being alone in suffering) and a religious-metaphysical reaction. In the last mentioned reaction, the individual suffers, just as heroes suffer, except that the individual is not alone in suffering, but is supported by a higher power (Jaspers 1970). Influenced by existential philosophy and phenomenology, Paterson and Zderad (1976) propose that existential awareness is connected to oneself and the Other, which in turn is very close to what Jaspers (1970), Kierkegaard (1844/1980), Gadamer (1960/1989), Levinas (1979/1987) and Buber (1970) call authenticity. Authenticity is an honest and true way of being and acting. Limit situations have the potential to evoke a person's authenticity. Jaspers (1970) argues that we become our authentic selves when we enter limit situations with our eyes open. Serious illness and death are examples of limit situations, when existential issues are brought to the forefront and our ontological existential limitations become visible. Even if such situations are associated with suffering, they can simultaneously generate power and constitute an opportunity to discover new values.

4. RATIONALE FOR THE THESIS

The literature review shows that there is increasing interest in existential issues in nursing research. Most of the studies regarding this area are qualitative and descriptive, focusing on patients' perspectives and identifying existential issues often facing patients with cancer, such as hopelessness, fear of death and/or meaninglessness. Furthermore, there are qualitative studies describing nurses' perceptions of existential issues. Nurses from surgical wards have only been included in a few of these studies. However, although it has been established that health care professionals, including nurses, do find existential issues difficult to handle, intervention research on how to improve handling and communication on these issues is still lacking. There are only a few international studies evaluating interventions, and those that have been found target oncologists or nurses and communication on meaning when caring for patients with cancer. No Swedish educational intervention study has been found on how to improve communication on existential issues in surgical care. This is despite the fact that surgical nurses care for severely ill and dying patients who, according to the descriptive studies, have existential issues, and that it has been clarified that many patients wish that health care professionals would address not only their medical and physical needs but also other issues related to the disease, such as existential issues. As nurses often have limited training or education on how to acknowledge and handle these issues, the way they deal with these issues differs, and consequently patients' existential issues are sometimes left unattended and neglected. To be able to support nurses in acknowledging these issues, there is a need to enhance knowledge and deepen understanding of how they experience and perceive caring situations involving existential issues. Based on this understanding, interventions can then be tested to establish how the nurses may best be supported in such situations.

The first two studies in this thesis deepen knowledge of surgical nurses' experiences of dealing with existential issues when caring for patients with cancer. The last two studies contribute to filling the gap regarding the need for intervention studies on education and training for surgical nurses about existential issues. The thesis as a whole is hoped to contribute to a deeper understanding of and broader knowledge about existential issues in the surgical care context by integrating and analysing written descriptions of critical incidents, interview data and the responses to questionnaires addressing existential issues.

5. AIMS

5.1. Overarching aim

The overall aim of this thesis was to explore surgical nurses' experiences of existential issues when caring for patients with cancer, to pilot test an educational intervention on existential issues and examine whether it may support nurses in addressing and handling existential issues when caring for these patients.

5.2. Specific aims

Specific aims were:

- I To explore, through analysis of dialogues in supervision sessions, if health care staff in surgical care discussed existential issues when caring for cancer patients.
- II To gain a deeper understanding of surgical nurses' experiences of existential care situations, through their descriptions of critical incidents.
- III To pilot test an educational intervention on existential issues and to explore surgical nurses' perceived attitudes towards caring for patients dying of cancer. Specific aims were:
 - to examine the effect of the educational intervention on nurses' perceived confidence in communication; and
 - to describe nurses' experiences and reflections on existential issues after they have participated in an educational intervention.
- IV To describe surgical nurses' perceived work-related stress in care of severely ill and dying patients after participating in an educational intervention on existential issues.

6. METHODOLOGY

6.1. Design

This thesis includes two qualitative studies (I-II) and two studies with a mixed methods design using qualitative and quantitative methods in a randomized controlled pilot study (III-IV). The pilot study was conducted in order to test, develop and refine methodology before a larger intervention was conducted (cf. Polit & Beck 2012). The mixed methods approach according to Creswell (2009) meant that the different methods were used throughout research process, i.e. in the data collection, data analysis and interpretation of results. Otherwise it would have been considered a multi-method design, where each data set is complete in itself and not blended (Teddlie & Tashakkori 2003, Creswell 2009). The concurrent use of mixed methods in studies III and IV included repeated measurements over time, triangulating qualitative and quantitative methods (Creswell 2009). Results from qualitative data from face-to-face interviews contributed to broaden and deepen understanding of the results from the small-scale quantitative data from questionnaires when participants provided nuances when asked about similar areas as in the questionnaire (Polit & Beck 2012). The use of mixed methods provided opportunity to explore and evaluate the pilot educational intervention on existential issues from different angles. An overview of the design of all studies is presented in Table 1.

Table 1. Overview of studies I-IV

Qualitative design			Mixed methods design	
	Study I	Study II	Study III	Study IV
Aim	To explore, through analysis of dialogues in supervision sessions, if health care staff in surgical care discussed existential issues when caring for cancer patients	To gain a deeper understanding of surgical nurses' experiences of existential care situations, through their descriptions of critical incidents	To pilot test an educational intervention on existential issues and to explore surgical nurses' perceived attitudes towards caring for patients dying of cancer. The aim also included examining whether the educational intervention had effects on nurses' perceived confidence in communication and to describe nurses' experiences and reflections on existential issues after participating in an educational intervention	To describe surgical nurses' perceived work-related stress in care of severely ill and dying patients with cancer after participating in an educational intervention on existential issues
Participants	Health care professionals (N=8) from three surgical wards: one physician, five nurses and two assistant nurses	Nurses (N=10) from one surgical ward	Nurses (N=42) from three surgical wards divided into an educational group (n=21), and a non-educational group (n=21)	
Methods for data collection	Previously collected material from supervision sessions (1998-1999)	Written descriptions of critical incidents and face-to-face interviews (2010)	Face-to-face interviews and questionnaires in connection to an educational intervention pilot study (2009-2010)	
Methods for data analysis	Qualitative secondary analysis	Hermeneutical analysis	Qualitative content analysis and statistical analyses	

6.2. The educational intervention on existential issues

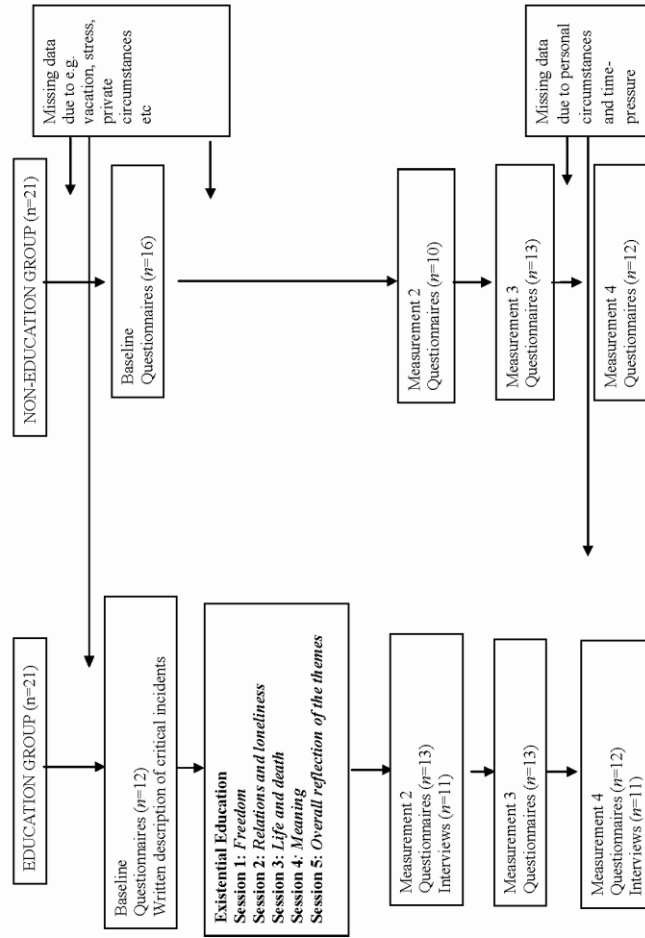
The education aims to support health care professionals' reflections on existential issues, development of strategies and enhanced self-confidence regarding communication on existential issues when caring for severely ill patients, including patients dying of cancer. Development of the education programme was collaboratively performed by a research team from two universities in Sweden. The educational intervention is based on findings from previous research (Strang et al. 2001; Hensch et al. 2007; Melin-Johansson, Axelsson & Danielson 2007; Hensch & Danielson 2009; Browall et al. 2010). In addition the theoretical framework of Yalom (1980) inspired the educational material designed for this intervention. The areas life and death, freedom, relations, loneliness, and meaning are described in the written material that was handed out to the participants. The material includes proposed discussion questions that nurses can use in dialogues with patients and their families in daily work. The education consists of five 90 minute sessions including theoretical group lectures and self-studies. Before the first session nurses were encouraged to write down a care situation in which they perceived a patient had existential questions.

Session 1: Except an introduction to existential issues the session also focused on basal communication techniques. The nurses were encouraged to capture opportunities to practise the communication techniques between sessions in their daily work in dialogues with patients regarding existential issues.

Sessions 1-4: Every session started with an introduction focusing on the existential issues of life and death, freedom, relations, loneliness, and meaning, followed by group discussions and reflections. The aim is to deepen participants' skills to deal with and discuss existential questions, and to inspire them to reflect on the usefulness of this kind of knowledge in their daily care for patients with cancer. Between every session nurses are urged to read the texts in the educational material regarding existential areas, in addition to individually reflecting on the proposed discussion questions in the given material.

Session 5: A joint reflection focusing on experiences from the education as a whole and an overall discussion of all themes.

Figure 1. Overview of the educational intervention



6.3. Setting and participants

6.3.1. Study I

This study was conducted at one of three surgical wards in a county hospital in Sweden. At the ward, care was provided for women with breast cancer. There were approximately 22 beds at the ward. All health care professionals at the surgical ward were invited to participate in the original study. In the 18 hours of supervised sessions, there was one group consisting of eight participants (one physician and seven nurses). Since a qualitative secondary analysis was used, no new participants were recruited.

6.3.2. Study II

This study was conducted at a surgical ward in another county hospital in Sweden. The hospital has almost 500 beds divided among 17 departments; the surgical ward contains 27 beds for hospitalized patients and four (used frequently) for overflow. Patients with a cancer diagnosis and/or other gastroenterological diseases were being cared for at the ward. Each month, two to four patients died on the ward. In this study, a purposive sample of 10 registered nurses and assistant nurses working at least half-time at the surgical ward were included.

6.3.3. Studies III and IV

These studies were conducted at the same hospital as in Study I where approximately 75% of the patients were admitted with a diagnosis of some form of cancer. During 2009, 122 (3%) cancer patients passed away on the three surgical wards. In all, the hospital treats approximately 370 hospitalized patients/day. The three surgical wards have a total of 66 beds (22 on each ward) for hospitalized patients treated for some kind of cancer disease, mainly breast-, prostate-, and gastro-intestinal cancer. Registered nurses and assistant nurses who had worked in the care setting (on one of the three included wards) for at least 6 months, at least half-time (50% of working hours), who had experience of caring for patients with cancer and who were interested in participating in the study, were invited. Out of a total of 115 nurses permanently employed (80 registered nurses and 35 assistant nurses) 42 nurses gave their written consent to participate in the study and were randomized into either an educational group or a non-educational group.

After randomization, the 21 nurses in the educational group consisted of nine assistant nurses and 12 registered nurses aged 24-61 (median=45) years, with 1-40 (median=8) years' experience of nursing in surgical care. This group were offered participation in the educational intervention.

The 21 nurses in the non-educational group consisted of ten assistant nurses and eleven registered nurses aged 28-61 (median=42) years and had 2-30 (median=17) years' experience of working in surgical care. This group received no education.

6.4. Selection procedures

6.4.1. Study I

In the original data collection (Ödling, Danielson & Jansson 2001), those who wanted to participate in the study wrote their name on a list in the nurses' office after approval from the director of the department. They were then contacted by telephone by one of the researchers.

6.4.2. Study II

The director of the department and health care facilitator were first contacted. After approval was obtained from the clinical director, two ward supervisors were contacted, one of whom agreed to allow the study to be carried out on the ward. The ward supervisor who declined was new in her position and proposed to wait, even though her predecessor had agreed to the study being carried out. Upon request the ward supervisor who showed an interest identified five assistant nurses and five registered nurses, of diverse age, who worked during the period for which the study was planned. The proposed participants were then contacted via e-mail before meeting in person.

6.4.3. Studies III and IV

Approval from the director of the department was given before written information was provided to all registered nurses (N=80) and assistant nurses (N=35) at the surgical wards. All were invited to participate in an information meeting. Approximately 45 nurses attended the meeting. Forty-three of them signed up to participate, but one was excluded because of her upcoming vacation as she would not have been able to participate in more than two of the education sessions. Among those who signed up, 21 were randomized to the educational group and 21 to the non-educational group. In randomization procedure SPSS 17.0 (SPSS Inc., Chicago, IL, USA) was used.

6.5. Methods of data collection

6.5.1. Group discussions in supervision sessions

In Study I supervision sessions, during which health care professionals had the opportunity to discuss difficult care situations, were recorded and transcribed verbatim in the original study (Ödling et al. 2001). Every session lasted 2 hours and were held every third week at the ward, which accommodated women with breast cancer and other surgical patients. The transcribed text from the recordings of the supervision sessions was used in a secondary analysis where the content was explored with a new aim.

6.5.2. Critical Incident Technique

In Study II Critical Incident Technique (CIT) was used. CIT is a qualitative research methodology developed by Flanagan (1954). It provides a retrospective focus on individual subjective perceptions of an incident and has been used in several nursing research studies (Kemppainen 2000; Schluter, Seaton & Chaboyer 2007; Bradbury-Jones & Tranter 2008). In line with Kemppainen (2000) the term "critical" refers to the critical or significant role of the described event. Until 1981, there was little interest in CIT, but after the study by Dachelet, Wemett, Garling, Craig-Kuhn, Kent et al. (1981), in which critical incidents was collected regarding learning among nursing students, the technique was increasingly used in nursing research. In 1992 a study by Norman, Redfern, Tomalin and Oliver (1992) was published criticizing Flanagan (1954) for being too rigid in setting criteria for valid critical incidents. Norman et al. (1992) argued that since nursing is so complex, the critical incidents do not always have to be clearly defined situations, but may also involve more general description and still retain validity for research purposes. Today, CIT has developed into a much more flexible data collection method, having evolved from direct observations to frequently being used in the interview context as well as in written collection methods (Bradbury-Jones & Tranter 2008). Various qualitative analytical methods such as grounded theory, phenomenology and hermeneutics are commonly used in analysing critical incidents (Schluter et al. 2007, Bradbury-Jones & Tranter 2008). Byrne (2001) states that a common misconception is that there are links between CIT and phenomenology, and argues that it is important to select the analytical method that is most consistent with the study aim and research question.

In this thesis, CIT was used in several different data collection methods for eliciting written descriptions and conducting interviews. In study II, nurses were asked to describe a care situation they interpreted containing existential issues. In addition, they were asked to write down their thoughts and reactions in the

situation. In the interviews that followed, nurses were asked to reflect on the incidents they had previously described.

6.5.3. Interviews

In Studies II, III and IV, research interviews were conducted using open-ended questions (Kvale 2006). To incorporate the participants' own narratives about situations, experiences and handling of the existential aspect when caring, interviews were conducted as one of several data collection methods in these studies (Tong, Sainsbury & Craig 2007). The purpose of the interviews was to let the participants' narratives, experiences and perceptions regarding existential areas to be heard. Interviews were conducted at the with the participants workplace (II-IV). All interviews lasted between 30 and 90 minutes, and were tape-recorded and transcribed verbatim. In Study II, participants were asked to reflect on the written care situations they had described in writing. In the mixed methods studies (III-IV), participants were asked to reflect on similar existential areas as covered in the questionnaires, i.e. meaning, death, freedom and loneliness. In addition they were asked about their experiences and perceptions of the education and of the intervention as a whole (including the measurements). In the interviews participants had the opportunity to further explain their perceptions and give a more nuanced answer than in the questionnaires when allowed to express themselves freely by adding or asking something not included in the questions (Creswell 2009; Polit & Beck 2012).

6.5.4. Questionnaires

In Studies III and IV, questionnaires were used. The questionnaires were found to be relevant for the purpose and design of the studies, based on previous literature on death (Neimeyer & Moore 1994) and on previous studies on existential issues with a focus on nurses (Frommelt 2003; Morita, Murata, Hirai, Tamura, Kataoka et al. 2007; Iranmanesh et al. 2008; Morita, Murata, Kishi, Miyashita, Yamaguchi et al. 2009; Iranmanesh, Axelsson, Häggström & Sävenstedt 2010). The following questionnaires were used: the 13-item Sense of Coherence (SOC-13) questionnaire (Antonovsky 1993), the Frommelt Attitude Toward Care of the Dying (FATCOD) (Frommelt 1991), the Death Attitude Profile-Revised Scale (DAP-R) (Wong, Reker & Gesser 1994), and the Attitudes Toward Caring for Patients Feeling Meaninglessness Scale (Morita et al. 2007, 2009). The participants received the questionnaires in the same order on all occasions. The questionnaires were placed in the following order: SOC-13, FATCOD, DAP-R, and the Attitudes Toward Caring for Patients Feeling Meaninglessness Scale. In this thesis, the answers to questions in the SOC-13 scale (Antonovsky 1993) and Attitudes Toward

Caring for Patients Feeling Meaninglessness Scale (Morita et al. 2007, 2009) were analysed.

The SOC-13 scale was included to investigate possible links between work-related stress when caring for patients feeling meaninglessness and the nurses' SOC. This questionnaire is divided into three scales that measure comprehensibility, manageability and meaningfulness. The original questionnaire contains 29 items and both the abridged SOC-13 and the original SOC-29 scales are used today (Feldt, Lintula, Suominen, Koskenvuo, Vahtera et al. 2007; Lindmark, Stenström, Gerdin & Hugoson 2010). The SOC scale is based on Antonovsky's theory about sense of coherence (Antonovsky 1993) and the questionnaire has been translated into at least 33 languages (Lindmark et al. 2010). Among these, it has been translated into Swedish and has been shown to have high reliability (0.88 in a test-retest study) (Langius, Bjorvell & Antonovsky 1992). Every statement in the SOC scale is graded on a 7-point Likert scale, where high scores indicate a high SOC (with some items reversed). Nurses' coping capacity was measured using the SOC-13 measuring comprehensibility, manageability and meaningfulness (Langius et al. 1992; Antonovsky 1993; Pallant & Lae 2002; Eriksson & Lindström 2005).

The questionnaire Attitudes Toward Caring for Patients Feeling Meaninglessness Scale was originally developed in Japanese, but was translated into Swedish and adapted to Swedish conditions in the run-up to this study. For this purpose, it was first translated into English by an independent translator, then translated from English into Swedish by two independent translators before a third party compared the translations and merged them into one compilation. The research team then jointly reviewed the compilation, which was then back-translated into English by an independent reviewer. The questionnaire was then tested on a number of junior and senior lecturers in health sciences. After minor adjustments the questionnaire was used in this pilot study. It has been tested for reliability and validity in Japan and is used to assess similar training programmes on existential issues for Japanese nurses (Morita et al. 2009). The questionnaire measures how confident health care professionals feel about conducting conversations with patients at the end of life. Each statement is graded on a 5, 7 or 10-point Likert scale where higher scores indicate greater willingness to help, with some items reversed. Feelings of work-related stress are also evaluated by the questionnaire (Morita et al. 2007, 2009). A validity and reliability test of this questionnaire in Swedish has been undertaken and is soon to be reported.

6.6. Methods for data analyses

6.6.1. Qualitative secondary analysis

In Study I, the analytical method was qualitative secondary analysis (Thorne 1994; Hinds, Vogel & Clarke-Steffen 1997; Polit & Beck 2012). In secondary

analysis, the material is collected for a purpose other than that governing the secondary analysis and has therefore previously been assessed in connection with a different research question. For the purpose of secondary analysis, the context of the collected material is expanded and the perspective of the analysis is different than in the original analysis (Thorne 1998). The text from the transcribed discussions in the supervisions sessions was read several times in the analysis (I) before meaning units were identified, condensed and coded. Gradually, themes emerged within two domains. During the whole analysis process, findings were discussed. In such analysis, specific ethical considerations need to be taken into account. For example, the participants have not been informed about the secondary analysis study and therefore have not given (i.e. could not give) their consent to participate. It is also important to find out as much as possible about the original data collection (Thorne 1998). Yet another way to achieve validity and reliability is by clarifying the steps taken in the analysis process and anchoring the results using quotes from the material. However, qualitative secondary analysis may be a way of giving the participants justice by letting their voices be heard when the material is being re-analysed and taken into further consideration instead of being forgotten. Finally, it is crucial that the results of the secondary analysis are not only true and faithful to the original data, but are also consistent with the initial research results (Thorne 1998).

6.6.2. Hermeneutical analysis

In Study II, hermeneutical analysis inspired by Gadamer's philosophy (1960/1989) was conducted. Gadamer's hermeneutics, influenced by Heidegger, focuses on understanding and pre-understanding which, according to Gadamer, is always based on processes of interpretation (Gadamer 1960/1989). Gadamer's hermeneutical approach is well suited for the subject and aim of Study II, as it is not merely a method for interpreting a text, but a way of understanding the world based on interpretation and on dialogue. For Heidegger (1927/1962) understanding is an "existential", i.e. something that a priori comes with being human. Similarly, Gadamer writes that humans are in constant interpretation of the world. As in the work of Heidegger (1927/1962), who renamed different aspects of being, for example *Dasein*, in order to be free from pre-understanding of words, in hermeneutics, language and dialogue also play a key role.

In Study II, Gadamer's philosophy guided the interpretation of the text, where the caring situation contained existential issues. In the first part of the analysis, the focus was on what had happened and how it had happened, before moving deeper in search for underlying meaning. There was a dialogue with the text when asking questions, for example "What is the nurse-patient relationship? What does it mean?" Gadamer (1960/1989) proposed that a text can never be completely exhausted of meaning in the sense of becoming fully understood. He stressed that

context and pre-understanding influence interpretation and argued that awareness can lead to a “fusion of horizons” that enables interpretation and thus understanding of a deeper content and meaning. When we do not immediately understand the reality in which we find ourselves, and when pre-understanding is insufficient, we interpret in the sense that we endow a particular standpoint with subjective significance (Gadamer 1960/1989). To overcome this limitation the reading continued beyond the familiar in order for new understanding to come to light (cf. Gadamer 1960/1989). Awareness of pre-understanding was increased through writing down impressions, thoughts and emotions, and discussing these with the co-authors. When the text was repeatedly read it was prompted by questions such as: How do nurses act and react in the various situations? What sort of relationships do they have with the patients? The first part of the analysis gave a primary understanding of what was described; what had happened and how. The continued reading of the text focused on the essential meaning. The constant dialogue with the text involved mobility between what was described and the underlying meaning. New questions arose, e.g. how is the relationship between nurse-patient-context? Different parts of the text expressed similar meaning in different words providing a first notion of themes, which were then discussed between all authors identifying and interpreting the final themes.

6.6.3. Qualitative content analysis

Qualitative content analysis was used in Studies III and IV to describe the nurses’ experiences and perceptions of care situations and existential issues. Content analysis is a technique that can be conducted in various ways and includes several steps, for example coding a unit of text (Krippendorff 2004). The analysis may be conducted on different levels where interpretations of a text are more abstract than the descriptive level, which is closer to what is actually said in the text. Content analysis of communication was first used by the Church when they analyzed text materials threatening their authority. However, it was first during the World War II that the concept “content analysis” was used, then in a more quantitative way of analysis of newspapers and propaganda texts (Krippendorff 2004). Berelson (1952) introduced content analysis of communication as a scientific technique and it was spread from newspaper and opinion research to include several disciplines in social sciences and health sciences. Content analysis has moved from logical positivism towards increasingly influenced by hermeneutics (Krippendorff 2004).

In studies III and IV the analysis was descriptive. The material from the repeated interviews was first compiled as one text. The first and second reading was done to gain an understanding of the text as a whole. Before the third reading the text was differentiated between the two interview occasions to explore nuances and developments over time. As categories are more mutually exclusive

(Krippendorff 2004), themes were found to be more appropriate to aims and materials. Themes are more recurrent even if they are presented in different shapes and nuances, and in different words and expressions, since they describe the same topic area. During the analysis process in Studies III and IV, there was constant discussion among the authors in order to keep close to the original text, bringing out the essential parts of the text.

The analysis of the qualitative data in Study III was supported by the areas from the quantitative data set. For example, how did nurses describe caring for severely ill and dying patients? How did they reflect on existential issues such as death? In the analysis the text was divided into meaning units which were then condensed and sorted into codes, sub-themes and themes. The analysis process involved a search for patterns regarding existential issues.

In Study IV, stress related to work was not asked about in the interviews but was an issue spontaneously described. The analysis was kept as close to the text as possible (Krippendorff 2004). The text areas that concerned work-related stress were lifted out of the compiled text and were then organized into meaning units, condensed meaning units, codes and themes. A development over time was found regarding stress and decision making, which were then combined to the results regarding stress from the quantitative data set.

6.6.4. Statistical analyses

In Studies III and IV statistical analyses were used to describe the results of the Attitudes Toward Caring for Patients Feeling Meaninglessness Scale (Morita et al., 2007, 2009), and SOC-13 scale. Data were analysed and correlation of ordinal values was done using non-parametric measures because of the small sample, and skewed data (Siegel & Castellan 1988; Pallant 2005). Changes between baseline and follow-up data within the educational group were analysed with Wilcoxon's signed-rank test (III-IV). Mann-Whitney U-test was used to analyse any differences between the educational and the non-educational groups (III-IV). Spearman's rank correlation coefficient was used to assess the relationship between nurses' SOC and perceived work-related stress (IV). All analyses were performed using SPSS, version 18.0 (SPSS Inc., Chicago; IL, USA).

The DAP-R (Wong et al.1994) was not analysed nor included in any of the studies, as it was not considered to provide any new information that had not already been covered by questions in the Attitudes Toward Caring for Patients Feeling Meaninglessness Scale and the FATCOD. The FATCOD-results have been integrated, validated and presented in an unpublished study (Henoch, Browall, Melin-Johansson, Danielson, Udo et al. 2012).

6.7. Ethical considerations

Ethical approval was granted for all studies (Regional Ethical Review Board in Umeå, reg. No. 09-058M, and Regional Ethical Review Board in Gothenburg, reg. No. 426-08 and 531-09). All participants in Studies II-IV were given oral and written information and the participants gave their written consent to participate. In Study I the informed consent was collected in the original study. Since Study I was a secondary analysis on a previously collected material, no new consent was collected from the participants. These were anonymous to the authors in Study I. The fact that no new informed consent was given from the participants implies an ethical dilemma that is important to discuss; although the participants had once given their consent, they were unaware of the new study and also of the new aim guiding the secondary analysis of their narrations. This makes the researcher's responsibility to be true to what was actually said in the interviews/dialogues even more important (if possible). In addition, it is important that the researcher should be aware and clearly state in what context the data were collected, as well as make the analysis as transparent as possible.

One of the main ethical considerations of this project is the autonomy principle. Based on this, participants were informed that they would be participating in a research study and that it was strictly confidential and voluntary. Participants were informed that throughout the entire intervention they had the option to withdraw from or refuse to participate in the study and/or the intervention. Should they decide not to complete the interview and/or the questionnaire this decision would be respected. As existential issues are often very private and intimate issues in modern Western culture, a great deal of sensitivity and respect is demanded from the researcher. In addition, the researcher needs to be aware that not all people are used to discussing issues such as death and meaninglessness, and that reflecting on these issues may awaken unexpected emotions and thoughts that are very personal. Therefore, as well as the responsibilities of a researcher, there is also a need to remember the responsibility as a fellow human and not push the participants too hard, for example demanding rich interviews or with regard to returning the questionnaires. This balance was sometimes difficult to find. In Studies II-IV participants had the opportunity to speak with a trained social worker, if the interviews and/or the educational intervention in any way should have evoked emotions of such nature that there was a need for additional support. None of the participants in any of the studies in this thesis expressed the need for further support.

7. RESULTS

The overall results from the studies in this thesis show that existential issues are present in surgical cancer care and that the nurses included in the study were exposed to these issues in their daily work. Study I, consisting of secondary analysis of group discussions in supervision sessions during one year, was undertaken at the same ward as included in Studies III and IV. Therefore the overall results provide a longitudinal perspective on how existential issues were handled and acknowledged by nurses working within a surgical care context. According to the descriptions in Study I, the participants saw patients caught in despair and feeling distress, isolation and meaninglessness, and themselves felt insecurity and lack of strategies to handle and communicate on these issues. In the pilot study (III-IV) under-taken at the same surgical wards 10 years later, nurses still expressed awareness of and difficulties in dealing with existential issues when caring for severely ill and dying patients with cancer. When nurses care for patients in limit situations on the edge between life and death, it often triggers parallel processes, such as their thoughts of life and death, meaning, suffering, powerlessness and stress (I-IV). The nurses described being challenged emotionally. Consequently, they experienced the encounter with patients' existential issues on both a professional and a personal level (II). The results in this thesis are presented below under the following subheadings; "Components obstructing or supporting nurses in acknowledging patients' existential issues" and "Increased awareness and confidence when encountering patients with existential issues".

7.1. Components obstructing or supporting nurses in acknowledging patients' existential issues

7.1.1. Medical-oriented care hindering existential dialogues

According to nurses' descriptions they had various focus when caring (II). Some nurses had a more strict focus on the medical issues that had brought patients to the hospital, and did not include issues such as the patient's emotional and/or existential reactions (I-It dialogues). They did not see it as their responsibility to address existential issues. They explained that they sometimes found patients' sorrow just too hard to handle and that they consequently ignored it. Furthermore, they described that the patients probably had their existential reactions at home, and not in hospital (II). In Study I, however, the nurses described that unrecognized distress and feelings of abandonment increased patients' existential distress and loneliness. When existential questions were expressed by patients in the ward, nurses often referred these to others, mainly the physician, interpreting questions on death as physical medical questions (II). Some

nurses expressed that their fear of death was sometimes awakened by caring for dying patients. They suspected that this might contribute to their own feelings of discomfort when discussing death (II-III). In addition, they were sometimes intimidated by not knowing how they themselves or the patients would react to such discussions (II).

7.1.2. Lack of strategies

Nurses described lack of strategies and uncertainty as to how to address existential issues. This contributed to neglecting to address patients' existential issues (I-II). As a consequence, many nurses felt they did not provide the care they wanted to. According to descriptions in Study II, nurses who put more emphasis on medical caring (with I-It dialogues), but who were striving towards patient-centred caring (with I-Thou dialogues), described that they were hindered by their uncertainty and fear of saying or doing the "wrong" things. This made them neglect discussion of issues such as existential, since they were afraid that a dialogue might increase the patients' despair and hopelessness (I-II). The participants' descriptions show that the nurses were often aware of patients' questions and cues on dying and death, but sometimes saw these as equivalent to hopelessness. In addition, nurses experienced difficulties in finding a balance between closeness to and distance from the patients, meaning that their fear of becoming too attached to a patient sometimes led to keeping a distance between themselves and the patient they were caring for. As a consequence nurses sometimes left patients with existential issues unattended; alternatively, sometimes the nurses stayed with the patient, but changed the subject (I-II).

7.1.3. Work environmental and organizational constraints

Nurses' described their work as being performed under time pressure, with many patients to attend to (IV). It was described as especially stressful when there were many severely ill and dying patients on the ward, who, according to the participants, needed special encounters and demanded more time (I-II, IV). Time pressure was described by nurses as hindering high quality, flexible caring and unique encounters (II, IV). The limited time often made it difficult for nurses to stay on for a few minutes with a patient, which contributed to feelings of insufficiency and guilt at leaving patients alone when the nurses felt they should not be leaving them (IV). Another external factor that contributed to a more distanced caring was patient clothing (I). When nurses saw patients in their own clothes (e.g. in a personal dressing gown) instead of hospital clothes, their views shifted from seeing a patient to seeing a person. Patients became individuals in the

eyes of the nurse when wearing their own clothes, which was described as facilitating a more personal encounter (II).

7.1.4. Reflection and valuable support from colleagues in caring

Reflection and collegial support was described as having an important impact on nurses' caring (II). Study I show that joint reflection in supervision sessions revealed different ways of caring and also brought about an awareness among nurses that they were affected by the situation. Reflection in supervision sessions contributed to nurses becoming more aware of their own reactions to a patient's life situation and of their perceived dilemmas when caring for severely ill patients with cancer (I). Individual reflection and inner dialogues deepened nurses' awareness and broadened their perspective of caring, which contributed to their perception of their work as meaningful (II). According to results in Study II, nurses' inner reflective dialogues also contributed to openness to a patient's uniqueness. Reflecting on both the patient's situation and on their own emotional reactions it enabled genuine and authentic dialogues with patients (II). Sharing experiences and deliberating with colleagues was crucial for nurses' inner dialogue, which in turn supported their handling of difficult caring situations and contributed to feelings of meaningfulness. One was the care provided for a young mother at the end of life. With support from colleagues, the nurse was able to invite the patient's family and small children to participate in the caring process; the support also facilitated dialogue with the family in the demanding and challenging situation (II).

7.2. Increased awareness and confidence when encountering patients with existential issues

7.2.1. The process of nurses' caring

Directly after the educational pilot study on existential issues, there were significant changes in attitudes towards caring for patients with cancer regarding enhanced efforts to find out how to best assist the patient, to understand the patient's pain and to understand what the patient thinks is important in life (III). These aims of using increased effort to understand the patient were repeated in the nurses' descriptions in the interviews, where they expressed enhanced understanding for the patients' situation in addition to increased awareness on existential issues. For example, all nurses described that they had first interpreted the concept "existential" as mainly concerning death. After the educational intervention, they came to think of the concept in a broader sense, to include also other issues, such as meaning, freedom and loneliness regarding both the patients

and themselves. When nurses reflected on freedom and loneliness in the interviews, they described these from a practical and physical perspective, for example patients' limits to physical freedom. They described that seeing patients' limited freedom influenced them to reflect on their own freedom, which was great by comparison. For instance, they were able to bicycle to and from work. Their reflections on their own freedom made them think about how this situation could suddenly change (III). These kinds of thoughts triggered their gratitude, but they also triggered a fear of a sudden and uncontrollable change. At the same time, the nurses described feelings of guilt at being able to choose so many things in life, unlike their patients.

Long-term changes that were found in Study III concerned a decrease in nurses' anxiety from thinking about their own death, an increased effort to understand the patient's perceived meaning, an increased willingness to take action to relieve the patient's pain. Results in study IV indicated decreased feelings of work-related stress as well as decreased stress associated with work-load. However, in the same study nurses also reported increased temporary feelings of exhaustion in the third measurement. Although in the quantitative data set, the nurses reported decreased anxiety from thinking about their own death, descriptions in the interviews showed that thoughts and fear of death were often triggered when caring for dying patients. Fear of death was described to influence how they acted in caring situations, where personal experiences from meeting dying persons or the lack of having done so made them more, or less, comfortable. Nurses explained that feeling uncomfortable from thinking about death sometimes led to avoidance of a dying patient. They said those who were more used to dealing with issues such as death and meaninglessness, were also more likely to acknowledge and discuss patients' existential issues, while others found it very difficult to enter this type of existential landscape along with the patient. When the experience was new and unfamiliar to them it contributed to their insecurity. The nurses expressed that they were not only professionally but also personally affected by caring for patients with cancer. Their own powerlessness, helplessness and fear of death as well as perceived dilemmas were sometimes triggered by seeing patients' vulnerability, and by physical, social, emotional and existential exposure (III). In the long term, nurses reported feeling less disappointed at work (IV). Increased feelings of optimism for the future were also indicated (III).

Long-lasting results (i.e. significant changes in more than one measurement) after the educational intervention indicated increased effort to understand the patient's needs in addition to increased feelings of value when caring for a dying patient (III).

7.2.2. The process of nurses' communication

In the short term, nurses reported decreased feelings of wishing to escape the situation when a patient in the last stage of life expressed they had no reason to live (III).

In the same study results indicated long-lasting significant changes in attitudes regarding communication with patients. These results were supported by their descriptions in the interviews. Long-lasting results regarding communication (excluding the results showing significance already at baseline) indicated increased confidence and decreased powerlessness regarding communication. The nurses also reported feeling less uncomfortable when talking to a patient about the impending death and feeling increased gratitude for being told. These quantitative indications were supported by the nurses' descriptions in the interviews. They described they were more confident to listen to patients' talk about existential issues and therefore they were more open and sensitive to what was expressed in the caring situation. The educational intervention was described to have contributed to a unified language which facilitated communication about existential issues with both colleagues and patients (III). However, although a new and shared vocabulary was gained from the education sessions which facilitated collegial support, the nurses explained in the interviews that time pressure was still preventing them from being flexible and from applying this unified language in discussions with colleagues (or patients) during the day (IV).

7.2.3. The process of nurses' reflections

In the interviews the nurses related that reflecting together with colleagues in the education sessions not only deepened their understanding of the patients' situations, but also inspired them to develop new caring strategies. The nurses described the education as an opportunity to develop the habit of reflecting on dilemmas and difficult care situations, which often contained existential issues and/or ethical dilemmas. With regard to discussing experiences and caring, in relation to existential philosophy and psychology, with a group leader, the nurses described this stimulated their individual reflection also when caring (III). To be able to discuss challenging situations with fellow colleagues during the day, in a coffee or lunch break, was important in providing the energy to continue to the next patient without feeling drained (III-IV). However, this was often hindered by external constraints such as time limitations and large patient volume. Despite these external constraints, in the interviews 6 months after the educational intervention the nurses related how discussions with colleagues during the educational sessions had inspired them to make more personal decisions, based on their own caring intentions and more in line with what they perceived to be the patients' needs (IV).

In the interviews, reflecting on loneliness the nurses described it as a lack of friends and family, but also as feelings of being totally alone in a severe situation despite many people around. Especially when a patient's thoughts and emotions were not acknowledged, the nurses saw how this added to the patient's deep loneliness (III). They felt urged to stay with the patient during these moments of utter and groundless isolation, but when restricted by external constraints they ended up facing difficult dilemmas (IV). On the other hand, when nurses did stay on with the patient, they experienced feelings of satisfaction at having been able to help and support the patient (III-IV).

Nurses described that their personal view of life and relationships was affected by caring situations, especially after the educational intervention. For example, seeing a patient in conflict with their loved ones at the end of life made them try to avoid unresolved arguments at home with their own family. They also tried to live more in the moment when reminded, through patients' situations, how life can suddenly change. As a consequence, many nurses expressed a wish to be a step ahead in their personal lives and discuss arrangements with their loved ones, in case of sickness or death (III).

8. DISCUSSION

The overall aim of this thesis was to explore surgical nurses' experiences of existential issues when caring for patients with cancer and to pilot test an educational intervention on existential issues to examine whether it might support nurses in addressing and handling patients' existential issues. The longitudinal perspective provided by Studies I, III and IV reveals that little has changed about how surgical nurses deal with existential issues when caring for severely ill and dying patients with cancer: the secondary analysis in Study I show nurses difficulties in encountering patients' existential issues, which were due to feeling insecure in communication on existential issues, lacking strategies and working under high time pressure. The same difficulties were described ten years later in Studies III and IV.

All studies in this thesis show that existential issues are present when working in surgical care and that these issues are understood and handled differently by nurses, affecting them at both a personal and a professional level. In all the studies in this thesis, and especially in Studies II and III, it was noticeable how closely related nurses' understanding, focus and personal attitudes were to their ways of caring and communicating.

Modest significant changes were reported in the pilot study after the educational intervention, which indicate that the education primarily seemed to influence confidence in communication, with the nurses feeling less uncomfortable and less powerless when talking to a patient about their impending death (III). Since the non-educational group reported similar improvements this pose questions about spill-over effects. However, as existential issues are highly complex and relate to both personal and professional levels, it is difficult to know exactly what and how existential experiences and attitudes are affected for each individual. For example, in the items relating to understanding the patient's needs and trying to understand what is important to the patient, the (modest) inter-group differences were due to deterioration in the non-educational group rather than to improvements in the educational group. In other items where significant differences were found, such as wanting to escape the situation, feeling grateful for being told by a patient about their existential needs, willingness to help, less anxiety from thoughts of death, and ability to find a life goal and mission, differences were reported already at baseline (III).

Main results of this thesis are interpreted as a whole and discussed under the following sub-headings: "Cure orientation in a care situation", "Affirming life when caring for patients dying of cancer", "The responsibility to communicate on existential issues or the freedom not to", and "Humanistic nursing in surgical cancer care".

8.1. Cure orientation in a care situation

The cure-oriented work environment and medical focus on surgical wards are of course appropriate and useful as the intention is to help and cure patients as much as possible. However, sometimes cure is not possible, and instead palliative treatment is given. When the emphasis of the cancer treatment is almost entirely on the physical-medical perspective, to the exclusion of other issues likewise affecting the patient's well-being and quality of life, there is a risk to obstructing caring encounters and preventing authentic dialogues (cf. Buber 1970) (II).

These results are similar to Berg and Danielson's (2007) findings, which suggest that attitudes of openness and awareness are needed from the nurse if he or she wants to achieve comprehensive care and caring relationships. This is especially so when caring for patients with cancer who often strive for an interpersonal respectful relationship with the nurse (Nåden & Saeteren 2006). This kind of striving and reaching out in limit situations (cf. Jaspers 1970), is also described in this thesis. In Study I, health care staff in supervision sessions discuss how they are aware that patients sometimes reach out for support, for example when expressing that their existential loneliness is driving them to thoughts of suicide. Yalom (1980) states that although existential loneliness cannot be eliminated it can be alleviated, for example by being confirmed by a fellow human. It is therefore important to support nurses' courage and confidence to do so. Rchaidia, Dierckx De Casterlé, De Blaeser and Gastmans (2009) show in their review on cancer patients' perceptions of a good nurse that regardless of culture they wish for a caring relationship with the nurse.

Studies I-IV in this thesis show that the surgical care context (a medical-oriented care context) often hinders comprehensive caring relationships since nurses often lack time and strategies to communicate with the patient on existential issues, and are on constant call to the next patient. In addition, Study IV reveals that not being able to fulfil caring intentions contributes to further stress for nurses. Berg, Skott and Danielson (2007) report that continuous interruptions in a hectic context prevent caring relationships, which may in turn make it more difficult for the patient to uphold their dignity. Study IV shows that when nurses are aware that their work-related stress may have consequences also for the patients this further contributes to draining them of energy. This may contribute to their moral stress, consisting of feelings of not doing what is ethically appropriate when neglecting the patient's unique needs (Lützén, Cronqvist, Magnusson & Andersson 2003; Kälve mark, Höglund, Hansson, Westerholm & Arnetz 2004). In terms of existential philosophy, the feelings of not acting according to human responsibility may lead to feelings of guilt (Kierkegaard 1844/1980; Jaspers 1970). Furthermore, Berg et al. (2007) suggest that to support the patient's search for meaning and prevent suffering, nurses' engagement is needed in addition to a will to be

involved. Study II adds the knowledge that for nurses to attain engagement there is a need to understand the uniqueness of the patient's situation. In addition, Study IV highlights the need for nurses to mobilize courage to make caring decisions that are in line with what they perceive as patients' individual needs, despite contextual hindering factors.

Caring for vulnerable patients in surgical care is complex. This is illuminated in all the studies (I-IV). When a nurse considers her or himself in "the fast lane" this imply insufficient support and training regarding existential issues. Consequently, nurses are left to their own devices regarding these often challenging issues. Ödling et al. (2001) described how caring for severely ill patients and dying patients with cancer involves difficult caring situations which often evoke feelings of powerlessness and reduced self-esteem. Study IV shows that because of the time pressure these nurses work under, they have no time for deeper discussions about difficult caring situations with their colleagues. Not being able to "let go of" a difficult caring situation before moving on to the next adds to further stress, as reported in Study IV. That caring for a dying patient is emotionally demanding for nurses was a prominent topic in descriptions in Studies I and IV, and it is not difficult to understand that this also affects nurses emotionally and increases their stress at different levels.

8.2. Affirming life when caring for patients dying of cancer

The results of nurses' different understanding and focus when caring, i.e. that some nurses' had a strict focus on physical medical issues in caring and communication while some nurses included also emotional and/or existential issues in caring (II-III), are in line with Paterson and Zderad's humanistic nursing theory, which highlights that nurses' individual experiences in life contribute to their knowledge and ways of caring (Paterson & Zderad 1976; McCamant 2006). Descriptions in Study III show that to connect theory about existential issues with experiences from real life and reflecting together with colleagues is important.

There is also a need to reflect on the content in the education sessions both individually and together with colleagues in order for the information to be integrated in caring and communication (III-IV). It has been shown in previous studies that reflection is useful in relating theories to actual care situations and asking oneself how they have affected the interaction (Nussbaum 2001; Horton-Deutsch & Sherwood 2008). Similarly, Eriksson (1992) describes that real caring is not just an abstract idea or philosophy, but does involve real encounters and real suffering.

To enable us to help a person and alleviate suffering, we need to try to get into that person's unique position (Kierkegaard 1844/1980). Nurses have to be prepared for this so they may encounter suffering patients' in practice and not be taken by

surprise. If challenging and difficult caring situations are continuously discussed and reflected upon, this may contribute to integrating phronesis-based knowledge with episteme-based knowledge, contributing to nurses' deeper understanding, which according to the results of this thesis, can affect communication and ways of caring. Connecting theories to practice supports nurses' emotional knowing (James et al. 2010), which is especially valuable when caring for severely ill and dying patients as it enables the nurses to affirm the patients' vulnerability, as well as their hope and quality of life, when near death (Melin-Johansson, Ödling, Axelsson & Danielson 2009; Wu & Volker 2009; James et al. 2010). According to nurses' descriptions, reflections on caring situations from an existential philosophy perspective contribute to develop understanding and, therefore the courage to be present with patients forced to face limit situations (III-IV). Studies II and III show that nurses who are more familiar with the often challenging issues of death and meaninglessness are less threatened by communicating on existential issues in caring situations and consequently more often affirm life in situations that concern dying.

The educational intervention (III-IV) was described by nurses as alleviating their self-expectation of having to provide "the right" answers to patients' existential questions. Instead they had realized that being present and listening was enough. The increased confidence in communication with dying patients and the decreased powerlessness in communication that followed the educational intervention (III) are in line with the results presented by Morita et al. (2009) in a quantitative study regarding nurses' increased confidence, post-intervention, in communicating with patients feeling meaninglessness. It became apparent that when the more experienced nurses shared their thoughts with nurses who were less experienced and familiar with existential issues, collegial support enhanced through joint reflection, seemed to support the nurses' confidence in communication when dealing with patients' problems (III-IV). These mixed methods results suggest that if previous experiences are reflected upon and, further, if attitudes derived from them are brought to awareness, this may guide caring instead of allowing the attitudes to affect caring behaviours without any control over this process.

One common attitude among nurses that appeared in all studies in this thesis was that their thoughts that cancer and death are closely related. This was also found by Lee & Loiselle (2012) who showed how deeply rooted it is in people's beliefs that cancer means death, even though survival in cancer is increasing. Again, this implies that to be able to care for severely ill and dying patients, nurses need to be aware of attitudes towards death so that successful caring encounters can be achieved, instead of hindered by nurses' fear of cancer and death.

The need for nurses to meet and reflect with colleagues is also highlighted by Fillion et al. (2009). They formed a meaning-centred intervention with reflection for palliative care nurses which is described to have the potential to provide insight

into nurses' own personal reactions and emotions associated with the care and fate of patients. If promotion of health from a holistic perspective is the goal, it is important for the nurse to be supported in seeing the patient as a whole person with unique needs, and to be supported in acknowledging the complexity of human issues. Results in Studies III and IV indicate that an educational intervention focusing on existential issues may contribute to support this perspective on patients. The modest results (III-IV) suggest that to facilitate nurses' efforts to affirm life when caring for dying patients, there is a need to provide opportunities for nurses to reflect on existential issues, so that self-awareness and enhanced knowledge, may contribute to increased understanding of the patient's unique life-situation, which in turn can contribute to increased confidence and enhanced caring strategies.

8.3. The responsibility to communicate on existential issues or the freedom not to

Existential philosophical perspectives are valuable and very useful when discussing nurses' responsibility to act and their freedom to choose not to acknowledge patients' expressions of existential needs. For example, nurses in Study II sometimes moved towards a broader and deeper communication in caring in I-Thou relationships, trying to move away from the more strict physical medical focus in communication in I-It relationships (Buber 1970) despite being in a context where the focus is strictly medical. In a study by Jangland et al. (2011), it was described that nurses sometimes have a patient-centred focus and sometimes provide more task-focused caring. Study II is in line with above mentioned study that reports how nurses' caring intentions can differ. Study II shows that nurses with main emphasis on I-It relationships (cf. Jangland et al.'s task-focused approach) often neglect to acknowledge patients' existential needs, while nurses who try to accomplish I-Thou relationships (cf. Jangland et al.'s patient-centred caring) include these in communication. As nurse-patient relationships are hierarchal (Schuster 2006) the responsibility regarding communication rests more heavy on the nurse, as a professional, than on the patient.

In all the studies of this thesis, it became apparent that caring for patients' in limit situations also affect the nurses, sometimes causing inner struggles also for the caring nurse when there were parallels between patients' existential crises and nurses' inner reactions (I). When feeling emotionally affected, nurses also expressed a wish for a common philosophy on the ward regarding how to deal with issues such as patients' existential needs (II). This is understandable and relevant. Kierkegaard (1843/2002) argued that as humans we are free to choose in a deeper sense, i.e. our choices reveal what is meaningful, and in the most difficult and challenging choices, humans often desire for a doctrine or a policy which will

help them make a choice. According to Kierkegaard (1843/2002) accepting a policy without reflection may be a way to try to avoid making the ethical choice and taking responsibility. Applied to nurses' caring, as discussed in the present thesis, Kierkegaard's argument would mean that the ways of caring in limit situations do show who the nurses are and what they perceive as meaningful and valuable. In addition, as professionals, our choice of caring is also based on an ontological view of the human being. In other words, although nurses act in their professional capacity, the nurse-patient encounter is still primarily a human encounter.

When interpreting surgical nurses' caring in the light of Kierkegaard's (1844/1980) and also of Jaspers' (1970) philosophies, it seems that when caring for a patient exposed to a limit situation this may lead to confronting the awareness of the possibility of nothingness (cf. Heidegger 1927/1962). Some of the nurses in Study II wanted to avoid this inner turmoil triggered by being present in a limit situation. However, according to both Kierkegaard (1844/1980) and Jaspers (1970), in order to live life authentically and genuinely, situations like these must be faced instead of avoided. Jaspers (1970), (influenced by Kierkegaard among others), states that anxiety is involved in all limit situations, which implies, that, in relation to the present thesis, nurses are often exposed to anxiety (*angst*) when caring for dying patients.

In Study I, patients' anguish was often witnessed by the nurses and described by them as a despair which was derived from utter and unacknowledged existential loneliness when their lived body was threatened by a severe illness (cf. Merleau-Ponty 1945/1962). When nurses empathize with patients' uniqueness by acknowledging the patients' individual issues, unnecessary anxiety and distress can be avoided for the patient (Jangland, Gunningberg & Carlsson 2009; Lelorain, Brédart, Dolbeault & Sultan 2012). If limit situations are possible "existenz-openers", as Jaspers (1970) asserted, these kinds of caring situations also have the potential to bring about a more authentic caring from nurses if the situations are genuinely faced instead of avoided. Nurses' feelings of guilt at not providing the intended care (IV), which prompted them to strive to find the right path in caring (II), suggest that they do feel responsible for achieving a genuine encounter with the patient. Feelings of guilt among nurses have also previously been described in a study by Noble and Jones (2010) who report nurses' trying to address oncology patients' spiritual needs, but feeling insecure and finding it difficult. Surgical nurses' self-doubt regarding having done enough for a patient, reflected in their descriptions of helplessness and fear of death in Study II, have previously also been highlighted by Torjuul, Elstad and Soerlie (2007), along with feelings of responsibility as contributing to ethical dilemmas. Based on results (I-II) in the present thesis, there seems to be an urgent need to discuss nurses' responsibility to address patients' existential issues in relation to how much freedom they have in choosing not to. This is especially important when knowing that ignoring patients' existential cues and questions might convey the message that existential issues are

not normal, and that if ignored these questions and cues may lead to existential distress (Blinderman & Cherny 2005). In addition, Studies I and II show that even though nurses do not always address patients' existential issues, they are often affected personally when caring for severely ill and dying patients, for example through awakened fear of death.

In Studies III and IV, descriptions show that despite the high tempo and time pressure of the surgical ward, nurses often feel responsible to communicate on existential issues and wish to provide high quality care based on individual needs. If nurses are given opportunity to do so it may contribute to reduce their work-related stress. Consequently, this ought to be supported.

Although all studies in the present thesis reveal that it is often personally challenging for nurses to respond to patients' existential cues and questions, according to many existential philosophers, including Buber (1970), and Paterson & Zderad (1976), it is not possible to achieve a meaningful dialogue other than by responding to the patient's needs in this regard. Levinas (1979/1987) likewise stresses the importance of having a genuine dialogue with *the Other* and adds that the most basic unavoidable ethical responsibility of human beings is to respond to the Other.

8.4. Humanistic nursing in surgical cancer care

Based on all the studies in this thesis, there seems to be a need, and a desire among nurses to respond to the uniqueness in every patient's life situation in favour of giving solely routine-based caring. As nurses' ways of caring affect patients' satisfaction (Palese, Tornietto, Suhonen, Efstathiou, Tsangari et al. 2011), it is important for nurses to establish a caring that is balancing between patients' needs, possibilities within the organizational structure, and personal caring intentions. Especially Study IV reveals that nurses' openness can either be facilitated or obstructed by the hospital context. Similar to the present thesis, Rudolfsson, Von Post and Eriksson (2007) highlight the need for increased humanistic caring in the peri-operative context to achieve alleviation of the patient's suffering.

The nurses described the surgical context as highly stressful, hindering them from providing the intended caring, especially regarding the most severely ill patients (IV). These results are not new since the hospital environment has previously been found obstructive to caring (Mohan, Wilkes, Ogunsiji & Walker 2005; Su, Boore, Jenkins, Liu & Yang 2009). This highlights the need for directors of the department and supervisors at the wards to consider how to support nurses' caring so that strategies can be developed, nurses' stress might be decreased and patients may feel more acknowledged. That hospital managers have the possibility to decrease nurses' work-related stress by supporting increased communication skills, has also been suggested by Sveinsdóttir, Biering and Ramel (2006). In the

current thesis, the nurses expressed that they lacked a common philosophy regarding how to handle existential issues (I-III). In addition, they often felt they lacked the time to encounter patients as they wished (IV).

The expressed need of surgical nurses for support from their superiors has previously been highlighted by Torjuul and Soerlie (2006). Corner's findings (2002), that supportive settings and time to reflect with colleagues decrease stress, are in line with the results in the present thesis emphasizing the need for work environmental and organizational support. However, as caring is a process with no fixed answers, there is a need for continuous reflective discussions, in addition to education and training, to inspire the development of a common philosophy and skills to be able to provide high quality care. To address the uniquely personal and intimate issues that often constitute existential issues need to be flexible (III-IV). Moreover, care should be patient-centred and constitute of meaningful encounters with I-Thou dialogues (II), instead of being generalized and objectified and containing I-It dialogues (Buber 1970). In fact, according to nurses' descriptions in Studies I-IV, the quality of nursing would benefit from existential issues being dealt with already in nursing education, so that nurses can be prepared for the issues they will be exposed to when caring for severely ill and dying patients.

Responsibility for quality nurse-patient encounters also rests heavily on the nurse leaders, as suggested in Study IV and argued by Rudolfsson et al. (2007). Based on the overall results in the present thesis, it would be valuable to have discussions in surgical context about how to integrate humanistic caring into the clinical/medical context of surgical care.

9. METHODOLOGICAL CONSIDERATIONS

In this thesis qualitative and quantitative methods were used to explore nurses' experiences of existential issues in surgical care from different angles, with emphasis on the qualitative data. In Study II, triangulation of methods was used when collecting written descriptions as well as conducting interviews with a focus on care situations containing existential issues. In the mixed methods studies (III-IV), triangulation methodology was used when including qualitative and quantitative methods. Below, methodological considerations in relation to the different designs and perspectives are outlined.

9.1. Rationale for conducting a pilot study

The pilot study was needed before a larger intervention and was meaningful and of value considering both positive and negative aspects. Burns and Grove (2005) propose that even "failed" pilot interventions are important because they provide insights on what needs to be adjusted, for example when revealing unanticipated effects. There is no set number of participants needed for a pilot study (Nieswiadomy, 2011). However, the sample should be large enough to reveal possible weaknesses in the planned design and methodology (Burns & Grove 2005). Treece and Treece (1986) recommend that a pilot study should include one-tenth of the size of the proposed intervention. The participants in the pilot study in this thesis came from a similar population as those who will participate in the larger intervention project. In addition the usability of all measurements methods was tested on a small scale. Through the pilot study it was also possible to evaluate how much time is needed to complete the questionnaires and whether instructions were clear, and to consider other feedback and comments from the participants regarding the questionnaires. In the interviews, participants were given the opportunity to comment, not only on the questionnaires and the education, but also on the intervention as a whole.

9.2. Validity and reliability

In the pilot study (III-IV), the return rate of the questionnaires was lower than expected and there were drop-outs from both the educational group and the non-educational group. Missing data are a common problem for many researchers, especially in longitudinal studies (Palmer & Royall 2010). The impact of the missing data had to be taken into account when discussing results not only do missing data bias results and limit power but they also reduce generalizability (Hardy, Allore & Studenski 2009; Wang, Hall & Kim 2012). The missing data were discussed with the participants as well as the research team, as they constituted a

threat to both internal and external validity, as well as the overall trustworthiness of the studies (Ulmer, Robinaugh, Friedberg, Lipsitz & Natarajan 2008; Hardy et al. 2009). However, this was a pilot study and since educational interventions studies are still few in surgical care, it is important to test and conduct these kinds of studies within clinical settings despite methodological threats.

There were several possible reasons for the attrition rate in the quantitative measurements in the pilot study (III-IV). For one, during the measurement period a policy change was carried out regarding co-determination with regard to nurses' vacations and working-schedule, including a debate on salaries, for nurses and their organization. This situation naturally stirred up strong feelings among the nurses and drained considerable energy from the study participants. Another reason may be the fact that the non-educational group and the educational group came from the same ward with risk for spill-over effects. If randomization was between wards instead of individuals such risks would probably be diminished and more control on the non-educational group might have been possible. However, if significant changes were found, it might then be explained by the fact that it was something differing between the wards. The high attrition rate may also depend on the very nature of the subject: Existential issues that concern death and meaninglessness are delicate issues, which may stir up deep and sometimes repressed feelings, thoughts and attitudes. The non-educational group, who did not receive training in how to reflect upon and thus address these issues, may have experienced feelings of discomfort. Also, there might be a possibility that at surgical wards there is normally a heavy focus on the technical, medical and surgical issues where there is sometimes little habit to also include the emotional, existential and ethical sides of the patients' situation of on-going treatments and surgery. Finally, "risks" are always associated with research involving interventional studies conducted in a clinical setting, but the fear for an unsuccessful study must not stop the interventions research in real clinical settings. Although surprises may be avoided through good planning and trying to anticipate events, this is not always possible. People and organizations are often in process and it is not always possible to predict all reactions and behaviours (and if everything was predicable there would be less need for research studies).

Regarding the statistical data, the decision was taken to treat ordinal level measurement in the questionnaires as interval-level data (Crocker & Algina 2008). Distances between levels were treated as numerically equal distances which facilitated descriptions and comparisons. This is also how the questionnaires were handled previously by researchers (Morita et al. 2007, 2009; Hensch et al. 2007). Although aware of the troublesome fact that psychologically, distances between levels on a Likert scale are never exactly the same, presenting data numerically does provide indications. In addition, the qualitative data from the interviews provide further information, since the interviews gave the same participants opportunity to add further nuances and descriptions. The tendencies found in the

sample in the pilot study have been thoroughly and honestly described with the aim to be understandable, keep the data and process as transparent as possible, and not disconnect the indicated results (Mays & Pope 2000; Munhall 2001).

No power calculation was made as this was a pilot study (III-IV) which represented a first step in testing the education content and design. Power calculations have been carried out for the larger intervention and the power analysis has shown that with a significance level of 0.05 and a power of 0.80, a total of 120 participants (60 in the educational group and 60 in the non-educational group) should be included in a larger intervention.

Because of the problems, described in Studies III and IV, of conducting the pilot educational intervention, the question has to be asked to what extent conclusions can be legitimately drawn from the way the study was constructed including the overall settings, intervention and validity of the questionnaires, i.e. the content validity (cf. Polit & Beck 2012). The SOC-13 was the only questionnaire of the four questionnaires included, that had been tested and whose validity and reliability had been proved in Swedish conditions before the educational intervention. All questionnaires used in this thesis have been tested in their original languages and contexts. A face validity test was conducted on all questionnaires before using them in this intervention study (Polit & Beck 2012): six junior and senior lecturers (all RNs), teaching the Health Care Sciences, evaluated the questionnaires. However, construct validity in the Swedish context had not been conducted before the pilot study. Using the questionnaires in Studies III and IV may be considered as a starting point in the process of validity and reliability testing them in Swedish conditions. The questionnaires Attitudes Toward Caring for Patients Feeling Meaninglessness Scale and FATCOD have now been reliability and validity-tested in the Swedish context in research soon to be reported.

One strength in the pilot study was that the whole design of the educational intervention was tested. In addition, there was a use of mixed methods, constituting different data collection methods at several qualitative and quantitative follow-ups, up to 6 months after the educational intervention. These different angles provided a broad perspective of the pilot study.

9.3. Trustworthiness

In qualitative studies it is of utmost importance that all steps in the analysis process are based on what is said in the interviews and that findings really are derived from the original data (Polit & Beck 2012). Trustworthiness cannot be achieved by starting to reflect on it in the end of the research process. Therefore the whole process of this thesis, not only during the analysis process, was permeated with reflection. In this thesis confirmability of findings was achieved through continuous discussion of the data among the authors. Pre-understanding was discussed as much as possible in order to avoid bias. Dependability of the

interviews in Studies III and IV was achieved by repeated interviews with the same participants, who also answered the questionnaires. Credibility is one of the main aspects of trustworthiness (Polit & Beck 2012). In this thesis, credibility was maintained by the rigorous and transparent analysis of the qualitative data, going back and forth between different steps of an analysis, for example when checking codes and themes against what was expressed in the meaning units. Member checking was performed when participants read their written descriptions of critical incidents at the beginning of the interviews (Polit & Beck 2012). This increased reliability of the qualitative data.

Although the purpose is not to generalize, transferability of the results in the qualitative studies (I-II) may be applicable to other settings than surgical since nurses are likely to encounter patients with existential issues in different settings. However, it is up to the reader to evaluate if the results are useful also in their context (cf. Polit & Beck 2012).

10. CONCLUSIONS

This thesis contributes to increased knowledge regarding existential issues in surgical cancer care from the perspective of health care professionals, mainly nurses. Although nurses' responsibility in caring is discussed from an existential inter-relational perspective, the responsibility to enable a supportive work environment are multi-faceted. Responsibility for quality caring naturally rests heavily on the organizational structure and the quality of caring is often determined by political considerations.

Nurses who are able to handle their personal fears of death and their insecurity in communication on existential issues may manage to forge encounters with patients and be able to recognize them as unique individuals. When nurses reflect on caring situations they attain deeper encounters with patients and they become receptive of patients' existential expressions.

Despite modest results from the pilot study, it indicates that understanding the patients' situations derives from enhanced awareness and increased reflection, and precedes increased ability in communication. When feeling confident in how to encounter and communicate with patients, nurses may also feel less stressed. In addition, nurses increased understanding of existential issues will most likely contribute to improved psycho-social well-being for patients with cancer in hospital. Although the small-scale pilot intervention study presented in this thesis indicates positive results, to be solid and reliable it must be tested on a larger scale. However, this thesis shows the value of performing a pilot study before conducting an intervention large scale.

11. IMPLICATIONS AND RECOMMENDATIONS FOR FURTHER RESEARCH

Surgical nurses' experiences of external restrictions in caring is extremely important to consider when discussing how to support nurses to encounter and communicate with patients in a highly economically pressured organisation, demanding nurses to run faster. Is care still effective when patient numbers keep increasing and patients have ever shorter hospital stays? What is the human cost in a high-pressured organization? The priorities in healthcare need to be discussed in relation to the intentions not only by nurses, but at different levels in society, including the leaders at the wards in order to reach a broad awareness with ability to change the care system.

The process of professional and personal development that nurses constantly find themselves in from entering the nursing education and then as a clinical nurse needs to be supported and encouraged. Many other inter-relational professions (such as the social worker's) include regular supervision. In nursing this opportunity for personal and professional development is not always given. Joint reflection with colleagues and recurrent training should be made available for both nurses and nursing students, in order to develop strategies for dealing with existential issues and other challenging care situations.

In future research it might be of value to conduct intervention studies exploring not only nurses' perceptions but also patients'. How can structured reflection and training regarding perceived difficulties in caring be possible to integrate in nurses' daily work and how does it influence nurses' ways of caring as well as their sense of stress? To evaluate this there is a need for intervention studies. In addition, observation studies in caring situations might be feasible.

12. POPULÄRVETENSKAPLIG SAMMANFATTNING (SUMMARY IN SWEDISH)

Existentiella frågor i kirurgisk sjukvård – Sjuksköterskors och undersköterskors erfarenheter och attityder i vårdandet av patienter med cancer

Bakgrund

I Sverige insjuknade under år 2010, 55 342 personer i någon form av cancer. Det är viktigt att komma ihåg att de allra flesta idag överlever sjukdomen. Trots detta utgör cancer ändå den näst vanligaste dödsorsaken i Sverige. De allra flesta av de som insjuknar i cancer har någon gång kontakt med kirurgisk sjukvård. Denna avhandling har handlat om existentiella frågor, som patienter med cancer ger uttryck för, beskrivet utifrån kirurgsjuksköterskors och undersköterskors perspektiv, genom deras erfarenheter och attityder i vårdandet av patienter med cancer. Eftersom termen existentiell är ett grundläggande begrepp i denna avhandling är det viktigt att klargöra vad det inbegriper: Med "existentiell" menas de villkor som är rotade i individens existens och följaktligen är en ofrånkomlig del av att vara människa. De existentiella villkoren är gemensamma för alla människor oavsett kultur eller religion och utgör livets yttersta angelägenheter och inkluderar ofta frågor som berör mening, isolering, död och frihet. Även om de existentiella frågorna är universella är hanterandet av dessa frågor individuellt. Somliga finner svar på de stora livsfrågorna i t.ex. en religiös tro, medan andra inte gör det.

Forskning visar att personal som vårdar patienter med cancer ofta tar emot existentiella frågor och tankar, men upplever att de många gånger är oförberedda att bemöta patienters existentiella frågor. Vanligtvis är vårdpersonalen utbildad för att bemöta fysisk smärta, medan utbildning saknas gällande kommunikation om de mer psykologiska och känslomässiga aspekterna och det finns bland annat en rädsla att säga "fel saker". Därför är det av stor vikt att finna fungerande stöd för hur personalens bemötande och kommunikation gällande dessa aspekter kan stödjas och utvecklas.

Syfte

Det övergripande syftet är att undersöka kirurgisk vårdpersonals erfarenheter av existentiellt bemötande till patienter med cancer samt undersöka om en intervention i form av en existentiell utbildning utgör ett stöd för att bemöta existentiella frågor hos patienter med cancer. Specifika syften var:

- I Att belysa om och hur kirurgisk personal som vårdar patienter med cancer diskuterar existentiella frågor i handledningssessioner.
- II Att fördjupa förståelsen för hur kirurgiska sjuksköterskor och undersköterskor erfar och hanterar existentiella frågor i vårdsituationer med patienter med cancer genom deras beskrivningar av kritiska händelser.
- III Att genomföra en pilotstudie för att testa design, metoder och genomförbarhet av en utbildningsintervention med existentiella frågor och att undersöka om interventionen har några effekter på sjuksköterskors och undersköterskors upplevda attityder, samt beskriva deras erfarenheter och reflektioner i vårdandet av patienter med cancer.
- IV Att beskriva kirurgsjuksköterskors och undersköterskors upplevelser av arbetsrelaterad stress vid vårdandet av svårt sjuka och döende patienter med cancer efter att ha deltagit i en utbildningsintervention med existentiella frågor.

Metod

Olika insamlings- och analysmetoder har använts i studierna. Insamling av data har övervägande bestått av enskilda intervjuer med sjuksköterskor och undersköterskor, skriftliga beskrivningar av vårdsituationer (critical incident technique) samt enkäter. De två första delstudierna hade kvalitativ ansats. De två sista delstudierna hade mixad design där kvalitativa och kvantitativa metoder genomfördes parallellt och kombinerades. De analysmetoder som har använts är; kvalitativ sekundär analys (delstudie I), hermeneutisk analys (delstudie II), mixad metod med kvalitativ innehållsanalys och statistiska icke-parametriska tester (delstudier III och IV).

Resultat

Delstudie I: Existentiella frågor hos vårdpersonal i kirurgisk cancersjukvård - diskussioner i handledningssessioner

Kirurgisk vårdpersonal upplever att patienter har existentiella frågor. Personalens diskussioner i de inspelade handledningssituationerna visade att de upplever parallella spår mellan vårdandet av svårt sjuka patienter med cancer och deras egna reaktioner och upplevelser av dilemman i vårdandet. Följande teman illustrerar vårdpersonalens egna reaktioner på patienternas situation: "känslor av maktlöshet", "identifikation med patienter" och "närhet eller distans", och följande teman illustrerar personalens diskussioner om vad de anser vara patienternas existentiella reaktioner; "känslor av förtvivlan" och "känslor av isolering". Diskussionerna från handledningssessionerna visade att personalen såg patienters

existentiella utsatthet och uppfattade deras frågor, men avstod ofta att bemöta dessa bland annat på grund av osäkerhet i kommunikation och rädsla att säga "fel saker".

Delstudie II: Existentiella frågor hos sjuksköterskor och undersköterskor i kirurgisk vård - en hermeneutisk studie av kritiska händelser

Majoriteten av de beskrivna "kritiska händelserna" berörde sjuksköterskors och undersköterskors upplevelser av att vårda patienter döende i cancer. I analysen framkom tre teman som betonar vikten av integrering mellan sjuksköterskors och undersköterskors personliga jag och deras yrkesroll i existentiella vårdsituationer (dvs. vårdsituationer där patienter uttrycker existentiella frågor); "inre dialoger för meningsfull omvårdnad", "sökandet efter rätt väg i vårdandet" och "hinder att följa patienter bortom medicinsk vård". Resultaten visade att när sjuksköterskan/undersköterskan hade ett strikt fysiskt medicinskt fokus fanns ofta en rädsla att bli känslomässigt berörd av situationen och patienten, vilket utgjorde hinder för en ömsesidig dialog där patientens existentiella uttryck kunde inkluderas. När sjuksköterskan/undersköterskan istället förde en reflektiv inre dialog om patientens situation, deras utsatthet och samtidigt var observant på egna reaktioner i situationen, underlättade det för en öppenhet att vara närvarande för den unika patienten just där och då. Följaktligen beskrevs olika bemötande av patientens existentiella frågor. Intressant i denna studie är att flera av de sjuksköterskor och undersköterskor som hade ett mer fysiskt medicinskt fokus sökte strategier i att vara mer öppen för en dialog med patienten där deras unika behov, och då även existentiella frågor kunde inkluderas.

Delstudie III: Kirurgiska sjuksköterskor och undersköterskors attityder till vårdandet av döende patienter med cancer - en pilotstudie av en utbildningsintervention med existentiella frågor

Blygsamma signifikanta kortsiktiga och långsiktiga förändringar rapporterades. De viktigaste resultaten gäller de långsiktiga resultaten av ökat självförtroende och minskad maktlöshet i kommunikation samt sjuksköterskornas och undersköterskornas känsla av ökat värde att vårda en döende patient. Deltagarna beskrev också i intervjuerna att de upplevde en ökad medvetenhet om vad existentiella frågor är och hur dessa kan bemötas. Deras beskrivningar visade att en ökad och fördjupad reflektion föregick förändrade attityder i vårdandet av svårt sjuka och döende patienter.

Delstudie IV: Kirurgiska sjuksköterskor och undersköterskors arbetsrelaterade stress vid vårdandet av svårt sjuka och döende patienter med cancer efter att ha deltagit i en utbildningsintervention med existentiella frågor

Sjuksköterskorna och undersköterskorna beskrev i denna delstudie att hög tidspress på avdelningarna ofta hindrade ett flexibelt och individuellt bemötande. De upplevde att deras intentioner med vårdandet skilde sig från det som var organisatoriskt möjligt inom den kirurgiska kontexten. Bland annat beskrev sjuksköterskorna och undersköterskorna att de ibland önskade stanna upp och samtala, framför allt med de svårast sjuka patienterna, men på grund av det höga patientantalet och underbemanning kände de sig tvungna att snabbt fortsätta till nästa patient. Tidspress och glappet mellan deras intentioner med vårdandet och vad som var möjligt inom organisationen, ledde till att sjuksköterskorna och undersköterskorna upplevde hög arbetsrelaterad stress. Dessutom upplevde de att patienterna inte alltid uttryckte sina behov då de såg hur stressade sjuksköterskorna och undersköterskorna var och ville då inte störa eller avbryta dem. Sex månader efter avslutad utbildningsintervention rapporterade sjuksköterskorna och undersköterskorna något minskad arbetsrelaterad stress. Samtidigt beskrev de i intervjuer att deras beslutsfattande gällande vårdandet nu var mer i linje med deras egna intentioner och det de upplevde som patienternas behov.

Övergripande slutsats

Sjuksköterskor och undersköterskor vid kirurgiska avdelningar, som vårdar patienter med cancer, befinner sig ofta i existentiella och etiska dilemman. Dessutom upplever sjuksköterskor och undersköterskor ofta arbetsrelaterad stress med t.ex. hög tidspress. De två första delstudierna i denna avhandling påvisar behov av tid och möjlighet för reflektion samt utbildning, stöd och tid gällande kommunikation av existentiella frågor. Sjuksköterskorna och undersköterskorna är ofta medvetna om patienternas existentiella behov, men upplever att de saknar strategier för att hantera dem och är osäkra i hur de ska kommunicera om dessa frågor. Ofta är de rädda att säga "fel saker", som kan förvärra patientens situation och frånta deras känsla av hopp. Resultaten i delstudie II tolkades inom ramen för Bubers filosofi om relationer, och visade att de olika formerna av dialoger (Jag-Du och Jag-Det dialoger) innebar olika relationer med patienter under omvårdnadsprocessen. Sjuksköterskor och undersköterskor som integrerade det personliga med det professionella (Jag-Du dialog) var också mer öppna och orädda för de existentiella frågorna som patienten ibland gav uttryck för, medan andra hade mer strikt fokus på vad de ansåg ingå i sin professionella roll vilket innebar att de ofta var mer strikt fokuserade på det rent medicinska (Jag-Det dialog). Intressant är att några sjuksköterskor och undersköterskor beskrev att de kände sig osäkra och befann sig någonstans mellan en mer uppgiftsorienterad Jag-Det dialog

och en mer patient-centrerad Jag-Du dialog i sin strävan efter att ökad öppenhet och flexibilitet inför patientens olika behov. De uttryckte behov av ett mer samlat och gemensamt förhållningssätt hos personalen gällande bland annat existentiella frågor.

I en pilotstudie testades en utbildningsintervention med reflektion om existentiella frågor och denna presenteras i delstudier III och IV. Resultaten antyder att utbildningsinterventionen bidrar till en ökad medvetenhet och reflektion, som kan ge en fördjupad förståelse för patientens situation och som i sin tur leder till attitydförändringar gällande kommunikation med patienter. Trots att denna kliniska studie hade mycket högt bortfall är det viktigt att genomföra studier i klinisk verklighet eftersom det är i denna kontext som sjuksköterskor och undersköterskor förväntas integrera sin nya kunskap. Ambitionen har varit att presentera pilotstudien av utbildningsinterventionen så ärligt och tydligt som möjligt. Utbildningsinterventionen fokuserade inte på stress och upplevelser av stress efterfrågades inte heller i intervjuerna. Dock var detta ett ämne som sjuksköterskorna och undersköterskorna spontant beskrev i samband med de andra frågorna i intervjuerna där de beskrev stress som ett hinder för att kunna bemöta patienternas existentiella frågor. Trots att pilotstudien av utbildningsinterventionen var småskalig och hade ett högt bortfall, indikerar deltagarnas beskrivningar i intervjuerna att utbildningen kan påverka sjuksköterskors och undersköterskors arbetsrelaterade känsla av stress. Detta är en viktig kunskap att beakta inför en större intervention. Även om denna pilotstudie visar positiva resultat, är det viktigt att interventionen testas i större skala i syfte att nå solida resultat.

13. ACKNOWLEDGEMENTS

First I would like to thank the participants, of who without there would be no research. Thank you for sharing more than the obvious.

Ella Danielson, my main supervisor, for having the courage to invite a social worker into nursing research. For that I am sincerely and deeply grateful. Your unbelievable energy and untiring patience have helped me through the process. Thank you.

Christina Melin-Johansson, co-supervisor, thank you for your encouragement, structure, driving force and your positive attitude.

Ingela Henoch, co-supervisor, for your engagement and fast feedback. I am so grateful for your pedagogical and humble guidance in the world of statistics.

Bertil Axelsson, co-supervisor, for wise reflections.

Gunvor Ödling for giving permission to use the research material in a secondary analysis.

The Health Care Sciences Postgraduate School, Karolinska Institute, who made it possible for me to dive into doctoral studies through the financial support and providing great courses and seminars. Thank you to all staff, especially to Lena von Koch and Jan Ekstrand for your untiring and positive support to us doctoral students on and off meetings.

Mid Sweden University for all assistance, support, and providing great working conditions and inviting me into a great group of colleagues! Especially thanks to Maud Magnusson for your continuous administrative support and patience.

To Dalarna University for providing such stimulating and supportive atmosphere.

To Kuratorsenheten in Falu Hospital and CKF, for believing in me and for keeping me in contact with clinical reality.

Gunilla Martinsson, for being the engaged, smart, authentic and fun friend and colleague you are. I am still laughing *when pointing the little arrow...*

To Susanne Anteskog-Lövenås, for "taking a leap" and leading the educational sessions in the pilot intervention study, and for sharing a deep genuine interest in human conditions and existential issues. Remember; we have many interesting courses to attend to in the future! To my supportive and wise "fadder" Henrietta Forsman, for sharing reflections on science and life. To all the great doctoral colleagues of HK-08! To Margareta Johansson and Helén Olsson at Mid Sweden University; I think of our talks and laughs from our inspiring research trips! To Åsa Auduly for your smartness, openness and kindness. Maria Warne for your friendship, wisdom and great discussions. To Linda Hogsnes for being such a positive colleague and Ulrika Eriksson for being understanding and supportive.

To Elevvårdsenheten in Ovanåkers kommun, especially Chris Sommar and Lena Wehlander-Öhman for the early support and encouragement for my research interest.

To Ylva, my most trusting and dear friend! To Lotta, always convincing me to stay on the route of science. Thank you both for inspiring me with kindness and intelligence.

Till mamma och pappa, Anna och Harry. Vi vet alla att doktorandstudier, inklusive alla resor, aldrig hade varit möjlig utan ert ihållande, dagliga, praktiska stöd. Tack!

Till älskade och underbara, Melinda and Samuel. Istället för att skriva här om hur betydelsefulla och älskade ni är, fortsätter jag istället tjata om det varje dag☺
Till min make Anders...

And last, but not least to Friskis & Svettis in Falun for the training opportunities and wonderful atmosphere which have repeatedly helped me connect my brain to my body again after a hard day's work by the computer.

14. REFERENCES

- Ackrill J. (1981) *Aristotle the Philosopher*. Oxford University Press, Oxford, UK.
- Antonovsky A. (1993) The structure and properties of the sense of coherence scale. *Social Science and Medicine* 36, 725-733.
- Arranz P., Ulla S., Ramos J., del Rincón C. & López-Fando T. (2005) Evaluation of a counselling training program for nursing staff. *Patient Education and Counseling* 56, 233-239.
- Benner P.E. (1984) *From Novice to Expert: Excellence and Power in Clinical Nursing Practice*. Addison-Wesley, Menlo Park, CA, USA.
- Benner P., Hooper-Kyriakidis P. & Stannard D. (1999) *Clinical Wisdom and Interventions in Critical Care: A Thinking-in-Action Approach*. W.B. Saunders, Philadelphia, USA.
- Berelson B. (1952) *Content Analysis in Communication Research*. Free Press, New York, USA.
- Berg L. & Danielson E. (2007) Patients' and nurses' experiences of the caring relationship in hospital: an aware striving for trust. *Scandinavian Journal of Caring Sciences* 21, 500-506.
- Berg L., Skott C. & Danielson E. (2007) Caring relationship in a context: Fieldwork in a medical ward. *International Journal of Nursing Practice* 13, 100-106.
- Berger P.L. & Luckmann T. (1966) *The Social Construction of Reality: A Treatise in The Sociology of Knowledge*. Anchor Books, New York, USA.
- Blinderman C.D. & Cherny N.I. (2005) Existential issues do not necessarily result in existential suffering: lessons from cancer patients in Israel. *Palliative Medicine* 19, 371-380.
- Bradbury-Jones C. & Tranter S. (2008) Inconsistent use of the critical incident technique in nursing research. *Journal of Advanced Nursing* 64, 399-407.
- Braun M., Gordon D. & Uziely B. (2010) Associations between oncology nurses' attitudes toward death and caring for dying patients. *Oncology Nursing Forum* 37, 43-49.
- Breitbart W. (2002) Spirituality and meaning in supportive care: spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. *Supportive Care in Cancer* 10, 272-280.
- Breitbart W., Gibson C., Poppito S.R. & Berg A. (2004) Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality. *Canadian Journal of Psychiatry* 49, 366-372.
- Browall M., Melin-Johansson C., Strang S., Danielson E. & Hénoch I. (2010) Health care staff's opinions about existential issues among patients with cancer. *Palliative and Supportive Care* 8, 59-68.
- Buber M. (1970) *I and Thou*. Charles Scribner's Sons, New York, USA.

- Burns N. & Grove S.K. (2005) *The Practice of Nursing Research. Conduct, Critique, & Utilization*. 5th ed. Elsevier, Philadelphia, USA.
- Burr V. (2003) *Social Constructionism* 2nd ed. Routledge, London, UK.
- Byrne M. (2001) Critical incident technique as a qualitative research method. *AORN Journal* 74, 536–539.
- Chochinov H.M., Krisjanson L.J., Hack T.F., Hassard T., McClement S. & Harlos M. (2006) Dignity in the terminally ill: revisited. *Journal of Palliative Medicine* 9, 666–672.
- Corner J. (2002) Nurses' experiences of cancer. *European Journal of Cancer Care* 11, 193-199.
- Creswell J.W. (2009) *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. 3rd ed. Sage Thousand Oaks, CA, USA.
- Crocker L. & Algina J. (2008) *Introduction to Classical and Modern Test Theory*. 3rd ed. Cengage Learning, Mason, Ohio, USA.
- Dachelet C.Z., Wemett M.F., Garling E.J., Craig-Kuhn K., Kent N. & Kitzman H.J. (1981) The critical incident technique applied to the evaluation of the clinical practicum setting. *The Journal of Nursing Education* 20, 15-31.
- Descartes R. (1641/1996) *Meditations on First Philosophy*. (Transl. Cottingham J.). Cambridge University Press, Cambridge, UK.
- De Vogel – Voogt E., Van Der Heide A., Van Leeuwen A.F., Visser A., Van Der Rijt C.C., Van Der Maas P.J. (2007) Patient evaluation of end-of-life-care. *Palliative Medicine* 21, 243-248.
- Delgado C. (2007) Meeting Clients' Spiritual Needs. *Nursing Clinics of North America* 42, 279-293.
- Dunn K.S., Otten C. & Stephens E. (2005) Nursing experience and the care of dying patients. *Oncology Nursing Forum* 32, 97-104.
- Ekedahl M. & Wengström Y. (2007) Nurses in cancer care- Stress when encountering existential issues. *European Journal of Oncology Nursing* 11, 228-237.
- Eriksson K. (1992) The alleviation of suffering--the idea of caring. *Scandinavian Journal of Caring Sciences* 6, 119-123.
- Eriksson m. & Lindström B. (2005) Validity of Antonovsky's sense of coherence scale: a systematic review. *Journal of Epidemiology and Community Health* 59, 460-466.
- Fallowfield L., Saul J. & Gilligan B. (2001) Teaching senior nurses how to teach communication skills in oncology. *Cancer Nursing* 24, 185-191.
- Fallowfield L., Jenkins V., Farewell V., Saul J., Duffy A. & Eves R. (2002) Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled trial. *The Lancet* 359, 650-656.
- Feldt T., Lintula H., Suominen S., Koskenvuo M., Vahtera J. & Kivimaki M. (2007) Structural validity and temporal stability of the 13-item sense of coherence

- scale:prospective evidence from the population-based Hessup study. *Quality of Life Research* 16, 483-493.
- Fillion L., Duval S., Dumont S., Gagnon P., Tremblay I., Bairati I. & Breitbart W.S. (2009) Impact of a meaning-centered intervention on job satisfaction and on quality of life among palliative care nurses. *Psycho-Oncology* 18, 1300-1310.
- Flanagan J.C. (1954) The critical incident technique. *Psychological Bulletin* 51, 327-358.
- Frankl V.E. (1963) *Man's Search for Meaning: An Introduction to Logotherapy*. Washington Square Press, New York, USA.
- Frankl V.E. (1987) Logotherapy and the challenge of suffering. *Review of Existential Psychology and Psychiatry* 20, 1-3.
- Frommelt K.H. (1991) The effects of death education on nurses' attitudes toward caring for terminally ill persons and their families. *American Journal of Hospice and Palliative Care* 8, 37-43.
- Frommelt K.H. (2003) Attitudes toward care of the terminally ill: An educational intervention. *The American Journal of Hospice & Palliative Care* 20, 13-22.
- Gadamer H.G. (1960/1989) *Truth and Method*. 2nd ed. (Transl. Weisheimer J. & Marshall D.). Crossroad, New York, USA.
- Grumann M.M. & Spiegel D. (2003) Living in the face of death: interviews with 12 terminally ill women on home hospice care. *Palliative and Supportive Care* 1, 23-32.
- Hainsworth D.S. (1996) The effect of death education on attitudes of hospital nurses toward care of the dying. *Oncology Nursing Forum* 23, 963-967.
- Hallin K. & Danielson E. (2007) Registered nurses' experiences of daily work, a balance between strain and stimulation: A qualitative study. *International Journal of Nursing Studies* 44, 1221-1230.
- Hallin K. & Danielson E. (2008) Registered nurses' perceptions of their work and professional development. *Journal of Advanced Nursing* 61, 62-70.
- Halman L. & Riis O. (2003) *Religion in a Secularizing Society: The Europeans' Religion at the End of The 20th Century*. Leiden, Brill, UK.
- Hansson S.O. (2007) The ethics of enabling technology. *Cambridge Quarterly of Healthcare Ethics* 16, 257-267.
- Hardy S.E., Allore H. & Studenski S.A. (2009) Missing data: a special challenge in aging research. *Journal of the American Geriatrics Society* 57, 722-729.
- Hawley M.P. & Jensen L. (2007) Making a difference in critical care nursing practice. *Qualitative Health Research* 17, 663-674.
- Heidegger M. (1927/1962) *Being and Time*. (Transl. Macquarrie J. & Robinson F.). Harper and Row, New York, USA.
- Henoch I., Bergman B., Gustafsson M., Gaston-Johansson F. & Danielson E. (2007) The impact of symptoms, coping capacity, and social support on quality of life

- experience over time in patients with lung cancer. *Journal of Pain and Symptom Management* 34, 370-379.
- Henoch I. & Danielson E. (2009) Existential concerns among patients with cancer and interventions to meet them: an integrative literature review. *Psycho-Oncology* 18, 225-236.
- Henoch I., Browall M., Melin-Johansson C., Danielson E., Udo C., Johansson Sundler A., Björk M., Ek K., Hammarlund K., Bergh I. & Strang S. (2012). The Swedish version of the Frommelt Attitude Toward Care of the Dying Scale (FATCOD): Aspects of validity and factors influencing nurses' and nursing students' attitudes. *Cancer Nursing* (Accepted).
- Hinds P.S., Vogel R.J. & Clarke-Steffen L. (1997) The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. *Qualitative Health Research* 7, 408-424.
- Horton-Deutsch S. & Sherwood G. (2008) Reflection: an educational strategy to develop emotionally-competent nurse leaders. *Journal of Nursing Management* 16, 946-954.
- Houtepen R. & Hendrikx D. (2003) Nurses and the virtues of dealing with existential questions in terminal care. *Nursing Ethics* 10, 377-387.
- Iranmanesh S., Savenstedt S. & Abbaszadeh A. (2008) Student nurses' attitudes towards death and dying in south-east Iran. *International Journal of Palliative Nursing* 14, 214-219.
- Iranmanesh S., Axelsson K., Häggström T. & Sävenstedt S. (2010) Caring for dying people: attitudes among Iranian and Swedish nursing students. *Indian Journal of Palliative Care* 16, 147-153.
- James I., Andershed B., Gustavsson B. & Ternstedt B.M. (2010) Emotional knowing in nursing practice: In the encounter between life and death. *International Journal of Qualitative Studies on Health and Well-being* doi: 10.3402/qhw.v5i2.5367.
- Jangland E., Gunningberg L. & Carlsson M. (2009) Patients' and relatives' complaints about encounters and communication in health care: Evidence for quality improvement. *Patient Education and Counseling* 75, 199-204.
- Jangland E., Larsson J. & Gunningberg L. (2011) Surgical nurses' different understandings of their interactions with patients: a phenomenographic study. *Scandinavian Journal of Caring Sciences* 25, 533-541.
- Jaspers K. (1970) *Philosophy*. (Transl. Ashton E.B.). The University of Chicago Press, Chicago, IL, USA.
- Jenkins V. & Fallowfield L. (2002) Can communication skills training alter physicians' beliefs and behavior in clinics? *Journal of Clinical Oncology* 20, 765-769.
- Johansson K. & Lindahl B. (2011) Moving between rooms – moving between life and death: nurses' experiences of caring for terminally ill patients in hospitals. *Journal of Clinical Nursing* 21, 2034-2043.

- Kemppainen J.K. (2000) The critical incident technique and nursing care quality research. *Journal of Advanced Nursing* 32, 1264-1271.
- Kierkegaard S. (1843/2002) *Antingen – Eller: Ett livsfragment*. (Transl. Borg S.). Nimrod, Guldsmedshyttan, Sweden.
- Kierkegaard S. (1844/1980) *The Concept of Anxiety*. (Transl. Thomte R.). Princeton University Press, New Jersey, USA.
- Krippendorff K. (2004) *Content analysis. An introduction to its methodology*. 2nd ed. Sage Publications, London, UK.
- Kvale S. (2006) *Interviews: An Introduction to Qualitative Research Interviewing*. Sage Publications, London, UK.
- Kälvemark S., Höglund A.T., Hansson M.G., Westerholm P. & Arnetz B. (2004) Living with conflicts-ethical dilemmas and moral distress in the health care system. *Social Science and Medicine* 58, 1075-1084.
- Landmark B.T., Strandmark M. & Wahl A.K. (2001) Living with newly diagnosed breast cancer – The meaning of existential issues. *Cancer Nursing* 24, 220-226.
- Lange M., Thom B. & Kline N.E. (2008) Assessing nurses' attitudes toward death and caring for dying patients in a comprehensive cancer center. *Oncology Nursing Forum* 35, 955-959.
- Langius A, Bjorvell H. & Antonovsky A. (1992) The sense of coherence concept and its relation to personality traits in Swedish samples. *Scandinavian Journal of Caring Sciences* 6, 165-171.
- Laubmeier K.K., Zakowski S.G. & Bair J.P. (2004) The role of spirituality in the psychological adjustment to cancer: a test of the transactional model of stress and coping. *International Journal of Behavioral Medicine* 11, 48-55.
- Lavoie M., Blondeau D. & de Koninck T. (2008) The dying person: an existential being until the end of life. *Nursing Philosophy* 9, 89-97.
- Lee V. & Loiselle C.G. (2012) The salience of existential concerns across the cancer control continuum. *Palliative and Supportive Care* doi:10.1017/S1478951511000745.
- Leloirain S., Brédart A., Dolbeault S. & Sultan S. (2012) A systematic review of the associations between empathy measures and patient outcomes in cancer care. *Psycho-Oncology* doi: 10.1002/pon.2115.
- Lenzi R., Baile W.F., Costantini A., Grassi L. & Parker P.A. (2011) Communication training in oncology: results of intensive communication workshops for Italian oncologists. *European Journal of Cancer Care* 20, 196-203.
- Lethborg C., Aranda S., Bloch S. & Kissane D. (2006) The role of meaning in advanced cancer-integrating the constructs of assumptive world, sense of coherence and meaningbased coping. *Journal of Psychosocial Oncology* 24, 27-42.
- Levinas E. (1979/1987) *Time and the Other*. (Transl. Cohen R.A.). Duquesne University Press, Pittsburgh, PA, USA.
- Lin H. & Bauer-Wu S.M. (2003) Psycho-spiritual well-being in patients with advanced cancer: an integrative review of the literature. *Journal of Advanced Nursing* 44, 69-80.

- Lindmark U., Stenström U., Gerdin E.W. & Hugoson A. (2010) The distribution of "sense of coherence" among Swedish adults: a quantitative cross-sectional population study. *Scandinavian Journal of Public Health* 38, 1-8.
- Lütznén K., Cronqvist A., Magnusson A. & Andersson L. (2003) Moral stress: synthesis of a concept. *Nursing Ethics* 10, 312-322.
- May R. (1983) *The Discovery of Being, Writings in Existential Psychology*. W.W Norton & Company Inc., New York, USA.
- Mays N. & Pope C. (2000) Qualitative research in health care. Assessing quality in qualitative research. *British Medical Journal* 320, 50-52.
- Mazzotti E., Mazzuca F., Sebastiani C., Scoppola A. & Marchetti P. (2011) Predictors of existential and religious well-being among cancer patients. *Supportive Care in Cancer* 19, 1931-1937.
- McCamant K.L. (2006) Humanistic nursing, interpersonal relations theory, and the empathy-altruism hypothesis. *Nursing Science Quarterly* 19, 334-338.
- McGrath M. (2008) The challenges of caring in a technological environment: critical care nurses' experiences. *Journal of Clinical Nursing* 17, 1096-1104.
- Melin-Johansson C., Axelsson B. & Danielson E. (2007) Caregivers' perceptions about terminally ill family members' quality of life. *European Journal of Cancer Care* 16, 338-345.
- Melin-Johansson C., Ödling G., Axelsson B. & Danielson E. (2009) The meaning of quality of life: narrations by patients with incurable cancer in palliative home care. *Palliative and Supportive Care* 6, 231-238.
- Merleau-Ponty M. (1945/1962) *Phenomenology of Perception*. (Transl. Smith C.). Routledge, London, UK.
- Mohan S., Wilkes L. M., Ogunsiji O. & Walker A. (2005) Caring for patients with cancer in non-specialist wards: the nurse experience. *European Journal of Cancer Care* 14, 256-263.
- Mok E., Lau K.P., Lam W.M., Chan L.N., Ng J.S. & Chan K.S. (2010) Healthcare professionals' perceptions of existential distress in patients with advanced cancer. *Journal of Advanced Nursing* 66, 1510-1522.
- Molzahn A.E. & Shields L. (2008) Why is it so hard to talk about spirituality? *Cancer Nursing* 104, 25-29.
- Morita T., Murata H., Hirai K., Tamura K., Kataoka J., Ohnishi H., Akizuki N., Kurihara Y., Akechi T. & Uchitomi Y. (2007) Meaninglessness in Terminally Ill Cancer Patients: A validation study and nurse education intervention trial. *Journal of Pain and Symptom Management*. 34, 160-170.
- Morita T., Murata H., Kishi E., Miyashita M., Yamaguchi T. & Uchitomi Y. (2009) Meaninglessness in Terminally Ill Cancer Patients: A Randomized Controlled Study. *Journal of Pain and Symptom Management* 37, 649-658.
- Morse J.M., Sohlberg S.M., Neander W.L., Bottorff J.L. & Johnson J.L. (1990) Concepts of caring and caring as a concept. *Advances in Nursing Science* 13, 1-14.

- Munhall P. (2001) *Nursing research: A qualitative perspective*. 3rd ed. Jones and Bartlett Publishers, Boston, USA.
- Neimeyer R.A. & Moore M.K. (1994) *Validity and Reliability of the Multidimensional Fear of Death scale*. In: Neimeyer RA (ed) *Death Anxiety Handbook: Research, Instrumentation, and Application*. Taylor and Francis, Washington DC, USA.
- Nieswiadomy R.M. (2011) *Foundations of Nursing Research* 6th ed. Pearson Education Inc., New Jersey, USA.
- Nietzsche F. (1883/1961) *Thus Spoke Zarathustra*. (Transl. Hollingdale R.J.). Penguin, Harmondsworth, UK.
- Noble A. & Jones C. (2010) Getting it right: oncology nurses' understanding of spirituality. *International Journal of Palliative Nursing* 16, 565-569.
- Norman I.J., Redfern S.J., Tomalin D.A. & Oliver S. (1992) Developing Flanagan's critical incident technique to elicit indicators of high and low quality nursing care from patients and their nurses. *Journal of Advanced Nursing* 17, 590-600.
- Nussbaum M.C. (2001) *Upheavals of thought: The Intelligence of Emotions*. Cambridge University Press, Cambridge, UK.
- Nåden D. & Saeteren B. (2006) Cancer patients' perceptions of being or not being confirmed. *Nursing Ethics* 13, 222-235.
- Palese A., Tomietto M., Suhonen R., Efstathiou G., Tsangari H., Merkouris A., Jarosova D., Leino-Kilpi H., Patiraki E., Karlou C., Balogh Z. & Papastavrou E. (2011) Surgical patient satisfaction as an outcome of nurses' caring behaviors: A descriptive and correlational study in six European countries. *Journal of Nursing Scholarship* 43, 341-350.
- Pallant J. (2005) *SPSS Survival Manual. A Step by Step Guide to Dataanalysis Using SPSS for Windows (version 12)*, 2nd ed. Ligare Pty Ltd Sidney, Australia.
- Pallant J.F. & Lae L. (2002) Sense of coherence, well-being, coping and personality factors: further evaluation of the sense of coherence scale. *Personality and Individual Differences* 33, 39-48.
- Palmer R.F. & Royall D.R. (2010) Missing data? Plan on it! *Journal of the American Geriatrics Society* doi: 10.1111/j.1532-5415.2010.03053.x.
- Paterson J.G. & Zderad L.T. (1976) *Humanistic Nursing*. John Wiley & Sons, New York, USA.
- Polit D.F. & Beck T. (2012) *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 9th ed. Lippincott Williams & Wilkins, Philadelphia, USA.
- Razavi D., Delvaux N., Marchhal S., Bredart A., Farvacques C. & Paesmans M. (1993) The effects of a 24-h psychological training program on attitudes. Communication skills and occupational stress in oncology: a randomised study. *European Journal of Cancer* 13, 1858-1863.
- Rchaidia L., Dierckx de Casterlé B., de Blaeser L. & Gastmans C. (2009) Cancer patients' perceptions of the good nurse: a literature review. *Nursing Ethics* 16, 528-542.

- Rhodes M.K., Morris A.H. & Lazenby R.B. (2011) Nursing at its best: competent and caring. *Online Journal of Issues in Nursing* 16, 10.
- Richer M. & Ezer H. (2002) Living in it, living with it, and moving on: dimensions of meaning during chemotherapy. *Oncology Nursing Forum* 29, 113–119.
- Rolland R.A. & Kalman M. (2007) Nurses' attitudes about end-of-life referrals. *The Journal of the New York State Nurses' Association* 38, 10-12.
- Rudolfsson G., von Post I. & Eriksson K. (2007) The development of caring in the perioperative culture: nurse leaders' perspective on the struggle to retain sight of the patient. *Nursing Administration Quarterly* 31, 312-324.
- Sand L. & Strang P. (2006) Existential loneliness in a palliative home care setting. *Journal of Palliative Medicine* 9, 1376-1387.
- Sand L., Strang P. & Milberg A. (2008) Dying cancer patients' experiences of powerlessness and helplessness. *Journal of Supportive Care in Cancer* 16, 853-862.
- Sartre J.P. (1946/1948) *Existentialism and Humanism* (Transl. Mairet P.). Methuen, London, UK.
- Saunders C.M. (1978) *The Management of Terminal Malignant Disease*, 1st ed. Edward Arnold, London, UK.
- Schluter J., Seaton P. & Chaboyer W. (2007) Critical incident technique: a user's guide for nurse researchers. *Journal of Advanced Nursing* 61, 107-114.
- Schuster M. (2006) *Profession och Existens. En hermeneutisk studie av asymmetri och ömsesidighet i sjuksköterskors möten med svårt sjuka patienter*. Dissertation from Stockholm, Institutionen för samhälle, kultur och lärande. Daidalos, Göteborg.
- Siegel S. & Castellan N. (1988) *Nonparametric Statistics for the Behavioral Sciences*. 2nd ed. McGraw-Hill, New York, USA.
- Stark R. & Bainbridge W.S. (1985) *The Future of Religion: Secularization, Revival and Cult Formation*. University of California Press, Ltd, London, UK.
- Strang S., Strang P. & Ternstedt B.M. (2001) Existential support in brain tumour patients and their spouses. *Supportive Care in Cancer* 9, 625-633.
- Strang S. (2002) *Spiritual/Existential Issues in Palliative Care : With Special Reference to Patients With Brain Tumours and Their Spouses*. Dissertation from Gothenburg University Institute of Selected Clinical Sciences, Department of Oncology Gothenburg University.
- Strang S. & Strang P. (2002) Questions posed to hospital chaplains by palliative care patients. *Journal of Palliative Medicine* 5, 857–864.
- Su S.F., Boore J., Jenkins M., Liu P.E. & Yang M.J. (2009) Nurses' perceptions of environmental pressures in relation to their occupational stress. *Journal of Clinical Nursing* 18, 3172-3180.
- Sveinsdóttir H., Biering P. & Ramel A. (2006) Occupational stress, job satisfaction, and working environment among Icelandic nurses: A cross-sectional questionnaire survey. *International Journal of Nursing Studies* 43, 875-889.

- Svenaesus F. (1999) *The Hermeneutics of Medicine and The Phenomenology of Health: Steps Towards a Philosophy of Medical Practice*. Dissertation of Linköpings University, Linköping University.
- Teddle C. & Tashakkoori A. (2003) *Handbook of Mixed Methods in Social and Behavioral Research*. Sage Thousand Oaks, CA, USA.
- Ternstedt B.M. (1998) *Livet Pågår! Om Vård av Döende* (FOU-rapport, Vårdförbundet). Studentlitteratur, Lund, Sweden.
- The Swedish National Board of Health and Welfare (2011) *Cancer Incidence in Sweden 2010*. Available at <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/18530/2011-12-15.pdf>. (accessed February 2012).
- Thorne S. (1994) *Secondary analysis in qualitative research: Issues and implications*. In *Critical Issues in Qualitative Research Methods* Morse JM (ed.). Sage Thousand Oaks, CA, USA: 263–279.
- Thorne S. (1998) Ethical and representational issues in qualitative secondary analysis. *Qualitative Health Research* 8, 547-555.
- Tillich P. (1952) *The Courage To Be*. Yale University Press, New Haven, USA.
- Tomer A., Eliason G. & Wong P.T.P. (2008) *Existential and Spiritual Issues in Death Attitudes*. Lawrence Erlbaum Associates, New York, USA.
- Tong A., Sainsbury P. & Craig J. (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 19, 349-357.
- Torjuul K., Nordam A. & Sorlie V. (2005) Ethical challenges in surgery as narrated by practicing surgeons. *BMC Medical Ethics* doi: 10.1186/1472-6939-6-2.
- Torjuul K. & Sorlie V. (2006) Nursing is different than medicine: ethical difficulties in the process of care in surgical units. *Journal of Advanced Nursing* 56, 404-413.
- Torjuul K., Elstad I. & Soerlie V. (2007) Compassion and responsibility in surgical care. *Nursing Ethics* 14, 522-534.
- Travelbee J. (1971) *Interpersonal Aspects of Nursing*. F.A. Davis, Philadelphia, USA.
- Treece E.W & Treece J.W. (1986) *Elements of Research in Nursing*. Chichester John Wiley, C.V. Mosby, St Louis, USA.
- Ulmer M., Robinaugh D., Friedberg J.P. Lipsitz S.R. & Natarajan S. (2008) Usefulness of a run-in period to reduce drop-outs in a randomized controlled trial of a behavioral intervention. *Contemporary Clinical Trials* 29, 705-710.
- Vachon M. L. (2008) Meaning, spirituality, and wellness in cancer survivors. *Seminars in Oncology Nursing* 24, 218-225.
- Van Deurzen E. (1988) *Existential Counselling in Practice*. Sage Publications, London, UK.
- Van Deurzen E. (2010) *Everyday Mysteries: a Handbook of Existential Psychotherapy*. 2nd ed. Routledge, London, UK.

- Wang C., Hall C.B. & Kim M. (2012) A comparison of power analysis methods for evaluating effects of a predictor on slopes in longitudinal designs with missing data. *Statistical Methods in Medical Research* doi: 10.1177/0962280212437452.
- Watson J. (1985) *Nursing: Human Science and Human Care. A Theory of Nursing*. Jones and Bartlett Publishers International, London, UK.
- Westman B., Bergenmar M. & Andersson L. (2006) Life, illness and death—existential reflections of a Swedish sample of patients who have undergone curative treatment for breast or prostatic cancer. *European Journal of Oncology Nursing* 10, 169–176.
- Wikström O. (1999) *Dödsångest*. Socialstyrelsen, Stockholm, Sweden.
- Wilkin K. (2003) The meaning of caring in the practice of intensive care nursing. *British Journal of Nursing* 12, 1178-1185.
- Wilkin K. & Slevin E. (2004) The meaning of caring to nurses: an investigation into the nature of caring work in an intensive care unit. *Journal of Clinical Nursing* 13, 50-59.
- Wilkinson S.M., Leliopoulou C., Gambles M. & Roberts A. (2003) Can intensive three-day programmes improve nurses' communication skills in cancer care? *Psycho-Oncology* 12, 747-759.
- Wilkinson S., Perry R., Blanchard K. & Linsell L. (2008) Effectiveness of a three-day communication skills course in changing nurses' communication skills with cancer/palliative care patients: A randomised controlled trial. *Palliative Medicine* 22, 365-375.
- Winterling J., Wasteson E., Sidenvall B., Sidenvall E., Glimelius B., Sjöden P. & Nordin K. (2006) Relevance of philosophy of life and optimism for psychological distress among individuals in a stage where death is approaching. *Supportive Care in Cancer* 14, 310-319.
- Wong P.T.P., Reker G.T. & Gesser G. (1994) Death Attitude Profile-Revised: A Multidimensional Measure of Attitudes Toward Death. In: *Death Anxiety Handbook: Research, Instrumentation, and Application* (eds Neimeyer R.A.) Taylor and Francis, Washington, USA.
- Wu H.L. & Volker D.L. (2009) Living with death and dying: the experience of taiwanese hospice nurses. *Oncology Nursing Forum* 36, 578-584.
- Yalom I.D. (1980) *Existential Psychotherapy*. Basic Books, New York, USA.
- Yalom I.D. (2000) *Momma and the Meaning of Life. Tales of Psychotherapy*. HarperCollins, New York, USA
- Yalom I.D. (2005) *The Schopenhauer Cure*. HarperCollins, New York, USA.
- Yalom I.D. (2009) *Staring at the Sun: Overcoming the Terror of Death*. Jossey Bass Wiley, Chichester, USA.
- Ödling G., Danielson E. & Jansson C. (2001) Caregivers' descriptions of patients with advanced breast cancer in connection with supervision sessions in a surgical ward. *Cancer Nursing* 24, 28-34.

Ödling G., Norberg A. & Danielson E. (2002) Care of women with breast cancer on a surgical ward: nurses' opinions of the need for support for women, relatives and themselves. *Journal of Advanced Nursing* 39, 77-86.