Professional caregivers’ experiences of caring for women with breast cancer on a surgical ward

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Umeå 2004
To:

Dedicated to the memory of my father Oskar, brother Åke, my friends and colleagues Anna Widell and Gunilla Olsson, who all passed away during the time of my work with this thesis.
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ABSTRACT

The overall aim of the thesis was to describe caregivers’ experiences of caring for women with breast cancer on a surgical ward. The study was based on interviews with narrative parts and tape-recorded clinical supervision sessions. The interviews and clinical supervision sessions were transcribed verbatim, and analysed by content analysis.

Nurses (n=10) described life for women with breast cancer as either having freedom or not having freedom, with both physical and existential suffering. Dying occurred either naturally in patients’ own home or unnaturally in hospital. The nurses felt that it is possible to alleviate suffering during dying through providing adequate pain relief but also, through listening, providing information and changing the caring atmosphere (I).

Breast cancer as an illness was described from a dark point of view by caregivers (n=37). The descriptions focused on loss of breasts and control, progression of the illness and annihilation. The illness seemed, in the caregivers’ mind, to often end with a painful death. Caregivers who had the opportunity to follow the total care process described a lighter viewpoint (II).

According to nurses (=31) the most important needs among women, their relatives and nurses themselves were the needs to talk and receive information. There was a discrepancy between what was described as important needs and the descriptions of how these needs were provided for. Nurses, whose own needs for support were sometimes unsatisfactorily met (III), seemed almost to be unaware of the needs among women and their relatives.

In the clinical supervision sessions caregivers reflected on difficult care situations related to women’s, relatives’, and most often caregivers’ feelings (n=38). The care situations were described as evoking feelings of discomfort, powerlessness and reduced self-esteem. These feelings were described by caregivers as arising in connection with caring for especially women with advanced breast cancer in a changing organisation (IV).

Caregivers’ descriptions of caring for women with breast cancer show a lot of negative experiences of powerlessness and frustration. They met women and their relatives who suffered in various ways and had considerable need for support. Caregivers often found themselves unable to meet these needs due to organisational obstacles e.g. lack of time and lack of knowledge about other caregivers’ responsibility in the care.

Key words: Breast cancer, caregivers, clinical supervision, content analysis, dying, interviews, needs, suffering, support, surgical care.
**ORIGINAL PAPERS**

This thesis is based on the following papers, which are referred to in the text by their Roman numerals:

I  Ödling G. & Norberg A. Life, suffering and dying as narrated by nurses in a surgical ward. Submitted.


The papers have been printed with the kind permission of the respective journals.
PREFACE

This thesis reports part of a project dealing with women newly diagnosed with breast cancer, their relatives and caregivers, and focuses on the part concerning the caregivers*. The project also consists of a follow-up study concerning caregivers’ experience of receiving support by group supervision, in the care of women with breast cancer.

My interest for studying care of women with newly diagnosed breast cancer is based upon my work as a teacher in surgical care; I have met many patients with surgical diseases and among them women with breast cancer. After many years of personal experience as well as years of listening to nursing students’ narratives from their clinical studies on surgical wards, regarding crisis reaction among women newly diagnosed with breast cancer, I felt a need to investigate women’s experiences of cancer care in a surgical ward, because little knowledge relating to this was available in literature.

*In this thesis the term caregivers is used for professional caregivers.
INTRODUCTION

In Sweden, in the early 1990s there were few studies on women newly diagnosed with breast cancer. Studies by Gyllensköld (1976 pp. 83-141) and Drugge (1988 pp. 81-122) show that women newly diagnosed with breast cancer experienced stress in their situation and felt that they did not receive the desired support. In connection with surgery, and surgical care, women felt confused and lonely, and they described the caregivers as being hard-pressed and that they lacked the time to talk with them. Northouse (1989) and Wainstock (1991) show that women felt need for support from families, friends and caregivers, in the form of information and that someone/anyone had time to listen to them. Lewis’ (1990) research review on how family members react to cancer in the family shows that partners and school-age children need support. The study shows that although the need for support was significant the family often lacked support from the medical and nursing profession. The studies reported above showed that women and their relatives had considerable need for support during all stages of the disease, but few studies dealt with the women’s hospital stay in connection with breast cancer surgery.

The research on women with newly diagnosed breast cancer started as a pilot study. An interview study was carried out, at a county hospital in central Sweden with caregivers, patients and relatives, who were all Swedish (Ödling, Axelsson & Norberg, 1995). The aim of the study was to illuminate women’s experiences of surgical care in connection with surgery of newly diagnosed breast cancer, specifically communication with the caregivers and also the women’s attitude to the illness. In the study above some things struck me explicitly, women newly diagnosed with breast cancer seemed to have a ‘dammed up’ need to talk about their illness; even if the interviews focused on other aspects e.g. women’s experiences of surgical care. Some of the women described how no one had had enough time to talk with them, even if it was
noted in the daily case notes, that during the women’s stay at the hospital the women and the caregivers had had a lot of contact on the ward. The opposite was also described, that women had had several opportunities to talk about their illness with the caregivers. The physical care given and received was described as good but shortcomings were noted regarding psychological care. Some of the women also described how difficult the situation was for relatives.

As the studies above show that women with breast cancer and their relatives had need for support, and because there were few studies on women and their relatives’ experiences of surgical care, an intervention study was implemented, in which the objective was to acquire knowledge relating to the experiences of women with newly diagnosed breast cancer in connection with surgical care, as well as of their relatives and the caregivers. This thesis concerns the caregivers’ experiences of caring for women with breast cancer.
BACKGROUND

Being a professional caregiver

Being a caregiver means being involved in caring in various care settings. According to Benner and Wrubel (1989 p. 4) “…caring is primary because it sets up the possibility of giving help and receiving help.” Caring means providing both action and relationship, which fills the cared one with trust if the relationship is good. The opposite is uncaring (cf. Halldórsdóttir & Hamrin 1997). People have different needs of caring during their lifespan. A newborn child and an adult suffering from a cancer disease both need caring for, but in different ways.

Taking care of patients can give one pleasure in one’s work but also evoke a bad conscience. Fransson (1997 pp. 220-248) found in her study among women who worked as caregivers in various care settings that they often had a bad conscience because, as they said they did not have and found it impossible to take the time to do what they really wanted to do for, or together with, the patients. Taking care of someone calls for a feeling of sensitivity for that person (cf. Halldórsdóttir & Hamrin 1996). Svedlund, Danielson and Norberg (1999) illuminate that coronary nurses had to wait for the right moment before they could enter into a relationship with patients and lived “in between two poles”, those of distance and closeness, dealing with patients, relatives and caregivers.

Crockford, Holloway and Walker (1993) show that nurses on surgical wards, taking care of women with breast cancer, considered that it was their duty to act as advocates for the women and their families. In such situations, nurses experienced a lack of specialised knowledge about dealing with women’s vulnerability and stress. Åström, Norberg and Hallberg (1995) reported that nurses engaged in surgical care were of the opinion that they must meet the patients’ physical needs first of all, but that it was also important to help patients with their anxiety. Idvall and Rooke (1998) reported that nurses in surgical
wards wanted to sit down, listen and just be with patients, but they often lacked the time to do this.

Several studies describe how difficult care situations influence caregivers in various ways, (e.g. Andrae 1994, Maeve 1998, Sørlie, Jansson & Norberg 2003). Studies dealing with caregivers caring for women with breast cancer show that the daily contact with suffering women can also influence caregivers’ own situation, in such ways as providing them with a feeling of work satisfaction as well as feelings of dissatisfaction (Pålsson, Isovaara & Norberg, 1995, Pålsson & Norberg 1995). Quinn’s (2003) review research shows that interviewed nurses meant that their own experiences of having, or having had a family member with cancer had affected their approach to nursing care.

Andrae (1994 p. 3) starts her doctoral thesis, about physicians’ difficulties and coping strategies in the care of patients with cancer, with a quotation by a physician: “because their anxiety is also my anxiety;” this expression illuminates physicians’ daily life as a cancer expert. To be a physician among seriously ill patients is described as being both precarious and fruitful. Andrae (1994 pp. 63-100) shows that physicians in cancer care used various ways to cope with their work situation. One way was to find support by talking with others. Some of them tried to build up a relationship with the patient, while others said that they tried to limit their engagement, due to the risk for burnout. Difficulties described by Andrae (1994 pp. 63-100) dealt with such things as limitations in the organisation, as well as with the physicians, when they could not provide adequate medical help.

Pålsson and Norberg (1995) found that district nurses in home care felt that in some situations they formed too close a relationship with patients and their family, which often led to them distancing themselves from the patients’ problem. The opposite was experienced when patients distanced themselves from the district nurses, who consequently found it difficult to provide help.
Caring for seriously ill patients often entails finding a balance between feelings of powerlessness and satisfaction, like when the caregivers had been able to modify a negative situation. Corner’s (2002) review research about how nurses’ experience working with patients with cancer shows that nurses find the work rewarding but also emotionally demanding; the difficulties seem to be rather more associated with structural factors than with caring for dying patients.

While taking care of seriously ill patients the caregivers had to manage their own fear of illness and dying (Pålsson & Norberg 1995, Wilkinson 1991, 1999). Caregivers can also be troubled personally by the loss of a patient. To care for someone for a longer or shorter period of time leads to a relationship being formed - a bond that is broken in connection with the patient’s death (Tschudin 1997 pp. 164-169). Hopkinson, Hallett and Luker (2003), report that nurses taking care of dying patients had feelings of being alone in the care situation, and felt a sense of isolation even when they were together with other nurses. The relationship with patients and relatives could be both burdensome and pleasurable, filled with difficulties in controlling personal involvement with patients. Rittman et al. (1997) found that previous experiences of taking care of dying patients could influence nurses’ attitudes to death in care situations both positively and negatively. One nurse described how an earlier negative situation made it difficult for her to be involved with dying patients. Other nurses described how experiences of positive events in the past guided them in the care situations in which they were involved. Kuuppelomäki (2000) found that health care professionals were more afraid of death than patients with cancer and their families were. The author suggests that it might be difficult for care professionals to keep a distance and forget about death.

As illuminated by Rasmussen, Norberg and Sandman (1995 p. 351) becoming a hospice nurse implies “the struggle to maintain an experience of wholeness and meaning in the anticipation of death” and also shows that hospice nurses in palliative care tried to help the dying person and their family to live as
fully as possible. In the close relationships they attained with guests and their relatives, nurses emphasized how they acquired feelings of satisfaction, strength and the hope of maturing as a person.

The literature review above shows that taking care of seriously ill patients makes great demands on caregivers and influences them in their daily work, but also that it can provide them with feelings of satisfaction as well as with a bad conscience.

**Living with breast cancer**

To be able to understand the women suffering with breast cancer, and their relatives it is important for the caregivers to have knowledge about the family’s cancer journey (cf. Kristjanson & Ashcroft, 1994, Leydon, Byne-Sutherland & Coleman 2003).

Dunniece and Slevin (2000) interviewed nurses who were present when patients received a cancer diagnosis. They reported that being given such a diagnosis was a traumatic experience that affected the patients and their families profoundly. Being present had an impact on the nurses, which made it easier for them to develop a close relationship with the patients. Being taken ill with breast cancer is a dramatic experience. Information relating to the diagnosis can be shocking, leaving the affected woman with the feeling of a loss of control over her life situation (Krause 1993, Landmark, Strandmark & Wahl 2001). Women experience living with breast cancer differently during specific phases of life (Sammarco 2001). It is exceedingly difficult for women with breast cancer who have children dependent on them. Billhult and Segesten (2003) show how the mothers had to balance between being needed and perhaps not existing in the near future. Ballantyne (2004) reviewed research on women with breast cancer and concluded that breast cancer is currently ‘increasingly a disease of older women’ (p. 16) and emphasized that old age may mean limited ability to cope with the disease.
The time preceding surgical treatment and waiting for the result is very trying and chaotic (Hughes 1993, Northouse et al. 1998, Landmark & Wahl 2002). Women with breast cancer can feel as if they have received a death sentence in connection with the diagnosis and experience a loss of their femininity after the surgical treatment (Gyllenskåld 1976 pp. 83-141, Drugge 1988 pp. 81-122, Landmark & Wahl 2002). The woman finds that she is in tremendous need of support, including being provided with adequate information and the opportunity to have someone to listen and answer her questions (cf. Salander 2002).

Some women newly diagnosed with breast cancer try to “learning new ways of being in the world”, compare themselves with other women with breast cancer, with both positive and negative outcomes, while struggling to gain a meaning with life (Nelson 1996 p. 67). Quinn’s (2003) review research shows that many people with cancer search for a meaning with and reassess their life.

Moch (1998) discusses the concept ‘health-within-illness’ in relation to patients with breast cancer. Illness can be seen as a catalyst for growth. It can provide an opportunity to increase the experience of meaningfulness, connection with the environment and through the illness patients can also gain an awareness of self. When Wilkes et al. (1999) researched nurses' perceptions of needs of women with breast cancer and how these needs were met by health care professionals, they found that nurses were of the opinion that it was essential for supporting the women to provide information relating to the physical aspects of the disease as well as of the process. O’Baugh et al. (2003) found that nurses and patients stated in interviews that they felt that 'being positive' was central to being able to cope with cancer and its treatment.

The experiences, among women with newly diagnosed breast cancer, of the meaning of the illness are also described as a challenge; some of the women meant that their lives had changed in a positive way, they felt e.g. that it was important to prioritise other things in their life compared to previously, and did
so (Luker et al. 1996, Arman & Rehnsfeldt 2002). Jensen, Bäck-Pettersson and Segesten (2000) report that women acquired strength to cope with their illness by talking to others in the same situation. Landmark et al. (2001) illuminate existential awareness among women with newly diagnosed breast cancer; there were feelings of fighting death and having the will to live, in spite of a changed life situation and the knowledge that the future was uncertain.

Living with terminal cancer might help people to discover a spiritual meaning (Thomas & Retsas 1999). A similar result is reported by Arman et al. (2002), women suffering from breast cancer found a new understanding in their life and the suffering left the way open for existential questions. Several authors (Lindholm & Eriksson 1993, Strang, Strang & Ternestedt 2002) emphasise the importance of taking notice of spirituality in the care situation. When patients seek the meaning of life and suffering they also simultaneously seek the meaning of death. According to Glaser and Strauss (1968, pp. 163-165) seriously ill patients, with the prospect of a long drawn out dying in front of them, have to come to terms with their mortality. They must be aware of the threat to their continued existence as self, and the fear of such things as pain and physical disfigurement. Sears, Staton and Danoff-Burg (2003) used interviews and questionnaires in a longitudinal study of women with early stage breast cancer. They found that some women actually benefited from the experience and showed posttraumatic maturation.

The entire family situation changes in connection with a serious disease. Several studies (Lewis, Ellison & Woods 1985, Lewis 1999, Northouse 1989, Zahlis & Shands 1991, Helseth & Ulfsaet 2003) show that relatives had the same feelings of powerlessness and ambivalence as the women. The children were sad and afraid; sometimes they found it difficult to handle the situation. The husbands’ thought about the future, concerned with the extent of the illness, anxiety for recurrence and death, and when there were children involved how they would be able to take care of them if the wife died.
Pervading characteristics for all of the above mentioned studies deal with women’s, and their families’ experiences of the uncertainty for the future, concerning diagnosis, treatment and anxiety for death, searching for the meaning of the illness, as well as trying to find some positive outcomes of the illness.

Need for support for women, their relatives and caregivers

There is need for support among the affected women during all stages of the breast cancer disease (Pålsson & Norberg 1995, Halldórsdóttir & Hamrin 1996, Nelson 1996). This need for support changes over time, is individual and can be provided by relatives, friends and caregivers (Isaksen, Thuen & Hanestad 2003). Wengström, Häggmark and Forsberg (2001) show that individual interventions improved wellbeing in women with breast cancer. Support, as described by patients and caregivers, comprises emotional support, meaning that someone has time to listen, provide understanding and trust. The support also involves providing opportunities to talk about the new, often frightening life situation, as well as adequate information. O’Baugh et al. (2003) reported a review of literature about the importance of being positive to patients’ chance for survival and in interviews patients with cancer described being positive as a way to maintain at least some sort of normality. Support of family, friends and health professionals was identified by nurses and patients as factors that influence patients’ attitudes.

Studies by Northouse (1989), Suominen (1993), and Northouse et al. (1998) show that patients with cancer found it easier to cope with the disease if they were given adequate information and had been able to participate in the decision concerning treatment and care. Harrison et al. (1999) found that women’s needs of information in connection with radiotherapy were significant and did not differ over time. Their study also shows that younger women had a preference for more information than older women. Crooks’ (2001) study about older women with breast cancer shows that these women would have liked more
information than they actually received about e.g. treatment, and that they did
indeed actively search for this. Krishnasamy (1996) describes that individuals
living with a cancer disease often identified emotional and informational
supportive behaviour, e.g. showing respect, listening and understanding, as
being helpful care. Halldórsdóttir and Hamrin (1996) point out that supporting
people living with cancer involves being able to provide ‘sensitive listening’, the
need to be respected as a person and understood by others. Widmark-Petersson,
von Essen and Sjödén (2000) found that patients’ feelings of good caring were
dependent on if the caregivers had recognised patients’ needs, listened to them
and given them support and information in an honest way. Opposite results are
presented by Landmark, Strandmark and Wahl (2002) i.e. lack of continuity and
information by health professionals left women feelings e.g. dismissed or
confused.

Several studies have focused on talking, especially when negative issues
are concerned, such as being diagnosed with a malignant disease. Authors state
that it is important to enable patients to learn to live with the changed life
situation (Tschudin 1997 pp. 1-9, Rogers & Todd 2000). Löfmark and Nilstun
(2000) show in their study that nearly all of the seriously ill patients suffering
from various diseases, e.g. cancer disease and heart failure, experienced being
able to talk about the disease and the prognosis as being positive. Their study
shows that some of the patients had little knowledge about their disease and
treatment, but the opposite could also be found, i.e. the patient had satisfactory
knowledge concerning the situation.

Boman, Andersson and Björvell (1997) show that women with breast
cancer were usually satisfied with the care they received in connection with
breast surgery during the short hospital stay. In the cases where dissatisfaction
was described it was related to lack of trust, information, practical assistance and
emotional support. Ödling, Axelsson and Norberg (1995) report similar findings,
about women newly diagnosed with breast cancer who described the importance
of having somebody listen to them and answer their questions. Graydon et al. (1997) found that women treated for breast cancer needed information during all stages of the disease, to be able to deal with their changed situations. Several studies show that information given in connection with the diagnosis has to be followed up. The patients can be blocked and experience afterwards that they have not been provided with any information (Gyllensköld 1976, pp. 83-141). Drugge (1988 pp. 90-95) shows in her study that some patients had felt that they had not enough energy to ask the doctor what he/she really said, due to the fact that, as they described it, “they felt empty” and “blocked”. Lugton (1997) reports that some women wanted to have friends or relatives to go along with them to the clinic so that they, depending on their feelings, would not forget the information or be unable ask questions.

Several studies have pointed out the need for the opportunity of support for the suffering woman and her family. Foy and Rose (2001) reviewed literature about men’s experience to their partners’ breast cancer and concluded that men often need support, in this nurses have an explicit role. Northouse et al. (1998) found that women and their partners, in connection with diagnosed malignant breast disease, described the period directly following the diagnosis as the most difficult. During this period women and their partners received little support. As Lindholm et al. (2002) show the whole family suffer. They also describe how the partners were given poor support and had to find this by themselves as they were not helped by the health care staff (cf. also Isaksen et al. 2003). Other studies show that partners wanted to know more about the outcome of surgery and continuing treatment, have more interactions with professionals and somebody to share their experience with (Kilpatrick et al. 1998, Samms 1999, Eriksson & Lauri 2000). Persson, Rasmusson and Hallberg (1998) present similar results from a study, which also shows that the need for information was individual. Some spouses did not want information, due to their inability of dealing with the disease.
Taking care of seriously ill patients influences the caregivers, and they need the opportunity to share their experiences with others. In a comparative study between hospice and emergency nurses Payne, Dean and Kalus (1998) found that the emergency nurses were unable to discuss problems with their colleagues and had a higher level of anxiety regarding death compared with the hospice nurses. Studies among caregivers in oncological care have shown that there is a risk for burnout, due to e.g. daily emotional stress (Kash et al. 2000). Corner and Wilson-Barnett (1992) found that newly qualified nurses lacked theoretical knowledge for taking care of patients with cancer and needed further education (cf. Danielson 1992 pp. 246-251).

Blocking behaviour, e.g. when nurses actively lead the conversation away from what the patients express, has been noticed among hospice nurses when in communication with seriously ill people who disclosed their feelings; this behaviour became less common when the nurses themselves had a professional supervisor, who showed interest in their welfare (Booth et al. 1996).

The studies presented above concerned mostly needs for support among women suffering from breast cancer and their relatives are significant, they all have individual needs of support such as talking, having someone who has time to listen, and being provided with information; these needs were often not sufficiently met. Studies concerning caregivers taking care of seriously ill patients show the need of support among them concerning to communicate as well as share their own feelings with other caregivers.

Clinical supervision as support to caregivers
The term clinical supervision is used for various kinds of support. In England (UK) clinical supervision has been traditionally used for supporting nursing students and nurses by implementing various kinds of models such as mentorship for nurses and preceptor ship i.e. assisting a newly graduated nurse for a shorter time period (Butterworth 1998 pp. 1-18). Fowler (1996) points out
that all of these ‘models’ depend on having a relationship between two or more in a group, in order to focus on the needs of one person. He also means that the supervision ought to be individual. Jones (2001, 2003) has described individual as well as group clinical supervision of nurses.

In the Scandinavian countries supervision has been group oriented (e.g. Paunonen 1991, Pålsson et al. 1994, Vänar Hermansen, Bruland Vrâle & Carlsen 1994 pp. 49-71, Olsson, Björkhem & Hallberg 1998, Lindahl & Norberg 2002). Clinical supervision of nurses aims at developing professionalism among them and thereby increasing care quality. The reasoning behind these Scandinavian approaches is that if caregivers are given opportunities, in a regular and organized way, to express and share the problems and possibilities of their profession, they can become aware of and work through their emotional reactions. It is reported that clinical supervision-groups have been successful in decreasing stress and increasing job satisfaction in nurses (Pålsson et al. 1994, Severinsson & Kamaker 1999). The aims guide the supervisor to choose an appropriate style for the supervision sessions. Severinsson and Hallberg (1996) interviewed nurse supervisors and found that nurse supervisors showed two different supervision styles; an emotional and a cognitive supervisory style. The emotional style means emphasis on emotional confirmation of nurses while the cognitive style means emphasis on theoretical understanding and problem-solving.

Hyrkäs and Paunonen-Ilmonen (2001) show that team supervision had effect on the quality of care on wards at hospital and could therefore be used in intervention of nursing practice. Another study by Hyrkäs, Appelqvist-Schmidlechner and Paunonen-Ilmonen (2002) about supervision in multiprofessional teams illuminates how e.g. work motivation had increased depending on the possibility to share experiences with each other (cf. Forsgärde, Westman & Jansson 2002). The opposite was also described when work motivation was less after the team supervision. An evaluation study by Fowler
and Chevannes (1998) shows differences in nurses’ evaluation of clinical supervision; the majority experienced less stress in the work situation related to clinical supervision, while a part of the respondents thought that it increased stress.

In a follow-up study among psychiatric nurses, group supervision in nursing care was shown to have influenced nurses’ feelings of security in their nursing situation, job satisfaction and personal development (Arvidsson, Löfgren & Fridlund 2000). Development of professional solidarity and trust between the psychiatric nurses in a group supervision programme was also described in a 4-year follow-up study Arvidsson, Löfgren and Fridlund (2001). The participants had experienced such as being confirmed, gaining knowledge and a feeling of personal development. Severinsson and Kamaker (1999) conclude the importance of providing nurses with supervision depending on the relationship between nurses’ satisfaction and the quality of care in connection with supervision. In a study by Berg and Hansson (2000), which focused on systematic clinical group supervision and supervised planned nursing care, results of confirming the nurse as a professional person and the patient as a human being, are reported.

Evaluation studies of clinical supervision have reported various kinds of effects. Hyrkäs, Koivula and Paunonen (1999) reviewed 11 empirical studies on effects of clinical supervision during the 1990s and found no reliable and convincing evidence that clinical supervision has effect on nurses or nursing care. Fowler and Chevannes (1998) found that although most of the participants felt decreased stress some participants experienced more stress in connection with clinical supervision. Teasdale, Brocklehurst and Thom (2001) found that clinical supervision helped by giving support in difficult situations, however results reported from their study did not show any effect of reducing the risk for burnout.
The literature review above shows that there are different views about the effect of clinical supervision. Some studies report development of both patient care and the nursing profession e.g. increased work satisfaction, quality of care and feelings of personal development, while other studies show that there is no evidence concerning the effects of clinical supervision
RATIONALE FOR THE STUDY

The literature review above shows that taking care of seriously ill patients makes great demands on caregivers and influences their own situations. However, it can provide caregivers both feelings of satisfaction and bad conscience in their work situation. Women with breast cancer and their families experience uncertainty for the future, concerning diagnosis, treatment and anxiety for death (Gyllensköld 1976 pp. 83-141, Drugge 1988 pp. 81-122, Landmark & Wahl 2002). The studies presented show that the needs for support among women suffering from breast cancer and their relatives are considerable, they all have individual needs of support such as talking and receiving information; these needs were often not sufficiently met (Pålsson & Norberg 1995, Halldórsdóttir & Hamrin 1996, Isaksen et al. 2003). The studies presented concerning caregivers taking care of seriously ill patients show that they also have need for support to be able to communicate with women and their relatives as well as share their own feelings with other caregivers (Andrae 1994 pp. 63-100, Pålsson & Norberg 1995, Hopkinson et al. 2003). Clinical supervision-groups can, as described, influence nurses’ feelings of security in their nursing situation, job satisfaction and personal development (Pålsson et al. 1994, Severinsson & Kamaker 1999, Arvidsson, Löfgren & Fridlund, 2000, 2001). The studies above also show that there is no evidence concerning the effects of clinical supervision (Hyrkäs, Koivula & Paunonen 1999).

In Sweden women with newly diagnosed breast cancer are admitted to surgical wards, at general hospitals to undergo surgery and receive postoperative care. The caregivers on these wards have to take care of these women as well as other patients with, often, an acute disease. The literature review shows that there is little research reported concerning caregivers’ experiences of taking care of women with breast cancer and their own needs for support in surgical care, which is why this study was carried out.
AIMS

The aim of this study is to describe professional caregivers’ experiences of caring women with breast cancer in a surgical ward.

This study comprises four papers regarding caregivers in surgical care with the following specific aims:

I. To describe experiences and outlook on life, suffering and dying among nurses caring for women with breast cancer.

II. To describe caregivers’ perceptions of breast cancer as an illness.

III. To describe nurses’ opinions of the need for care and support for women and their relatives in connection with surgery of breast cancer, as well as their own need for support, on a surgical ward.

IV. To describe the content of caregivers’ presentations of care situations at supervision sessions in a surgical ward.
METHODS AND DATA COLLECTIONS

The study was performed at a county hospital in central Sweden among caregivers in surgical care (Table 1).

Table 1. A schematic overview of the studies

<table>
<thead>
<tr>
<th>Paper</th>
<th>Participants</th>
<th>Data collection</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Nurses * (n=10) on a surgical ward</td>
<td>Semi-structured interviews with narrative parts</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>II</td>
<td>Caregivers ** (n=37) on a surgical ward</td>
<td>Semi-structured interviews with narrative parts</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>III</td>
<td>Nurses * (n=31) on a surgical ward the same as in paper II</td>
<td>Semi-structured interviews with narrative parts</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>IV</td>
<td>Caregivers*** (n=21) (partially new participants)</td>
<td>Tape-recorded supervision sessions (n=38)</td>
<td>Qualitative content analysis</td>
</tr>
</tbody>
</table>

*Nurses= RNs and ENs.

**Caregivers= RNs, ENs, physicians, social worker, physiotherapist, special breast nurse and specialist nurses.

***Caregivers= RNs, ENs, physicians, physiotherapist, special breast nurses.
Setting
The present study was carried out at a county hospital in central Sweden. The surgical ward where the study was implemented accommodated patients with acute surgical diseases; among them women newly diagnosed with breast cancer, those with recurrent breast cancer and women in the terminal stages of the condition. The proportion of patients with breast cancer and patients with other surgical diseases was 11% and 89% respectively. Women on oncology treatment (endocrine, and chemotherapy), both adjuvant and palliative, received this treatment at the oncology out-patient clinic at the same hospital and a medical oncologist from the regional hospital consulted at the surgical department once a week. Prescribed radiotherapy was given at the oncology centre located at the regional hospital.

The caregivers’ structure daytime, on the ward with 22 patients, comprised 9.8 RNs including the head-nurse, 10.0 ENs and 4.0 surgeons. The organisation also consisted of caregivers, 1.9 RNs and 1.9 ENs, who were solely on special night duty. Access to a ward medical secretary, social worker, special breast nurse and physiotherapist was also available. The social worker had personal contact with each of the women once or twice, in connection with their hospital stay, and also had telephone contact after they were discharged from the hospital. The special breast nurse used similar routines to the social worker and also met women concerning breast prostheses. Besides their other duties on both surgical and medical wards the physiotherapist instructed the women about physiotherapy before and after the surgical treatment.

Care on the surgical ward was organised as modified group care, i.e. in daytime one RN and two ENs cared for 11 patients with different diseases and among them women with breast cancer. The night duty staff, one RN and one EN, were responsible for the whole ward. The hospital stay in connection with surgical treatment of breast cancer varied between 3 and 5 days and nights. During the period of time the study was being carried out there was a
reorganisation of the entire hospital, which resulted in numerous organisational changes and changes of various types of routines. One surgical ward e.g. was closed and some of the caregivers from this ward were transferred to the ward where the study took place.

Participants
Registered nurses (n=19), ENs (n=12), physician (n=1), physiotherapist (n=1), social worker (n=1) and specialist nurses (n=3), (including 1 special breast nurse) were interviewed (n=37 of whom 1 male). The caregivers ranged in age from 21 to 61 years (MD=41) and had from 6 months to 30 years (MD=7) experiences of surgical care. Nine caregivers were on night duty only. Twenty-one caregivers on the surgical ward (RNs, ENs, physician, physiotherapist and special breast nurses) were offered clinical supervision, lasting 2 hours each session and given every third week during a period of one year. The participants (n=21 of whom 1 male) in the supervision sessions were between 25 and 55 years old (MD=38). They had worked in surgical care for one to 30 years (MD=10).

Social worker (n=1) and specialist nurses (n=2) only participated in the first interview presented in paper II.

Interviews
Semi-structured interviews (Polit & Beck 2004 pp. 341-342) with narrative parts (cf. Mishler 1986 pp. 53-59, Sandelowski 1991) were used in the first, second and third study (I-III), and aimed at having the participants describe experiences and events in their own words. The participants were asked to describe their experiences and outlook on life, suffering and dying among nurses caring for women with breast cancer (I), the perceptions of breast cancer as an illness (II), and the opinions of the need for care and support for women and their relatives.
in connection with surgery of breast cancer and the need among the caregivers themselves for support (III). The interview questions were open, like for example: ‘Please, tell me your perception of breast cancer as an illness’ (I-II), and opinions on the care for women with breast cancer (III). During the interviews (I - III) the interviewer followed up the answers with questions such as: ‘What do you mean?’ or ‘Please, describe that more.’ All interviews were carried out in this way. The interviews were tape-recorded and transcribed verbatim.

**Training in the care of women with breast cancer**

After the interviews the RNs and ENs were invited to participate in a training programme (40 hours) based on the results from the interviews (II, III) and jointly planned with the head-nurse on the surgical ward. The training covered psychological reactions, coping strategies, crisis intervention, communication including written records and assessment of the need in connection with the women’s hospital stay, and medical care for patients with breast cancer. The objective of this training was to gain an increased knowledge (among caregivers) about reactions among women with newly diagnosed breast cancer and how to take care of them as well as discuss implementation of changes in the care. Group discussions were also held regarding the results of the interviews. At the end of the training programme all caregivers taking care of patients with breast cancer (RNs, ENs, physicians, physiotherapist, social worker, special breast nurses and specialist nurses), were gathered together and the whole care process was described from the perspective of the different professionals. All caregivers who participated in the training programme were invited to participate in supervision sessions that started about one year later.
Tape-recorded clinical supervision sessions

The fourth study (IV) concerns tape-recorded clinical supervision sessions. The purpose of the supervision was to give the participants the opportunity to reflect on care situations in a way that would contribute to the development of patient care. Another purpose of the supervision was to provide an opportunity for the participants to share their experiences with each other, reflect and discuss and in this way gain support. I led the clinical supervision sessions and my roll as supervisor was to stimulate reflection on caregivers’ narratives about their experiences as caregivers from ethical, emotional and cognitive perspectives (Vånar Hermansson et al. 1994 pp. 49-71).

The caregivers who wanted to participate in the supervision sessions wrote their name on a list in the nurses’ office. The clinical supervision sessions were planned for one year and with a follow-up after six months. The participants could discontinue their participation at any time, and the supervision was open for new participants, who were able to be present in the sessions more than once.

Twenty-four caregivers announced their interest to participate in the clinical supervision sessions and the head-nurse divided the participants into three groups, comprising eight in each. The participants of these groups were "divided" to form three mixed groups consisting of: RNs, ENs (in every group), special breast nurses (in two groups), physicians (in two groups), and physiotherapist (in one group). Three participants from the “original list” left the group after the first sessions for various reasons, consequently reducing the number to 21 participants. In connection with the autumn term two participants moved to other wards, and two others replaced them in two of the groups. The clinical supervision sessions were located outside the ward, in order to provide the participants with as undisturbed participation as possible.

In the clinical supervision sessions each of the participants were asked to present one short care situation, self-experienced, from their own practice. This
was later reflected on in depth. The participants in the group decided which narrative should be reflected upon. Every session began with a review of the previous session; if a discussion had not been concluded, and the participants who had initiated it were there then it could be continued.

Data analysis

Content analysis can be carried out in various ways, but requires a context in which the available texts are examined (Krippendorf (2004 pp. 18-43). Qualitative content analysis of data has been used in all papers (I-IV). Creating categories is the core feature of qualitative content analysis (Graneheim & Lundman 2004). The analysis includes various steps. First the text is read several times in order to get a sense of the whole, thereafter the text is divided into meaning units which are condensed and coded. The codes are compared based on variations and similarities and abstracted in categories or themes. There is no consensus about the use of the terms categories and themes in the qualitative content analysis. In the present study categories were used in the analyses when the content was visible while themes were used when interpretation of the text was more pronounced.

In the present study the interview texts were read first in order to grasp the content as a whole. In the second reading notes were made in the margins with focus on what was described about the domains proceeded from the question areas: breast cancer as an illness, need of care and support for women, their relatives and the caregivers themselves (II, III). The text parts concerning breast cancer as an illness were extracted to form a separate text (II) and the rest of the material dealing with need of care and support formed another text (III), then a rereading was done in order to grasp the content of the new texts. In papers II-III thematic analyses were used and subthemes and themes were formulated (Baxter 1994). In the further analysis subthemes and themes were noted for each participant, in this way it was possible to see which subthemes and themes
reurred in the text (Patton 2002 pp. 452-453). After forming themes and subthemes the text parts were read again participant for participant and different dimensions were found in the text (II). A similar procedure was used for paper II as for paper III.

In the papers I and IV categories were formulated. Foundation for the categories of paper I consisted of the main domain: breast cancer as an illness. The narrative text parts, on the content areas dealing with life, suffering and dying were put together area for area and formed categories. In paper IV the purpose of the first reading was to grasp the content and ways of reasoning about the topics in the clinical supervision sessions. In the second reading, notes were made for every session, with focus on what was emphasized in the discussion of each group. As paper IV dealt with a large quantity of text the notes have been further marked with different colors for every area and typical words for feelings establish the categories. While analysing the text the author and the co-author/co-authors read the whole interviews (I, III) or parts of the interviews (II, IV). For each paper discussions about the entire content were carried out, until an agreement was reached, with the aim of giving the analysis credibility (Patton 2002 pp. 566-567). The results of the interviews II-III were reported and discussed together with the caregivers on the ward in connection with the training programme, and results of the clinical supervision sessions (IV) were presented at a surgical conference.

**Ethical consideration**

The project was planned in collaboration with the chief physician and the head-nurse on the ward. All caregivers received both oral and written information about the study and it was made clear that participation was voluntary. The caregivers gave their informed consent to participation, and were guaranteed confidentiality and anonymous publication. Before the supervision session started it was established that all stories about patients
should be narrated without patients’ name (even if all of the participants knew the patients) to be able to guarantee patients’ confidentiality and anonymous publication. The Ethics Committee of the Medical Faculty at Umeå University approved the study (§175/94).
RESULTS

Paper I
The first paper presents RNs’ (n=7) and ENs’ (n=3) experiences and outlooks on life, suffering and dying in connection with caring for women with breast cancer in a surgical ward. Three categories are present: life, suffering and dying.

Life was described as either having freedom or not having freedom. Having freedom generally meant being healthy and having a good life. For women with breast cancer, it meant being healthy in the sense that treatments had been completed without recurrence of the illness. Not having freedom implied that the women were ‘bound to’, or tied up with, their cancer, with the illness often ending in painful and agonizing death.

Suffering, regarding nurses’ descriptions of women with breast cancer, deals with both physical and existential suffering. Physical suffering included living with a changed appearance, due to breast loss and metastases (in the terminal stage of the illness it included also breathing difficulties such as suffocation) while existential suffering included anxiety about the future and the anguish of facing death. Some of the nurses had personal experiences of pain and breathing difficulties and referred to this in their narratives.

Dying was described as a process that occurs either naturally or unnaturally. Dying naturally was seen as passing on calmly, without fear and without pain, with the patient dying in his or her own home surrounded by family members. Dying unnaturally was mostly seen as dying in hospital. This process was associated with pain, anxiety and fear of death and with a great deal of medical technology surrounding the dying patient. The nurses gave both negative and positive examples from their own families’ cancer and dying, they said that these experiences had influenced them and subsequently they tried to make things as easy as possible for other dying patients.
The result presented in this paper shows, according to nurses, that women suffering from breast cancer had anxiety for the future and dying. The care milieu on surgical ward had a negative influence on women and their relatives. However, the nurses felt that it is possible to alleviate suffering during dying through providing adequate pain relief but also, through listening, providing information and changing the caring atmosphere.

**Paper II**

Paper II presents caregivers’ (n=37) perceptions of breast cancer as an illness. The overall descriptions show a dark picture. The results are presented in two parts; the first one comprises three themes: *loss*, *progression of the illness* and *annihilation*.

*Loss* of breast and control was described. The loss of breast was described as the worst thing that could happen to young women regarding changed womanhood and body image. The caregivers said that women felt a loss of control because of the prospect of an uncertain future and impossibility to plan their life. The caregivers also described their own fear of being stricken with the illness and the risk of identifying themselves with the women with breast cancer.

*Progression of the illness* deals with treatment, relapse and metastasis. The treatment was described as a long fight or extension of life. The possibility of extending life was however not always described in a positive way. Some caregivers meant that the disease could also develop in a distressing way as a result of the treatment. The caregivers often took it for granted that the illness would recur and the patients would return to the surgical ward. More than half of the caregivers referred to metastasis (*e.g.* to the brain), pain and anxiety.
Annihilation was related to death as the way to the end of the illness and the patient’s life. The illness seemed, in the caregivers’ mind, to often end with a painful death.

The second part in paper II deals with various dimensions found in the caregivers’ descriptions of breast cancer as an illness: ‘lived experience of a dark and a light dimension’, ‘lived experience of a dark dimension and theoretical awareness of a light dimension’, ‘lived experience of a dark dimension only’, ‘theoretical awareness of both a dark and a light dimension’ and ‘distanced approach (no engagement)’

Caregivers experienced both negative events, but also how women survived and had a good quality of life. Caregivers who had the opportunity to work at the outpatient clinic and met women who seemed to be feeling well described a lighter view of the illness. Caregivers experienced negative events but had also a theoretical knowledge of positive treatments effects. A majority of caregivers described breast cancer in this way. Some caregivers described only dark experiences of negative events and also their identification with the women. Other caregivers’ descriptions disclose solely theoretical awareness of breast cancer as an illness without lived experience while some of them had an onlooker’s perspective, *i.e.* caregivers behaved rather neutrally.

The result reported in this paper indicates that caring for women with breast cancer gave rise to predominantly negative and dark associations regarding the illness. According to caregivers living with breast cancer means loss of breast and control, difficult treatments and finally dying in pain and agony. Furthermore the result shows that caregivers on a surgical ward had a fragmented picture of the patients. This indicates that caregivers need to be provided with opportunities to follow the total care process, as those caregivers who were able to follow throughout the various stages of women’s illness more often had a positive picture.
Paper III

Paper III presents nurses’ (n=31) opinions of needs for nursing care and support among women and their relatives in connection with surgery of breast cancer during women’s stay on a surgical ward, as well as of their own needs for support. The results are presented in two parts. The first part focuses descriptions of needs as described by nurses constituting five themes: *the need to talk, the need for information, the need for physical care, the need for contact* (dealing with relatives) and *the need for education* (dealing with nurses).

The nurses mentioned *the need to talk* and *the need for information* as the most important among women, relatives and themselves. Only a few of the nurses described, often only after a question from the interviewer, that they thought that women had *need for physical care*; nurses also emphasized that women with breast cancer do not have any different needs than other newly operated patients. *The need for contact* as described above only concerned relatives, and was described by few of the nurses they also said that these needs were often not met adequately, the nurses either had short or no meetings at all with the relatives.

The nurses themselves expressed a pronounced need for support, and that this need was sometimes unsatisfactorily met. The nurses’ descriptions of needs for information focused on the care different professionals gave the women. *The need for education* for nurses was mentioned by only a few of them. They pointed out lack of knowledge in medicine and nursing but also need of knowledge in subjects such as philosophy, psychology and religion. In some descriptions there were also suggestions for supervision and organized meetings in some form.

The second part in paper III deals with descriptions of how nurses provide for women’s and relatives’ needs, and comprises three themes: *self-experienced situations, imagined situations* and *situations referred to others.*
Self-experienced situations reveals that examples were mostly derived from nurses’ daily work and showed how important the first meeting is for building up a good relationship with the women. When a good relationship was established it was easier to carry out a more profound conversation. Nurses spoke about women’s narratives about their anxiety for the future and their family as well as their need to receive information about the surgical treatment. Few of the participants mentioned needs of the relatives to talk and receive information, nurses often said that they had answered questions during phone calls concerning women’s condition after surgery.

Imagined situations reveals that few examples of women’s need to talk were given but nurses expressed that they hoped that the need would be satisfactorily met. Nurses on night shift thought that nurses on day shift had answered the women’s questions. Enrolled nurses thought that RNs were asked questions and RNs thought that other staff members were asked questions.

Situations referred to others shows women’s need to talk and receive information as very important. However, nurses pointed out that they themselves were not able to meet these needs. They expressed lack of time as a limitation and the fear of starting conversation when they felt uncertain if the women really wanted to talk or not. The nurses described their feelings of uncertainty, especially if the women expected to have a deeper conversation. Instead the nurses often referred to the social worker and the special breast nurse. The need for information was described as being considerable but the nurses themselves did not give it; the ENs felt insufficiency and RNs were uncertain as to what information professionals provided. The nurses were uncertain about how relatives’ needs were met and hoped that the social worker or the physicians dealt adequately with this, but they did not know if this was indeed the case.

The result presented in this paper shows that the nurses described the need to talk and receive information as being the most important need among women with breast cancer, their relatives and themselves. There was a discrepancy
between the descriptions about the needs among women and their relatives and how these needs were provided for. The descriptions were often given from a theoretical point of view with few examples from the daily care. However, in descriptions dealing with personal experiences there are some examples, which show that the nurses had had profound conversations with the women. It appeared that nurses were not fully aware of the needs among women and their relatives and therefore these needs may not have been met. The nurses themselves had a pronounced need for support and this was sometimes unsatisfactorily met.

**Paper IV**

Paper IV presents the content of presentations of difficult care situations in clinical supervision sessions (n=38) among caregivers (n=21) on a surgical ward. The descriptions in the clinical supervision concerned patients’, relatives’, and caregivers’ feelings, with special focus on the caregivers. The results are presented in three categories: discomfort, powerlessness and reduced self-esteem.

*Discomfort* includes the following words for feelings: agony, fear and guilt. Anger occurred when caring for seriously ill women with small children, when the routines around the treatment did not always function and both the women and nurses felt frustrated. Agony was described as occurring when the focus was on patients with an advanced disease in general. The caregivers meant that the agony felt by the patients created a similar feeling in them. In connection with their responsibility for taking care of women with breast cancer the nurses described a feeling of fear when they started with a modified form of primary nursing. It was understood that there was a risk of bonding too closely with the patients and there were difficulties in balancing between distance and closeness. There were also descriptions of guilty feelings when caregivers felt that they, due to lack of time, had been somewhere else when patients needed them. Some
patients committed suicide after being discharged and this was described as giving caregivers feelings of guilt for having failed to recognize the signals while taking care of these patients.

*Powerlessness* includes the following words for feelings: abandonment, helplessness, hopelessness and impotence. Feelings of abandonment were described *e.g.* when the caregivers experienced themselves as being unable to help dying patients, they expressed abandonment when, as they saw it, ‘only nursing care was left.’ Helplessness was described when patients experienced very severe pain and the physician was not able to come as soon as needed by patient and relatives. The caregivers who participated in the supervision sessions described feelings of helplessness when patients had to return to a negative home milieu, as caregivers saw it. Hopelessness was described when caregivers on the ward experienced that patients were offered meaningless treatment when the disease had advanced so far that no medical treatment could offer cure. The caregivers noted it would be better for patients to die in an earlier stage of the disease before so many complications arose. Feelings of impotence were described when patients’ disease developed very quickly and the relatives and caregivers were unprepared for the patients’ sudden death. There were also descriptions of patients who went into denial of diagnoses and refused to accept prescribed treatment or when patients declined pain relief and basic care.

*Reduced self-esteem* includes the following words for feelings: alienation, insecurity, insufficiency, uncertainty, unworthiness and violating. Alienation dealt with experiences such as feeling like an outsider in connection with working alone, or constant changes of organization and new routines. The caregivers described that they had no opportunity to influence their own situation. Insufficiency was described in connection with a stressing care milieu. Caregivers had to take care of seriously ill patients who appeared to be afraid and relatives who needed contact, and they felt that they did not have the strength to meet these needs due to lack of time, which subsequently caused
them to regard themselves as insufficient. Uncertainty was described specifically in connection with care of seriously ill patients and newly employed caregivers felt that they were unable to provide as good care as they would have like to, due to the fact that important routines and rules were lacking. In some situations the caregivers described themselves as ‘stupid’, because of misunderstandings between the professionals and relatives. Violating was described when patients and caregivers misunderstood each other and caregivers felt violated and thought that perhaps patients felt the same way.

The result presented in this paper shows the opportunity to reflect on difficult care situations. When caregivers were provided with the opportunity to describe and reflect on daily care situations, they choose these from difficult situations. These situations became the sources for discomfort, powerlessness and reduced self-esteem. The descriptions focused on women’s and relatives’ needs for support and personally experienced failure.
DISCUSSION

Discussion of results
Caregivers’ perspectives, regarding living as a woman with breast cancer, implied a great deal of suffering, which often ended in a painful death, (I) loss, progression of illness and annihilation (II). According to the nurses, patients, their relatives as well as caregivers themselves had considerable need for support (III). From caregivers’ perspectives, in clinical supervision sessions, taking care of women with breast cancer evoked feelings of discomfort, powerlessness and reduced self-esteem (IV).

To live with breast cancer as described by nurses, implied leading a life either having freedom or not having freedom and physical and existential suffering. Life was often described as being a good life when there was no suffering (which nurses said was not possible) and there was the prospect of a ‘good death’ (cf. Cronqvist et al. 2004), which would occur in a home-like milieu. The descriptions of suffering were often related to how the nurses themselves thought they would react if they were to suffer in this way. The suffering in form of loss, pain and breathing difficulties at the end seemed to frighten the nurses. Personal experiences of pain and breathing difficulties had as they said, influenced them in noticing symptoms relating to this. Studies show that caregivers’ attitudes to cancer and cancer care are influenced by personal experiences, e.g. if they themselves or their close relatives had suffered from cancer (Kuuppelomäki 2000, McCaughan & Parahoo 2000, Quinn 2003). These experiences could help caregivers to provide a better care but there was also a risk that they caused them to distance themselves from the patients (cf. Tarzian 2000). When nurses described suffering they described feelings of helplessness and inability to help the suffering and dying women. According to nurses dying could occur either naturally or unnaturally (I). Notable is that the narratives about dying unnaturally dealt with dying in hospital. The care atmosphere on a
surgical ward is characterised by stress and medical technology, which the nurses meant had a negative influence on the dying patients and relatives. In the present study nurses expressed wishes to create as good a care and milieu as possible for alleviating the suffering and the dying process. Similar results are reported by Andershed and Ternestedt (2001) who conclude that it is immensely important for the care culture to be adequately designed in order to allow the caregivers the opportunity to provide satisfactory care, which should include relatives’ involvement in the care and facilitating the patient’s death.

Descriptions concerning the loss of a breast occurred in many of the narratives (I, II). During the period of data collection breast saving surgery was practised in most of the cases, nevertheless most of the caregivers described the loss of a breast as something horrendous. This has to be seen in the light of almost all the participants being women (1 male), which made it possible for them to identify with the women referring to their own feelings if this would happen to them, to a daughter or mother of the same age as the patient.

The progression of the disease as caregivers saw it dealt with treatment, relapse and metastases and in a few cases recovery. Caregivers’ perceptions of the treatment were described in two ways, at the same time as it was positive and saved life or prolonged it, it also prolonged life in a negative way, *i.e.* the disease progressed and caused women unnecessary suffering. These thoughts were expressed both in the interviews (I-II) and during the supervision sessions (IV). Many of the caregivers indicated that some patients had received meaningless treatment, when it would have been better to allow them to die in peace and with dignity (I, II, IV). Similar results are described by Lindseth *et al.* (1994) and Cronqvist *et al.* (2004) where the caregivers found it unethical to give dying patients too much and meaningless treatment. Udén *et al.* (1992), Udén, Norberg and Norberg (1995) and Åström *et al.* (1993) found that the caregivers experienced the care situation as being very complex and therefore had difficulty in doing what they saw to be right from an ethical perspective.
In the present study breast cancer in some caregivers’ mind implied annihilation and that the progress to the end was painful. This has to be seen in the light of the fact that caregivers on the ward seldom saw women who recovered, they only met women at the beginning of their illness and the next time they saw the women with breast cancer was when the disease had recurred and the women were in poor condition. It seems reasonable to assume that the caregivers’ attitude regarding the disease depended on the possibility of them following the women during the whole care process. The caregivers who had also met the women at the outpatient clinic saw that the women felt good and that life continued in a positive way (II). Hanson (1994 pp. 90-103) found that nurses in the care of women with breast cancer were perhaps influenced by negative attitudes among medical professionals and mass media. In the present study the nurses pointed out that they did know that many of the women survived and experienced a good quality of life, but the nurses did not meet these women, i.e. their daily experiences influenced them in a negative way.

Nurses’ opinions of needs among women, relatives and themselves focused on talking and information (III). Several studies have shown the importance of communication in difficult situations among patients, but also among their relatives and caregivers (cf. Wilkinson 1991, 1999). All human beings communicate in some way. Watzlawick, Beavin and Jackson (1967 pp. 48-71) point out that it is impossible not to communicate. Information is one aspect of communication, while the other is relationship. The first message is what we communicate and the second is how we communicate. Communication can occur at different levels in all human encounters. In situations of communication the message can be full of contradictions because it can happen at different levels. One thing can be communicated verbally and another non-verbally. There are special situations when the message in the communication is difficult to understand. This can happen for example if we do not understand the language used, e.g. medical terms, or if we are blocked for various reasons. It is
imperative that the message gets through. If the receivers are stressed or blocked this can make it difficult for them to take in the message. The same thing would happen if the caregivers themselves were blocked. Wilkinson, Gambles and Roberts (2002) and Fallowfield et al. (2003) show that training in communication improves caregivers’ skills in cancer care.

It appears from this thesis that caregivers experienced lack of support both for patients, their relatives and themselves. Kash et al. (2000) found in their study about stress and burnout in oncology care, that negative experiences from daily work could contribute to burnout, and it is therefore necessary to support and restrain the caregivers. Lewis (1999) found that education and support groups, like those used to prevent burnout had positive effects on nurses’ ability to learn to cope with difficult situations in oncology care.

As described earlier the caregivers in the present study mentioned the need to talk and for providing information among patients and their relatives as being important, but many of them did not seem to have any personal experiences of meeting these needs (III). The reason for this could be organisational obstructions, or an uncertainty as to the responsibility of other caregivers. Corner’s (2002) review about nurses’ experience working with patients with cancer shows that nurses’ difficulties seem to be associated with structural factors rather than with caring for dying patients. Similar results are reported by (Hjörleifsdóttir & Carter 2000, Tishelman et al. 2004) when nursing students and nurses wanted to be with a dying patient, but lack of time and other acute situations had to be prioritised. Maslach and Leiter (1997, pp. 38-78) state that causes of burnout among caregivers, which has been in focus before, can be found in an insufficient organisation and not only in the persons themselves. The work situation for the employees has been more complex and intensive, often with reduced work satisfaction and feelings of lacking control.

Another point of view is, negative feelings, such as a personal fear of dying or uncertainty of women’s wish to talk. Some nurses expressed uncertainty
about how they would begin a talk and answer difficult questions. This could explain why the needs mentioned, to talk and receive information, and descriptions of how to provide for them were done in different ways, *i.e.* some of the caregivers, maybe did not have any personal experiences of providing for the needs to talk and gain information. The caregivers with personal experiences of providing for the need to talk and gain information described how they first tried to gain confidence and thereafter were able to enter into a relationship, which subsequently led to being able to have deeper conversations (*cf.* Houtepen & Hendrikx 2003). According to Fredriksson and Eriksson (2001) our ability to listen depends on what we bring with us. Our own experiences do actually colour what we listen to. Hanson (1994 pp. 27-28) points out that negative feelings can be transferred to patients. It appears from this thesis that some caregivers said that they behaved in a neutral way to the illness (II), but compared with the results above this seems to be impossible.

Support, in connection with suffering from breast cancer, was described as making it possible for all who get involved in the care to be able to talk and receive information. The nurses meant that relatives had the same need of talking and receiving information as the patients. However, as described (III) even although the nurses thought so, they did not know how these needs were met or if indeed they were met at all. Lindholm *et al.* (2002) found that relatives’ suffering was unrelieved, compared with suffering of women with breast cancer. Relatives described feelings of being in the background as well as being in conflict with their own suffering and their possibility to alleviate the women’s suffering.

In the clinical supervision sessions (IV) the discussions and reflections were about difficult care situations. In some particular situations discomfort was seen to be due to feelings of guilt in connection with the news that some patients had committed suicide after discharge (IV). The caregivers expressed that they perhaps had missed signals when taking care of those patients during their
hospital stay. Maybe communication had occurred at different levels or the message had not been received due to other reasons (cf. Watzlawick et al. 1967 pp. 48-71, Wilkinson 1991, 1999, Bakker et al. 2001). Another example of feelings of guilt was the caregivers’ experience of having been somewhere else when needed. The character of surgical wards, often with an atmosphere of stress and high tempo, was pointed out as being one of the reasons why this is not always the best place to be for seriously ill patients with a need to talk, receive information and have someone only to be there with them (cf. Crockford et al. 1993, Idvall & Rooke 1998, Wilkes et al. 1999). The caregivers had to prioritise acute care, which left them with feelings of disloyalty and an experience of having missed some other important aspect of care. Lundgren and Segesten (2001) found that nurses on a medical-surgical ward that spent more direct time actually caring for patients after an organisational change to an all RN staff.

Powerlessness (IV) dealt with feelings of abandonment. This was described especially by caregivers when they had to take care of dying patients when, as they saw it, ‘only nursing care was left.’ This can be compared with the study by Andrae (1994 pp. 63-100) dealing with physicians in cancer care, where some of them in connection with caring for dying patients felt doubtful of their medical capability and uncertain in connection with visiting patients if there was not something that could be done to help medically. Other difficult care situations, which were reflected on in the clinical supervision sessions were the caregivers’ feelings of helplessness, such as when patients went home to a negative home milieu; they felt that it was their responsibility to do the best for patients both during and after the hospital stay. This can be compared with results reported by Sundin-Huard and Fahy (1999) where the risk for moral distress and burnout occurred specifically when nurses acted as patients’ advocates.

Reduced self-esteem (IV) dealt with situations such as uncertainty about new routines or insufficiency depending on lack of time. The lack of knowledge
about other professionals’ duties led to misunderstanding and feelings of unworthiness, particularly when the caregivers experienced that patients with intolerable pain were receiving inadequate analgesic or meaningless treatment. Feelings of uncertainty as described by caregivers concerning the information given to women trying to deal with their cancer diagnosis led to difficulties when answering questions they had been asked by patients (cf. De Valck & Van de Woestijne 1996, Hjörleifsdóttir & Carter 2000). In a study by Oberle and Hughes (2001), among caregivers in terminal care, it was pointed out that moral distress experienced by caregivers could be minimised through discussion between professional groups involved in the care, and this could probably be the case in cancer care, through all stages of the disease.

The importance of helping patients to find meaning in what is happening and to maintain hope is described in nursing literature (e.g. Travelbee 1971 pp. 77-83) and reported studies (e.g. Rustoen & Hanestad 1998). Benzein and Saveman (1998) found that nurses’ actions in care situations could influence patients’ hope in both positive and negative ways, e.g. if the patients had confidence in the treatment or the opposite, felt they were treated badly; nurses own positive or negative attitudes seemed to influence the patients. Caregivers on the ward affirmed that they sometimes felt like the women were feeling, i.e. they shared women’s suffering (IV). A study by Fridfinnsdottir (1997) shows that women with breast cancer needed someone to share their fear with. Lewis (1999) has reported similar findings about caregivers’ need of someone to share their fear with, their dispiritedness and difficulties in connection with caring for seriously ill patients.

The present study illuminates that nurses seem to have an ideal image of nursing care (cf. Tishelman et al. 2004). The descriptions were often about the support the nurses’ thought the women and their relatives should receive, and they wanted to do the best out from that. However, on one side they pointed out that they could support patients by listening and just being there with them, on
the other side they talked about “only nursing care is left” when no cure is available. Maybe the nurses had adopted the medical profession’s view that to cure was the primary option and did not see caring of equal importance, or it may be an expression for the helplessness they felt when they could not do what they wanted to do. However in connection with cure there is also care. Caregivers’ descriptions of helplessness and their inability to change situations that they felt were wrong could well influence them in a negative way. Studies about moral stress have illuminated the risk for burnout when the caregivers know how to do but do not have the possibility to do what is right from an ethical point of view. Lützén et al. (2003, p. 319) have identified preconditions to moral stress such as, “nurses experience that external factors prevent nurses from doing what they think is best for the patients and nurses believe that they have no control over the specific situation.” Descriptions concerning feelings of lack of control occurred in many interviews as well as in the clinical supervision sessions.

Caregivers’ descriptions of caring for women with breast cancer show a lot of negative experiences of helplessness and frustration. They met patients who suffered in various ways and had considerable need for support. Caregivers often found themselves unable to meet these needs due to organisational obstacles such as lack of time, vague rules and routines as well as a lack of knowledge. In the narratives where caregivers felt satisfied with the care dealt with e.g. getting the chance to create a good relationship and in this way being able to hold a satisfactory conversation. The ‘satisfactory conversation’ was made possible due to being able to sit down and just be there for the patient.

In this thesis many negative statements have been reported. However, caregivers had both positive and negative experiences of caring for women with breast cancer, even if the negative experiences seemed to dominate. Caregivers were able to express their feelings in both interviews and clinical supervision
sessions, *i.e.* ‘shared their experiences with others’ and in this way probably gained support.

**Methodological considerations**

The results in this thesis are based on interviews and tape-recorded clinical supervision sessions. The interviews were semi-structured narratives, aimed at apprehending the participants’ narratives and descriptions of feelings and thoughts in their own words. In interview situations there can be a risk of the interviewer dominating the conversation or enhancing it with personal experiences (Sandelowski 1986). The aim here was that the participants would be able to narrate as freely as possible, with the exception that answers would be given for different areas of questioning. One weakness in the interview situations could be that I was well known on the surgical ward and the participants might have answered in a way that they thought I wanted them to do. The results of the interviews were reported and discussed together with the nurses in connection with the training programme. Some statements from the participants were about the dark image of breast cancer as an illness and the care of the women *e.g.* “This is just like how I feel”. The fact that I was familiar with the care of women with breast cancer and also with the caregivers could be seen as an issue of strength and/or a weakness in the study. There was a risk that because of my pre-understanding I was well initiated in the narratives and did not feel it was necessary to ask follow-up questions, but then again the positive thing about this was that when the participants missed some important area I noted this and asked them to describe it. Another strength of the study is that descriptions of caring for seriously ill patients have been illuminated both in interviews and in the clinical supervision sessions. Content analysis was used as the analysis method in the whole material (I-IV). According to Patton (2002 p. 556) this is triangulation of sources. The focus on the clinical supervision
material was on difficult care situations, with similar descriptions of experiences as earlier described in the interviews.

There are some risks for subjectivity in the work with the analysis and interpretation; this study was reduced due to the participation of the co-researchers. They had parts/whole of the text highlighted in red, which were based on the interviews and the clinical supervision sessions, and subsequently could follow the whole process of the analyses and together discuss the interpretation together.

The fact that the above described content analysis was used in all studies in this thesis could be seen as a weakness but also as a strength. One question is could other methods in a mixed design with qualitative and quantitative approach have led to other results. However, the purpose of this thesis was to describe caregivers’ perceptions of needs for support among women with breast cancer, their relatives and themselves in a surgical ward. Its strength is that using one analysis method in all studies made it possible to follow the results in the same way in all studies. The study (IV), regarding the clinical supervision sessions (n=38), is based on a considerable amount of data and conforms the results in the interview studies, which strengthens the trustworthiness of the thesis.

The study is limited to one surgical ward, and focused on caregivers’ experiences of caring for women with breast cancer. However, the qualitative results in this thesis can be transferred to similar context. The results ought also to be applicable on other hospital based cancer care.
CONCLUSION

The main results in this thesis show that caregivers’ descriptions of caring for women with breast cancer comprise a lot of negative experiences of powerlessness and frustration. They met women and their relatives who suffered in various ways and had considerable need for support. The most prominent needs among women and their relatives illuminated in the caregivers’ descriptions were to get responsibility to talk, to get information and that someone had time to listen and only be with them. Caregivers often found themselves unable to meet these needs due to organisational obstacles e.g. lack of time and lack of knowledge about other caregivers’ responsibility in the care. Caregivers personally felt that they did not get support as needed to give a good care.
SUMMARY IN SWEDISH-SVENSK SAMMANFATTNING

För att kunna ge god vård till kvinnor med bröstcancer är det av betydelse för vårdpersonal att ha kunskap om sina egna reaktioner på sjukdomen och hur kvinnan och hennes närmaste anhöriga upplever hennes sjukdom. Att drabbas av bröstcancer innebär svåra påfrestningar för den drabbade men även för de närmaste anhöriga. Känslor av maktlöshet och ängslan för behandlingar, eventuella återfall av sjukdomen och oro för framtiden påverkar hela familjen.

Att vårda svårt sjuka patienter kan upplevas både tillfredsställande och otillfredsställande. Känslor av tillfredställelse är kopplade till upplevelsen av att ha givit en god vård och stöd till kvinnan såväl som till de anhöriga. Känslor av otillfredsställelse hos personalen kan orsakas av att de inte har möjligheter att prioritera svårt sjuka och döende i vårdarbetet.

Syftet med forskningsprojektet var att beskriva vårdpersonalens upplevelser/erfarenheter av att vårda kvinnor med bröstcancer på en kirurgavdelning.


Delstudie I visar sjuksköterskor och undersköterskor syn på livet, lidandet och döendet i samband med vård av kvinnor med bröstcancer. Livet beskrevs i termer av frihet eller ofrihet. Att vara fri innebar frihet från sjukdom, och att bröstcancern var under kontroll. Lidandet beskrevs som fysiskt och existentiellt. Det fysiska lidandet var relaterat till kroppsförändringar och smärter medan det existentiella lidandet innehöll oro för framtiden och döendet. Döendet beskrevs som naturligt eller onaturligt. Det naturliga döendet beskrevs som att dö lugnt i sin hemmiljö omgiven av familjen och med kontroll över...
smärtan. Det onaturliga döendet förknippades med att dö på sjukhus med smärta, oro, ångest och med medicinsk teknik runt den döende patienten i en främmande miljö. Lidandet och döndeprocessen ansågs kunna lindras genom lyssnande, information, adekvat smärtlindring och förändringar i vårdmiljön.

Delstudie II visar att vårdpersonalen hade en mörk syn på bröstcancer som sjukdom. Det framstod som om personalens upplevelser av att ha vårdat många svårt sjuka i avancerat skede av sjukdomen påverkade deras syn på bröstcancer negativt. I beskrivningarna av sjukdomen betonades särskilt förlusten av brösten och egen kontroll av livet samt negativ utveckling av sjukdomen med svåra behandlingar som följd och en smärtfull död. Personalen hade olika erfarenheter av att vårda kvinnor med bröstcancer, en del beskrev egna erfarenheter av att kvinnorna hade god livskvalitet medan andra endast relaterade till teoretiska kunskaper om att kvinnor kan ha god livskvalitet. De senare mötte aldrig kvinnor som tillfrisknats. De av personalen som hade haft möjlighet att följa kvinnorna under hela vårdtiden hade en ljusare syn på bröstcancer som sjukdom.

I delstudie III beskrev sjuksköterskor och undersköterskor olika behov av vård och stöd i samband med bröstcancer. Att få möjlighet att tala med någon och motta information beskrevs som det mest betydelsefulla för kvinnorna och deras anhöriga samt för dem själva. Det fanns en skillnad mellan vad de beskrev som viktiga behov och hur de beskrev att dessa behov tillgodosågs. Behoven bland kvinnor och deras anhöriga verkade i en del fall vara okända för sjuksköterskor och undersköterskor med risk för att de inte blev tillgodosedda. Sjuksköterskor och undersköterskor hade ett uttalat behov av stöd, vilket också ibland var otillfredsställande tillgodosedd.

I delstudie IV redovisas att vårdpersonalen hade möjlighet att i handledning reflektera över vårdsituationer i relation till patienter, anhöriga och dem själva. Reflexionerna berörde oftast svåra vårdsituationer och personalens egna känslor dominerade i beskrivningarna. Svåra vårdsituationer i samband med vård av kvinnor med bröstcancer i avancerat skede eller andra svåra sjukdomstillstånd
beskrevs ge känslor av obehag, maktlöshet och minskad självaktning.
Beskrivningarna handlade också om hur personalen trodde att patienter och
deras närmaste anhöriga upplevde olika svåra situationer.

Vårdpersonalens beskrivningar av att vårda kvinnor med bröstcancer
visade på negativa erfarenheter som gav känslor av maktlöshet och frustration.
De mötte lidande kvinnor och deras anhöriga med stora behov av stöd men
ansåg sig ofta vara oförmöga att tillgodose dessa behov. Vårdpersonalens
bristande kännedom om varandras ansvarsområden och tidsbrist ansågs bl.a.
vara hinder för att kunna ge god vård.
ACKNOWLEDGEMENT

This study was carried out at the Department of Nursing, Umeå University. Numerous people have given me support and help throughout the years it took to complete this work and I would like to express my gratitude to everyone who made it possible:

First of all I would like to thank all participants in the study, and all other staff at the surgical clinic involved in the study, for giving time and sharing experiences throughout an already stressful work situation, former, chief physician Svend Borup, the Surgical Department of the County Hospital, who allowed me to ‘invade’ the surgical ward and for supportive discussion and advising talk.

My three supervisors: Associate Professor Ella Danielson the Sahlgrenska Academy at Göteborg University, Faculty of Health and Caring Sciences, Institute of Nursing, and former the Department of Health and Nursing Sciences, Mid Sweden University, for all ‘nights work’ and never ending energy and for friendship, Associate Professor Lilian Jansson Department of Nursing, Umeå University, for listening and advising me in connection with clinical supervision sessions and Professor Astrid Norberg Department of Nursing, Umeå University, for being a source of inspiration and humour and for constant encouragement throughout all stages of the study. The colleagues at the Department of Nursing, Umeå University, for letting me be part of your warm and developmental atmosphere, Mrs. Inga-Greta Nilsson, and Anita Sjöberg for always being supportive.

My colleagues and friends at the Department of Health and Nursing Sciences, Mid Sweden University, Östersund for support and interest in the work. My special thanks to Titti Melin Johansson, Margareta Paulson, and Marianne Swedlund who shared many times listening and discussing during the years of work with this thesis.
Mrs Kristina Hohwelieand Inger Hamrin, librarians at Mid Sweden University for excellent service and for always helping me with various sources. My thanks to all members of the staff at the library Mid Sweden University, and at the County Hospital Östersund. Gunilla Hallmans for typing the supervision sessions. Winifred Ross in memoriam, Brenda Höglund and Dorothy Björklund for revision of the English language.

Finally all my friends and, last but not least, my sister Ingrid and family, my sister-in-law Lotta and her daughter Katja with family, thank you for listening and sharing my experiences during all these years.

I am grateful for the financial support of the County Council of Jämtland, Research and Development Unit in the County Council of Jämtland, Mid-Sweden University, Swedish Foundation for Health Care Sciences and Allergy Research, the Joint Committee of the Northern Health Region of Sweden and Lion’s Cancer Research Foundation, Umeå University and the Cancer and Nursing Foundation, County Council of Jämtland.
REFERENCES


Danielson E (1992). *Nursing and its psychosocial elements: Nursing students’ perceptions of central terminology and reactions in relation to a nursing*


