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Nursing interventions in radiation therapy

- Studies on women with breast cancer

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To the men in my life

Jozsy, Daniel and Joel

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ORIGINAL PAPERS

This thesis is based on the following papers, which will be referred to by their Roman numerals:

- I. Assessing nursing problems of importance for the development of nursing care in a radiation therapy department. Wengström, Y. and Häggmark, C.
Cancer Nursing 21 (1): 50-56, 1998.
- II. Effects of a nursing intervention on subjective distress, side effects and quality of life of breast cancer patients receiving curative radiation therapy – A randomized study.
Wengström, Y., Häggmark, C., Strander, H., Forsberg, C.
Acta Oncologica, 38,(6), 763-770, 1999.
- III. Perceived symptoms and quality of life in women with breast cancer receiving radiation therapy. Wengström, Y., Häggmark, C., Strander, H., Forsberg, C.
European Journal of Oncology Nursing, In press March 2000.
- IV. Coping with radiation therapy- Effects of a nursing intervention on coping ability for women with breast cancer. Wengström, Y., Häggmark, C., and Forsberg, C.
International Journal of Nursing Practice. In press 2000.
- V. Coping with radiation therapy - Strategies used by women with breast cancer.
Wengström, Y., Häggmark, C, and Forsberg, C.
Submitted.

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ABSTRACT

The general aim of this thesis was to acquire knowledge to be used to improve the care of cancer patients during and after radiation therapy, in particular for women with breast cancer. The specific objectives were first to assess nursing care problems of importance for the development of nursing care in a radiation therapy department and secondly to evaluate possible effects on side-effects, coping ability, and subjective distress of a nursing intervention based on Orem's self-care theory.

A structured communication process according to the Delphi technique in three phases was used to assess perceived nursing care problems in the care of the cancer patient and in work with other professionals from the nurse's perspective. The nurses reported; poor follow-up of patients after completion of treatment, lack of time to document nursing care given and lack of time to treat patients as the most problematic areas of importance for the development of nursing care.

One hundred and thirty four patients participated in the randomized study. The experimental group consisted of 67 patients, as did the control group. No measurable effect of the nursing intervention was found for side effects or quality of life. However, the nursing intervention proved to have positive effects in minimizing stress reactions ($p < 0.05$). Further, the results showed that the intervention provided patients older than 59 years with stronger motivation to be emotionally involved ($df=2$, $F=3.463$, $p < 0.05$).

Side effects experienced the severity of the most commonly reported side effects, and quality of life during and up to three months after treatment, included analysis of the whole group ($n=134$). Experienced side effects and their severity increased as the treatment progressed. Fatigue, sleep disturbances, skin symptoms, dry mouth, sore throat, pain, nausea, cough and dyspnea were the most commonly reported side effects. Quality of life improved as treatment progressed.

The women used several strategies to cope with the treatment, and these changed over time. Family and friends had a positive impact on the coping process at all points of measurement. In addition, work and contact with colleagues provided the women with a sense of normalcy. The women used a broad spectrum of own activities to aid recovery.

In conclusion, there was a significant effect of the nursing intervention on the degree of emotional involvement for patients aged over 59 years. This type of intervention should be directed towards patients risking poor adjustment, such as older age groups.

The persistent pattern of symptoms and side effects implies that the period from the second week during treatment up to two weeks following its completion is the critical time for targeting interventions for symptoms and side effects of treatment. Nursing care in radiation therapy should be organized in a way that provides nurses with sufficient time for the provision of nursing care.

Social support such as family, friends and work outside the home seemed important to the women in order to cope with the treatment. The identification of patients risking poor adjustment such as single, widowed or unemployed women offers important challenges during and after completion of treatment, and interventions are required to meet their needs.

INTRODUCTION

The inspiration for the work in this study originates from my clinical experience as an oncology nurse at the Radiation Therapy Department of the Oncology Clinic, Radiumhemmet, Karolinska Hospital, Stockholm.

The art of nursing practice in radiation therapy includes respectful care, promotion of well-being and quality of life, and advocacy on behalf of the patient. The concept of optimal symptom control is a final measure of such advocacy and a trust that needs to be nurtured and guarded.

At the beginning of 1991 when I started working in the department a new organization of providing nursing care, the “primary nursing system” had recently been introduced. For me a new nurse examinee the system gave a sound foundation for nursing but also raised new questions and prompted a search for understanding the field of radiation oncology nursing and its foundation for the practice of nursing. My perspective is concerned with, where possible, facilitating change in nursing care, and for research to play a part in this. This thesis and the work presented in it hopefully illustrate my research issues and learning process.

BACKGROUND

BREAST CANCER

Breast cancer continues to be a worldwide health problem for many women. The incidence of breast cancer in Sweden has for the last decade continuously increased every year by 1.0 percent. In 1997 breast cancer represented 27.5 % of female cancers. This year approximately 5 300 women will receive a breast cancer diagnosis (National Board of Health and Welfare, 1999). Breast cancer represents the most common cancer diagnosis in Sweden as well as in other Western industrial countries (Rutqvist and Wallgren 1998). Invasive ductal cancer accounts for approximately 80 % of all invasive breast cancer (Leibel and Phillips 1998).

Diagnosis

In general, breast cancer presents itself as a painless mass discovered by the patient or a physician on routine examination. On occasion a painful breast mass may turn out to be malignant, but usually painful masses are associated with cysts. Other symptoms may be a bloody nipple discharge or a disfigurement of the nipple or breast. Inflammatory or locally advanced breast cancer may present itself as a redness, heat increase or thickness of the skin. Any palpable breast mass should be evaluated until a diagnostic conclusion can be reached. Diagnosis of a breast cancer tumor is based on a clinical examination including inspection and palpation, bilateral mammography and cytology using fine needle aspiration or a stereotactic aspiration technique (Rutqvist and Wallgren 1998).

The cause of breast cancer is not known but risk factors have been identified. Gender, age, geographical origin, previous cancer in one breast or epithelial hyperplasia of breast tissues are seen as predictive factors. Other factors include nulliparity, first pregnancy after 30 years of age, early menarche, late menopause, exposure to ionizing radiation, obesity and a high fat diet, estrogen use, alcoholic drinks and urban environment (Spratt, Donegan and Sigdestad 1998). The clinical/histopathological stage and the biological characteristics of the tumor are the main prognostic factors for primary breast cancer (Rutqvist and Wallgren 1998).

Psychological & psychosocial aspects

There is no doubt that the diagnosis of cancer is a universally stressful life event frequently associated with an increase in distress at population level (Spiegel 1997). Patients recently diagnosed with breast cancer suffer a variety of stressors. These include the fear of dying of the illness, going through demanding treatments, threats of disfigurement, loss of energy,

demands on time, vocational difficulties and social isolation (Maraste, Brandt, Olsson and Ryde-Brandt 1992; Carlsson and Hamrin 1994; Hassey Dow 1995; Woods, Tobin and Mortimer 1995).

A study by Ganz et al. (Ganz, Coscarelli, Fred, Kahn, Polinsky and Petersen 1996) showed that many breast cancer patients reported reduced energy, decreased recreational activities, pain and psychological distress. The women were still experiencing anxiety related to medical situations even three years after initial diagnosis and treatment. Fifty percent of the sample reported problems with body image and severe problems with sexuality.

TREATMENT AND THEIR SIDE EFFECTS

Choice and sequence of treatment for breast cancer are mostly based on results of controlled clinical trials. Surgery, chemotherapy, hormonal treatment and radiotherapy, as single modalities or combinations thereof, represent the major treatments available for breast cancer (Overgaard, Hansen, Overgaard, Rose, Andersson, Bach, Kjaer, Gadeberg, Mouridsen, Jensen and Zedler 1997; Ragaz, Jackson, Le, Plenderleith, Spinelli, Basco, Wilson, Knowling, Coppin, Paradis, Coldman and Olivotto 1997; Spratt, Donegan and Sigdestad 1998).

Surgery

Surgery remains the initial treatment in early breast cancer (disease restricted to the breast and local lymph nodes). Lumpectomy with axillary dissection and modified radical mastectomy continue to be the two most common procedures. Breast-conserving surgery consists of extirpation of the tumor with clear margins and removal of the axillary nodes. Modified radical mastectomy includes the removal of the entire breast and the axillary lymph nodes (Gordon 1997). Immediate breast reconstruction surgery is a common procedure today. Several different reconstructive techniques are used after the ablative procedure. Implants, such as permanent prostheses or expander prostheses, are placed under complete musculofascial cover. Myocutaneous flaps, the TRAM (Transverse Rectus Abdominis Myocutaneous), are also performed (Sandelin, Billgren and Wickman 1998; Wickman, Jurell and Sandelin 1998).

Postoperatively physical aspects include possible pain and post-surgical complications. Mastectomy wounds are prone to inflammatory and circulatory problems. In wide excision surgery seroma may develop. Shoulder stiffness and arm tightness is common after surgery. Infection or lymphoedema of the arm on the side where surgery took place can also occur. Infection can delay healing and increase the risk of lymphoedema, and when both

radiotherapy and surgery are performed the risk of lymphoedema also increases (Omne-Pontén, Holberg, Burns, Adami and Bergström 1992; Chaplin 1996; Wyatt and Friedman 1998). Ganz et al. (1996) reported in a follow-up study of breast cancer patients that persistent problems related directly to the surgery and radiation therapy were common two and three years after primary treatment. Problems included paresthesia leading to numbness, pins and needles, pain and skin sensitivity. These problems were prevalent whether the women had received mastectomy or breast-conserving surgery.

Chemotherapy

Chemotherapy has an important role in the palliative treatment of breast cancer, but also as an adjuvant to local treatment for patients with or without node involvement. The goal of adjuvant chemotherapy is to destroy any breast cancer cells remaining after definitive surgery. Metastatic breast cancer is often treatable, as it is one of the most responsive solid tumors to cytotoxic chemotherapy. Patients with responding disease may achieve months or years of symptom-free survival and also prolonged survival can sometimes be obtained. For some cases there is a 10-20% chance of complete remission. Chemotherapy is systemic and may be given as a single agent or as a combination (Seeger and Woodcock 1998).

Most treatment methods for cancer are associated with some degree of side effects (Kubricht 1984; Hassey 1987; Irvine, Vincent, Bubela, Thompson and Graydon 1991; Omne-Pontén, Holberg, Burns, Adami and Bergström 1992; Sitton 1992; Bjoordahl and Kaasa 1995; Cartwright-Alcares 1995; Faithfull 1995; Helgason, Fredrikson, Adolfsson and Steineck 1995; Ream and Richardson 1996; Rose, Schrader-Bogen, Korlath, Priem and Larson 1996). Chemotherapy affects organs and tissues to a varying degree (Seeger and Woodcock 1998). Toxicity from chemotherapy varies with dose and drug but the most common side effects are nausea, vomiting, mucositis, diarrhea, weight gain (Demark-Wahnefried, Rimer and Winer 1997), insomnia, alopecia and hemorrhagic cystitis. Cystitis is mostly common with high-dose therapy (Seeger and Woodcock 1998).

Endocrine therapy

Breast cancer cells are often dependent on the interaction between the estrogen receptors and the steroids for cell growth and survival. The purpose of endocrine therapy is to minimize the effect the existing hormones have on the growth of the breast cancer cells (Gordon 1997). Anti-estrogen drugs such as tamoxifen block the binding of estradiol to the estrogen receptor

and initiate the metabolism of the receptor. This type of treatment interrupts DNA synthesis, and cell destruction sets in (Nordensjöld 1998). Tamoxifen is effective at all stages of cancer and is used in both pre- and postmenopausal women (Jaiyesimi, Buzdar, Decker and Hortobagyi 1995; Spratt, Donegan and Sigdestad 1998).

There is evidence that tamoxifen should be selected as the primary endocrine therapy for hormone-receptor-positive tumors in postmenopausal women (Gordon 1997). However, the optimal endocrine therapy has not yet been established for pre-menopausal women.

Oophorectomy, radiological castration or hypothalamus irradiation and LHRH (lutensising hormone releasing hormone)-agonists are also used for this group of patients. LHRH-agonists inhibit estradiol production by reducing the influence of gonatrophines on the hypothalamus. This is a pharmacological type of castration, and thus reversible (Rutqvist and Wallgren 1998).

Currently available endocrine therapy is associated with unwanted side effects, the most common being hot flashes, weight gain, nausea, lethargy, vaginal irritation, bleeding and discharge (Hassey Dow 1995; Redfern 1998). Hot flashes, vaginal discharge and irregular menses are more common among women under 40 years (Spratt, Donegan and Sigdestad 1998; Carpenter and Andykowski 1999).

Radiation therapy

Adjunctive irradiation is recommended as an integral part of the primary management of patients with early breast cancer. Radiotherapy has been used as an adjuvant to surgery since the 1930s, and today it is the most effective postoperative treatment for prevention of locoregional recurrences (Rutqvist 1996; Overgaard et al. 1997; Ragaz et al. 1997). The aim of radiation therapy is to achieve tumor regression or symptom relief. This can be done by delivering a precise dose, to a well-defined tumor or target area, while at the same time keeping the side effects, due to an effect on surrounding normal cells, to a minimum (Leibel and Phillips 1998).

For early invasive breast cancer, conservative treatment such as lumpectomy and axillary dissection followed by irradiation of the remaining breast tissue using opposed medial and lateral tangential fields, is common. As an adjuvant treatment in conjunction with more extended surgery (mastectomy) for locally advanced tumors, treatment may include the chest wall and regional lymph nodes (parasternal, supraclavicular and axillary nodes). A total dose of 46-50 Gy to the target area is administered by giving 2 Gy / day for five weeks. A boost of

10 Gy using electron beam irradiation may be administered to the operative scar in the breast (Littbrand and Turesson 1998).

As a result of two recent randomized trials it has been suggested that all mastectomized patients with positive nodes, should receive irradiation to the chest wall. Internal mammary nodes including the locoregional ones, should be treated when necessary (Overgaard et al. 1997; Ragaz et al. 1997). The results published show an increase in survival when patients are treated with chemotherapy and radiotherapy as compared to chemotherapy alone.

The side effects of radiation therapy are usually due to complications induced in normal tissues included in the treatment area, and may be acute or late. The acute effects are found in tissues with a high cell turnover rate. Surrounding organs and tissues included in the treatment area for breast cancer patients include skin, remaining breast tissue, lung, heart and brachial plexus. Early skin alterations may include erythema, dry desquamation with pruritus and moist desquamation. Late skin alterations are progressive and include hyperpigmentation, telangiectasia, ulceration and fibrosis (Wittes 1991; Sitton 1992; Rose, Schrader-Bogen, Korlath, Priem and Larson 1996). Side effects also include fibrosis of the remaining irradiated breast or axilla. This complication may affect the cosmetic results and/or lead to lymphoedema of the arm on the affected side. An increased risk of cardiac mortality (Gagliardi 1998) and radiation-induced pneumonitis (Lind, Gagliardi, Wennberg and Fornander 1997) of the lung has been documented. Breast cancer patients have also reported feelings of generalized fatigue and malaise as a result of radiation therapy (Berglund, Bolund, Fornander, Rutqvist and Sjöden 1991; Holmes 1997; Irvine, Vincent, Graydon and Bubela 1998; Woo, Dibble, Piper, Keating and Weiss 1998).

The most common symptoms of radiation therapy treatment for breast cancer reported in a study by Wyatt and Freidman (1998) included cancer-related pain, fatigue, trouble in sleeping, breathing difficulties, dry mouth, weakness and loss of feeling. Pain and fatigue were the most frequent problems reported. Several authors also agree that fatigue seems to be a common problem for breast cancer patients, especially if primary treatment includes radiation therapy (Berglund, Bolund, Fornander, Rutqvist and Sjöden 1991; Ganz, Coscarelli, Fred, Kahn, Polinsky and Petersen 1996; Ferrell, Grant, Funk, Otis-Green and Garcia 1998; Smets, Visser, Garssen, Frijda, Oosterveld and De Haes 1998; Woo, Dibble, Piper, Keating and Weiss 1998)

THEORETICAL FRAMEWORK

OREMS SELF-CARE DEFICIT THEORY

Theory is valuable to nurses when it is applicable to current practice. The intervention reported in this thesis was based on Orem's self-care deficit theory (Orem 1995). Orem's theory should be seen as the "glue" that provided the intervention with a clear structure to make the nursing care given effective and to facilitate descriptions of outcomes. The theory offers a framework for radiation oncology nursing. It consists of six core concepts: self-care, self-care agency, therapeutic self-care demand, self-care deficit, nursing agency and nursing system. The nursing methods include the provision of a supportive environment, physical and psychological comforting, and instructions on guiding/acting/doing for the patient.

Self-care

Self-care is a human regulatory function for ensuring one's own functioning and development, or that of a dependant. It is deliberate action and thus differs from other regulatory functions such as neuro-endocrine regulation. Self-care includes activities of individuals to maintain life, health and wellbeing.

Orem (1995) states that health and wellbeing are interrelated in the sense that wellbeing when associated with health includes success in personal endeavors and sufficiency of resources. Health is characterized by development as a human being, with bodily and mental functions while wellbeing concerns spiritual experiences, pleasure, and personal fulfillment. Patients receiving radiation therapy may experience these elements of wellbeing under adverse conditions. Radiation therapy nursing care should be aimed at enhancing wellbeing and quality of life for the patient and family in the framework of outpatient care.

Self-care agency

Self-care agency is the capability of an individual to perform their own self-care to meet the everyday requirements for care that promotes life, health, and wellbeing. In radiation therapy, nurses should encourage patients to maximize their self-care agency, since they to a large extent become mainly responsible for their own self-care.

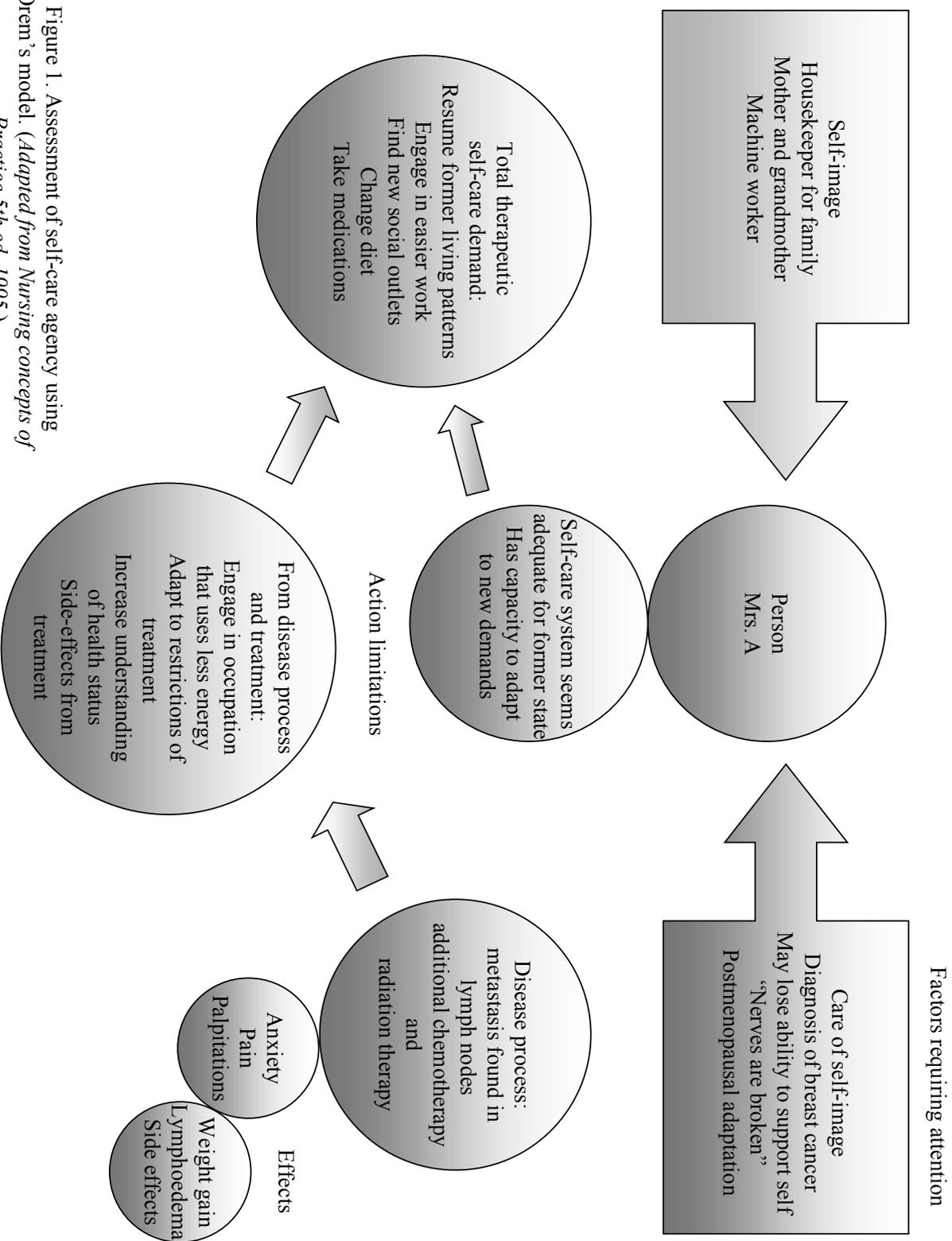


Figure 1. Assessment of self-care agency using Orem's model. (Adapted from *Nursing concepts of Practice 5th ed. 1995.*)

Self-care deficit

Self-care deficit refers to the relationship between therapeutic self-care demands and self-care agency/action. For example temporary limitations such as an illness or treatment may cause self-care ability to fall short of the demands for self-care. The limitations may be due to lack of knowledge, skill, motivation or basic conditioning factors such as loss of awareness of self and environment. In radiation therapy nursing it is important for the nurse to assist the patient or the family to identify existing self-care deficits. This approach to care can be used to establish reasonable and appropriate care regimes for the patient.

Therapeutic self-care demand

Orem (1995) defines therapeutic self-care demand as activities during a period of time or at specific times for meeting known self-care needs to maintain health and to promote wellbeing. Three types of self-care requisites are defined: universal, developmental and health deviation. The requisites rest on the following assumptions. Universal self-care requisites are the common needs of all humans and include air, water, food, elimination, activity, rest, solitude, safety and normalcy.

Developmental requisites are those of maintenance and promotion of conditions needed for advancing the development at each stage in life.

Health deviation requisites relate to abnormal states of health such as illness, disease or disability. Life-threatening illness and treatment are conditions that can adversely affect human development and health status. This may require a temporary dependency on others to meet the care needs and maintain wellbeing. In radiation therapy nursing the nurse must assess, plan and provide care that is aimed at overcoming the disruption disease and treatment causes health and human development, to liberate the patient as soon as possible from dependence on others.

Nursing agency

Orem (1995) considers nursing as a helping service. Nurses assess whether self-care deficits exist. Nursing agency is the power or capacity the nurse has to act, to know, and to help patients meet their therapeutic self-care demands. The nurse assists the patient to minimize or eliminate self-care requisites to promote the latter's self-care agency. The capacity for nursing agency is achieved through specialized education, training in clinical nursing practice with guidance from advanced practitioners, plus the nurse's clinical experience caring for individuals or groups of patients.

The helping methods include acting or doing for others, guiding, physical and psychological support and maintaining an appropriate developmental environment and teaching. The goal of the nursing care is to move patients toward normalcy or full integrity. For the patient receiving radiation therapy, this move toward normalcy can consist of easing the suffering from severe side effects while promoting self-care agency and working toward minimizing any self-care deficit.

Nursing system

The system of nursing care is a helping system. Nurses review and select valid ways of helping individual patients. There are three systems of nursing care in Orem's (1995) model: the educative/supportive, the partially compensatory and the wholly compensatory.

The *educative/supportive system* requires that the patient is competent in self-care and has the required knowledge of the disease or treatment. During the early stages of radiation therapy, for example the patient is capable of self-care, but as the treatment progresses and side effects start to occur. There arises a need for assessing of learning needs that are related to e.g. symptom management

The goal of the *partially compensatory system* is for the patient to perform some self-care measures. The sharing of responsibility of self-care measures between nurse and patient varies with the patient's medical limitations, knowledge, skills and psychological readiness to perform or learn such measures. Radiation therapy patients can be encouraged to promote independence by participating in decision making and self-care as much as illness and treatment permits.

The *wholly compensatory system* is used when patients are incapable of any self-care. These patients' self-care demands need to be provided by others. The nurse is the major provider and she also protects the patient's personal integrity and powers of self-care agency. In radiation therapy nursing the nurse can support and educate family members, e.g. by teaching care measures related to alleviating or minimizing side effects of treatment that the family can carry out for the patient (Orem 1995).

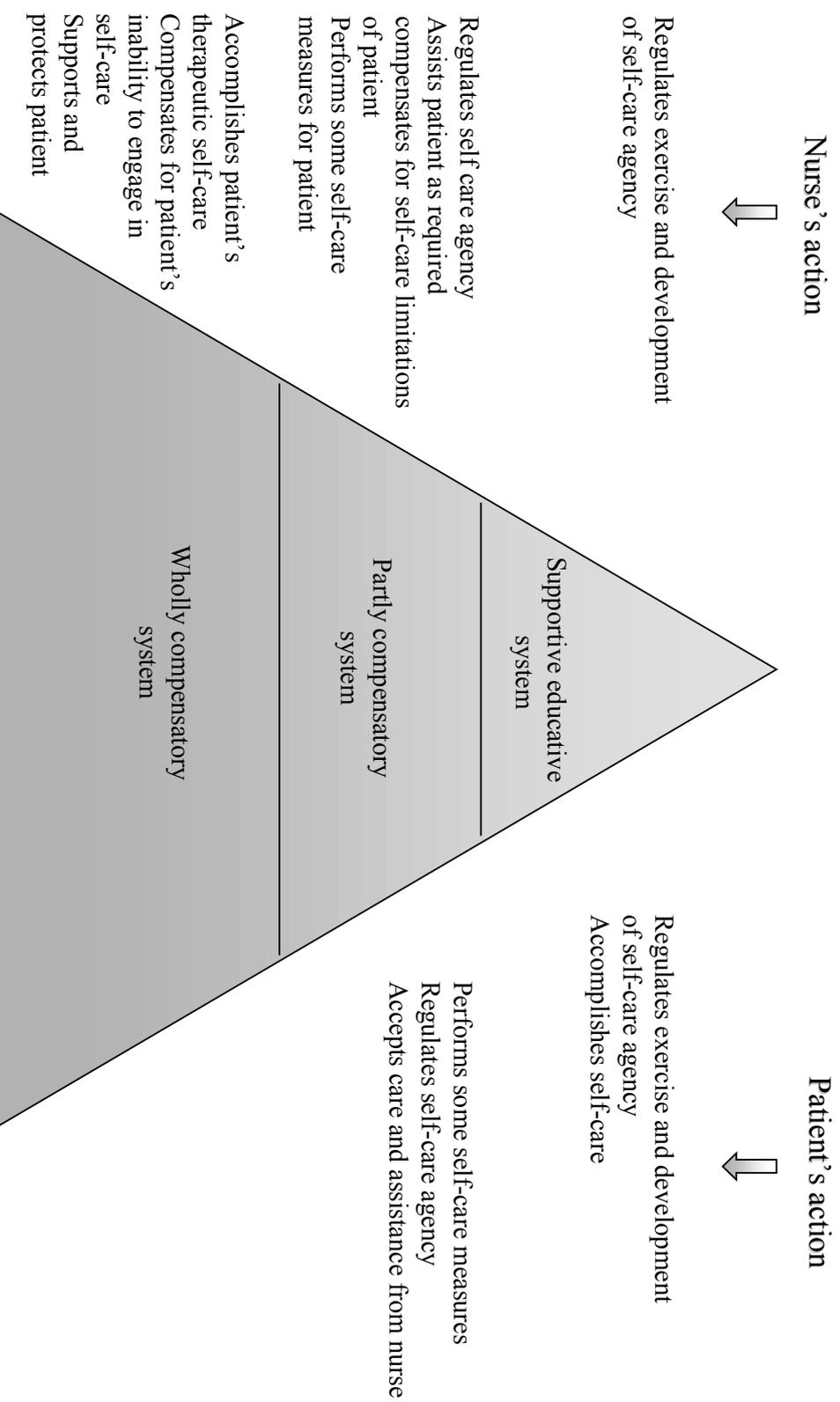


Figure 2. Orem's basic nursing system. (From *Orem's Nursing Concepts of Practice, 5th edition, 1995*)

CONCEPTS

SUBJECTIVE DISTRESS AND COPING

According to Lazarus & Folkman (1991) stress consists of many variables used to define a wide range of phenomena of great importance in human adaptation. Others have discussed stress in terms of *intrusion* and *avoidance* as a result of severely adverse life events. Intrusion is related to the experience of intrusive memories such as unbidden ideas, feelings and images related to the stressful event. Avoidance concerns conscientious avoidance of stress-related themes (Horowitz 1993).

In the context of this stress model and this thesis intrusion and anxiety appear consistent with Lazarus and Folkman's (1991) view of *appraisal*, while avoidance and depression can constitute either a complex aspect of appraisal or some form of coping effort. Appraisal describes the processes that evaluate an event and the resources available for managing it. Intrusive memories and avoidance are central to the diagnosis of posttraumatic stress disorder (PTSD). To receive a life-threatening diagnosis such as cancer may trigger PTSD according to the DSMV-IV classification (American Psychiatric Association 1994).

Individuals subjected to stress may be expected to show some general stress response tendencies. A distress reaction may be considered a normal and expected reaction for patients with cancer. The response tendencies may appear after a variety of stress events of different quantity and quality. Many distress responses persist long after the stressful event (Cordova, Andrykowski, Kenady, McGrath, Sloan and Redd 1995; Ganz, Coscarelli, Fred, Kahn, Polinsky and Petersen 1996; Wyatt and Friedman 1998). The responses include initial realization of the stress event, with increased reactive emotions such as anxiety. A second phase consists of denial and numbness. A mixed phase of denial and intrusive repetitions in thoughts, emotions or behavior then follows. Finally, there is a third phase of working-through emotions and acceptance (Horowitz 1986). Psychological distress then, in this study is defined as a state of feeling, an unpleasant emotional state signified by a cluster of signs and symptoms, affective, cognitive and behavioral.

Previous studies have revealed high levels of intrusion and avoidance in cancer patients (Kaasa, Malt, Hagen, Wist, Moum and Kvikstad 1993; Baider and Kaplan De-Nour 1997; Wettergren, Langius, Björkholm and Björvell 1999).

Avoidance and especially intrusion are strongly related to poor adjustment for cancer patients (Kaasa, Malt, Hagen, Wist, Moum and Kvikstad 1993). Baider and Kaplan De-Nour (1997) found in a study of women with breast cancer that intrusion explained 30% of the variability

in the patient's psychological distress. A study of cancer patients by Brewin et al. (Brewin, Watson, McCarthy, Hyman and Dayson 1998) found associations between the presence of intrusive memories and the extent of avoidance of these memories at diagnosis, and greater anxiety at the six-month follow-up. The results of these studies emphasize the importance of psychosocial support for cancer patients. For breast cancer patients, however, the results are somewhat contradictory and seem to depend on what type of treatment the patients are receiving. More intrusive and painful medical procedures may cause a higher prevalence of PTSD (Cordova, Andrykowski, Kenady, McGrath, Sloan and Redd 1995; Green, Rowland, Krupnick, Epstein, Stockton, Stern, Spertus and Steakley 1998).

Coping plays a central role in the appraisal theory of psychological stress described by Lazarus and Folkman (Lazarus and Folkman 1991). Coping is defined as an individual's thoughts and actions for solving problems and handling situations in such a way as to reduce stress. The strategies may include self-control, humor, crying and talking. If used in excess these regulatory strategies are seen as symptoms of internal disorganization.

Several factors determine how an individual copes with a life-threatening disease such as cancer. Relationships have been found between age and stage of disease and psychological adjustment (Schnoll, Harlow, Stolbach and Brandt 1998). Other factors that have been identified include a history of psychological distress and social difficulties such as longstanding marital, vocational and economic problems (Ganz, Hirji, Sim, Coscarelli Shag, Fred and Polinsky 1993).

The outcome of psychosocial adaptation during illness is shaped by the patient's ability to cope with problems. The outcome of coping can be seen as a transactional process, where the demands of a problem should trigger the amount of coping needed. Lazarus and Folkman (1991) have described two forms of coping: emotion-focused and problem-focused.

Generally, emotion-focused coping is a form of reality distortion directed at minimizing emotional distress. This form can be used when the individual perceives that nothing can be done to influence the threatening environmental situation. In contrast to this, problem-focused coping is used when it is possible to define the problem, generate alternatives and influence the environment or the self rather than altering one's perception of reality.

Researchers have given limited attention to the experience of patients with cancer who complete radiation therapy, although radiation is a common treatment (Bjoordahl and Kaasa 1995; Spiegel 1997; Chandra, Chaturvedi, Channabasvanna, Anantha, Reddy, Sharma and Rao 1998). In an exploratory study by Walker and associates (Walker, Nail, Larsen, Magill and Schwartz 1996), concerns, cognitive disruption and affect following radiation therapy

were studied. Most subjects experienced unexpected intrusive thoughts about cancer and treatment, while one-third avoided reminders of the disease. Avoidance, comparison, maintenance of normalcy and information-seeking were common coping strategies. Johnson and co-workers (Johnson 1996) conducted a theory-based nursing intervention seeking to facilitate coping with radiation therapy. Patients that received the intervention experienced less disruption in daily life, and pessimistic patients tended to have a more positive mood, than patients the control group.

QUALITY OF LIFE

Quality of life (QoL) is a broad concept used in many disciplines. It is a multidimensional concept that theoretically incorporates all aspects of an individual's life. The meaning of the concept arguably depends on the user's understanding, position and profile in the social and political environment (Bowling, 1995).

The challenge of defining the concept of QoL is reflected in the variety of definitions and dimensions available in the literature. Despite some areas of agreement no consensus exists (King, Haberman, Berry, Bush, Butler, Hassey Dow, Ferrel, Grant, Gue, Hinds, Kreuer, Padilla and Underwood 1997) and this may suggest that QoL is an evolving phenomenon whose meaning will develop over time through scientific and social interaction. As more attributes of the concept are discovered through research, descriptions and definitions of QoL will change accordingly.

QoL is defined by the World Health Organization's Quality of Life Group (WHOQOL, 1993) as follows:

"Quality of life is an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concern. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independency, social relationship and their relationship to salient features of their environment" (p.3, Bowling 1995).

This definition is frequently used because of its emphasis on the multidimensional nature of health.

When measuring QoL it has been suggested that at least the following dimensions be included: physical concerns, functional ability, social wellbeing, emotional wellbeing and sexuality / intimacy (Cella and Tulsy 1990; Bowling 1995; Langius 1995; Forsberg 1996; Ganz, Coscarelli, Fred, Kahn, Polinsky and Petersen 1996; King et al. 1997; Ferrell, Grant, Funk, Otis-Green and Garcia 1998; Ganz, Rowland, Meyerowitz and Desmond 1998). QoL is

increasingly referred to as health-related quality of life (HRQL). The extension of the concept is based on the individual perception of health state and the ability to lead a fulfilling life as a result of health or disease.

Relatively little is known about the HRQL of breast cancer survivors. A few studies have examined the effects of adjuvant therapy (Hassey Dow 1995; Ganz, Coscarelli, Fred, Kahn, Polinsky and Petersen 1996; Ferrell, Grant, Funk, Otis-Green and Garcia 1998; Ganz, Rowland, Meyerowitz and Desmond 1998). The overall findings indicate that women with breast cancer generally function at a high level when compared to healthy individuals. However, those treated with adjuvant therapy such as chemotherapy or tamoxifen experience significantly more sexual- and vasomotor- related problems that affected HRQL (Ganz, Rowland, Meyerowitz and Desmond 1998).

Ganz et al. (1996) reported, in a long-term follow-up study of breast cancer survivors, that, despite relatively high function in many of the QoL dimensions, the women experienced severe rehabilitation problems that persisted through one year after completion of treatment. The problems were related to physical and recreational activities, body image intimate relationships and sexual functioning (Ganz, Coscarelli, Fred, Kahn, Polinsky and Petersen 1996). Physical problems including decreased stamina, symptoms related to the operation scar and anxiety were significantly more common for women treated with radiation therapy (Berglund, Bolund, Fornander, Rutqvist and Sjöden 1991; Carlsson and Hamrin 1994; King et al. 1997; Ferrell, Grant, Funk, Otis-Green and Garcia 1998; Wyatt and Friedman 1998).

EVIDENCE BASED NURSING CARE

It is still said that much of nursing practice is based on experience, tradition, intuition, common sense and untested theories, and that there is a problem associated with the adoption of research findings into practice (Watkins Bruner 1993; Holmes 1997; Downing 1998; Wells 1998; Wengström and Forsberg 1999). The term “evidence based” is being used increasingly in the world of nursing and health care development. Evidence based practice is the conscious, explicit and rational use of the best evidence currently available in making decisions about the care of a patient. Evidence based practice means integrating individual clinical expertise with the best available evidence from systematic research. In this process it is also important to include the patient’s choice (Sackett et al 1996). Evidence based practice offers a potentially useful framework for improving individual and organizational performance by providing a set of tools which can help practitioners keep up with and appraise increasingly complex health routines. New evidence is constantly emerging and to

rely solely on traditional education seems ineffective. Nurses also need to focus on life-long self-directed learning that includes converting specific clinical circumstances into answerable questions. As nurses we need to track down our own best evidence for answering the questions, we need to learn to judge the research evidence for validity and usefulness and to apply the results to practice and evaluate performance. There is a need for systematic reviews and intervention studies based on the results of such reviews.

Findings from such a systematic review covering the scientific literature from 1993 to 1997 identified 345 studies (Wengström and Forsberg 1999). Of those, 70 were reviewed and graded for quality. The final review consisted of 28 studies. Five areas were identified concerning patient needs: informational needs, psychosocial reactions, self-care, side effects and sexual dysfunction.

Five studies addressed information needs. The main findings indicated that patients preferred cognitive information. Interventions provided, such as informational audiotapes, concrete descriptions of the experience, and nursing consultations, proved to increase knowledge and the use of self-care. Lower anxiety scores and less anxiety and disruption in daily life were also reported among the patients that received the interventions. Psychosocial distress such as anxiety and depression was identified. Psychosocial distress at completion and during follow up of treatment depends on the severity of side effects and late side effects of treatment.

Uncertainty and less hope were related to adjustment problems. However, women receiving radiation therapy for breast cancer experienced a long-term reassuring effect of the treatment. Three of the studies included focused on self-care. A multitude of physical, psychological, social, spiritual and cognitive changes related to treatment was reported. A significant association was found between patient knowledge of radiation therapy and self-care. Patients used little self-care activities for the side effects. Predictors for the grade of self-care activities included socioeconomic status and social support.

Twelve studies investigated side effects related to treatment. Symptoms from treatment varied by site of treatment. The way the patients viewed the symptoms affected the effectiveness of their symptom management strategies. The management of skin reactions to treatment focused on the mechanisms of skin injury. Washing during treatment reduced the acute skin reactions. No clinically important benefits were found when applying topical ointments to reduce skin reactions. Pelvic irradiation could result in a number of problems after completion of treatment such as nausea, loss of appetite, weight loss, cystitis, diarrhea and fatigue.

At the end of treatment a majority of radiotherapy patients experienced some symptoms. The symptoms decreased with time but for some patient's new symptoms could develop several weeks after the treatment was completed (See Table 1.).

Table 1. Studies focusing on side effects of radiation therapy.

Investigators	Sample size	Results	Instruments	Validity Reliability	Study design and Quality
Campbell & Illingworth (1992)	n=99	Washing of the skin during radiotherapy decreased acute skin reactions.	Skin reaction scoring and assessment.	No information	C 2
Lokkevik <i>et al.</i> (1996)	n=86	No clinically important benefits of Bephanthen cream for ameliorating acute skin reactions during and after radiotherapy treatment.	Acute skin scoring system	No information.	C 1
Sitton (1992:a)		Time of onset, duration, intensity of side effects in the skin are influenced by site of radiation field, time-dose relationship, radiosensitivity, type and energy of radiation, nutritional status and adherence to skin management.	Literature review		L
Sitton (1992:b)		Care for irradiated skin should focus on the mechanisms of skin injury. Topical preparations should be applied and the active ingredient and the vehicle must be appropriate for the condition treated. As reaction progresses recommendations will change to meet needs.	Literature review		L
Faithfull (1995)	n=33	How patients view symptoms effects the development of effective symptom management strategies.	Symptom Specific Questionnaire Symptom cards Semi-structured interview	No information	P 2
Widmark <i>et al.</i> (1994)	n= 181	Pelvic irradiation induced a relatively large number of minor problems after completed treatment.	Self assessment questionnaire	Yes, content validity coefficient	R 2

Woodtli & Van Ort (1993)	n=15	The most common nursing problems of patients treated for gastro-intestinal cancer include nausea, appetite loss, weight loss, skin problems, cystitis, diarrhea, constipation and fatigue.	Radiation Symptom Scale	Yes, content validity Coefficient alpha	P 3
Hassey (1987)		Treatment related side effects for rectal cancers vary in both type and severity and depend on the total dose and fractions delivered.	Literature review		L
Woodtli & Van Ort 1991	n=15	The most common nursing problems of patients treated for head and neck cancer include nausea, loss of appetite, weight loss, dry/itchy skin, dry mouth, difficulty swallowing, cough, and fatigue.	Radiation Symptom Scale	Yes, content validity Coefficient alpha	P 3
Schultz (1989)		Patients treated with irradiation for head and neck tumors are at risk of developing endocrine complications because these patients survive longer. Nurses will be closely involved in follow up.	Literature review		L
King <i>et al.</i> (1985)	n=96	Symptoms from radiation treatment vary by site of treatment, more than 30% of subjects' experience at least one persistent side effect 3 months post-treatment.	Symptom Profile	No	R 2
Rose <i>et al.</i> (1996)	n= 111	At the end of treatment 94% of patients experienced symptoms; 79% of patients experienced symptoms 14-21 days after treatment 18% of these had developed a new symptom.	Site specific interview questions	Yes, inter-rater reliability	P 2

L= literature review, C= prospective, randomized study, P= prospective study, R= retrospective study, O= other studies.

Only C, P and R studies have been assessed for quality according to a 1-3 scale.

1= strong evidence, 2= fairly strong evidence, 3= weak evidence

Studies focusing on sexuality and radiation therapy were scarce four are included in the present review. Patients with prostate cancer indicated high levels of sexual dysfunction. The effects on quality of life were contradictory. The problems included limitations of sexual interest, ability to achieve erection, difficulties to empty bladder, and diarrhea. Sexual dysfunction due to pelvic irradiation could be predicted if the nurse was aware of patient needs, expectations and desires.

Recommendations based on the findings include information about the treatment, general emotional support and practical help with the side effects of treatment. The information should include presentation, prevalence and duration of side effects. How the patient may experience the treatment, the roles of the different health care professionals involved should also be included. The most important aspect to consider is the patient's needs.

In summary, the scientific literature suggests that patients when undergoing radiation therapy need information about their treatment, general emotional support, and practical help with side effects and complications from treatment.

NURSING CARE IN RADIATION THERAPY

Individuals may make changes in their lives to help them cope with the presence of illness and facilitate health promotion while receiving active treatment for cancer. This is true especially if they are provided with well-designed and effective supportive care (Weintraub and Hagopian 1990; Maraste, Brandt, Olsson and Ryde-Brandt 1992; Grahn 1993; Berglund, Bolund, Gustavsson and Sjöden 1994; Carlsson and Hamrin 1994; Fawzy 1995; Porocho 1995; Pålsson and Norberg 1995). While focusing on the individuality and "whole" nature of each patient, nursing care in radiation therapy needs to be considered in two parts – care for the person with cancer and care for the person receiving radiation therapy. However, the two cannot be separated from each other. Coping with a diagnosis of cancer may affect the care that can be given since at times this may be all the patient can deal with. Hence the care provided needs to focus on the patient's multitude of needs rather than on a single immediate need generated by treatment and side effects (Holmes 1997). There is evidence that side effect burden has a negative impact on psychological adjustment and overall QoL. Nursing care in radiation therapy should be focused on maintaining the patient's wellbeing and quality of life (Wengström, Häggmark et al. 1999; Longman, Braden et al. 1999).

A need exists to clinically individualize nursing interventions that reduce side effects for women undergoing treatment for breast cancer. Interventions can do much to reduce the perception of illness severity and allow psychological adjustment and maintenance of the quality of life.

AIMS

The overall aim of these studies was to gain further knowledge about nursing care in radiation therapy. Such knowledge is of vital importance when developing nursing care guidelines for women with breast cancer receiving curative radiation therapy treatment.

The specific aims were as follows:

to assess nursing problems experienced in the care of cancer patients and in working with other health care professionals from the nurse's perspective,

to evaluate possible effects of a structured nursing intervention on subjective distress, side effects, quality of life and coping ability of women with breast cancer receiving curative radiation therapy treatment, and

to describe experienced side effects, quality of life and coping strategies used by women with breast cancer during and following radiation therapy.

MATERIAL AND METHODS

DESIGN

The studies in this thesis are related to different aspects of nursing care in radiation therapy. They are mainly prospective and descriptive in nature. Firstly, a qualitative design is used to describe the nurse's experience of problems related to nursing care in radiation therapy (Paper I). Then a randomized controlled (RCT) design is used to evaluate the effects of an experimental nursing intervention on subjective distress, side effects and quality of life (Paper II). Descriptive data are also used to describe the patient's experiences of side effects and quality of life (Paper III). The RCT design is employed to evaluate the effect of the intervention on coping potential in the two compared groups (EG and CG-see below) (Paper IV). Finally, a qualitative approach is used to describe the coping strategies used by the patients (Paper V). An overview of the RCT design is presented in Figure 3.

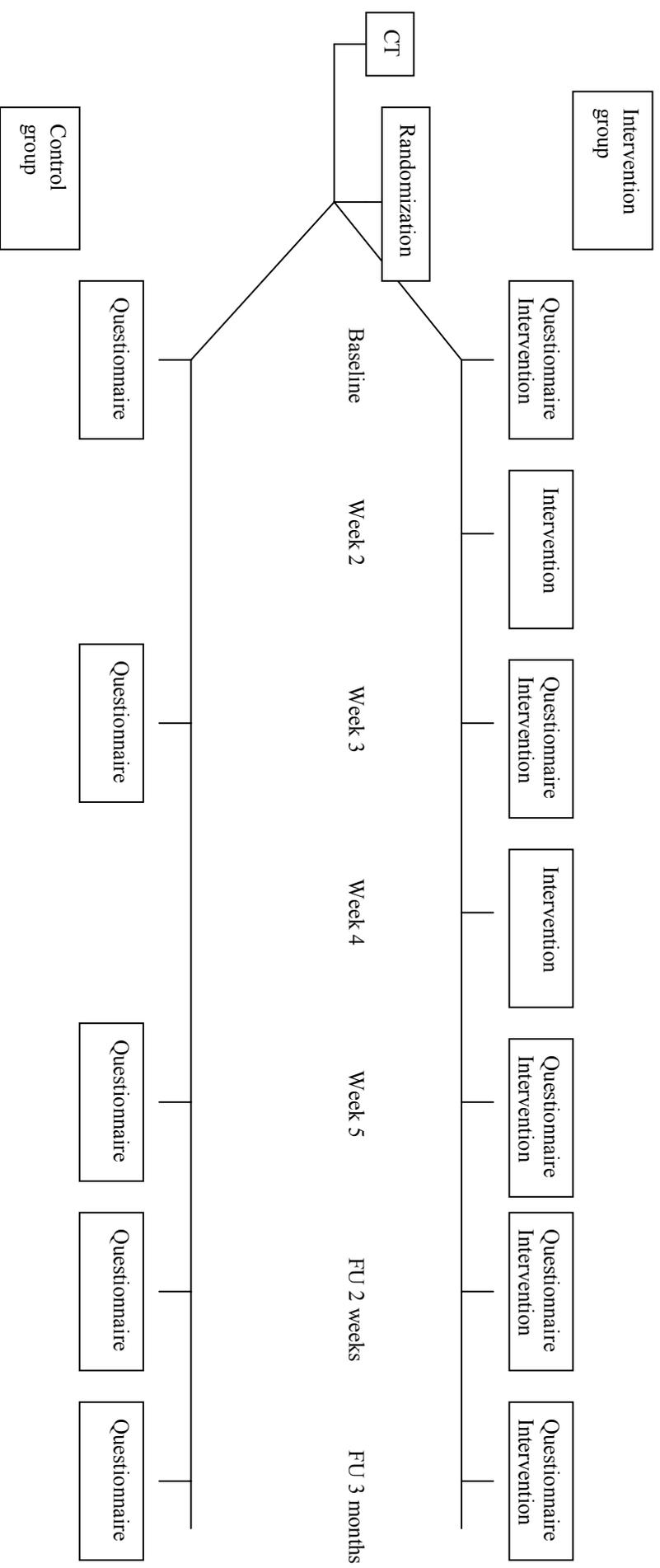


Figure 3. Flow chart of the intervention study design.

THE NURSING INTERVENTION

The nursing intervention on which this work is based was a complement to standard nursing care in the department during and after completion of the course of treatment. It was structured according to Orem's (Orem 1995) model for self-care. The following elements were included:

- Individual information and education about radiation therapy treatment and side effects. This was provided during the initial visit to the department before any radiation therapy procedures were started. This element was provided on an individual need basis during the treatment and follow-up period.
- During every visit each patient's needs pertaining to physical, psychological and social self-care deficits were assessed, as was her ability to manage self-care.
- The nurse planned the intervention together with the patient according to her needs.

The goal of the intervention was to free the patient from dependency on the nurse and to restore self-care to a sufficient level as soon as possible. This may be achieved early in the treatment by giving the patient:

- education about symptoms and about treatment side effects.
- support, guidance and self-care action pertaining to what the patient herself can do to prevent, alleviate or minimize the side effects.
- psychological support to cope with emotional reactions such as anxiety, depression and insecurity.
- education, and guidance to help the patient to modify her body image, and to revise daily routines to cope better with the effects on health of the illness and treatment.

Depending on the patient's need the nurse also gave, an informational and educational update regarding treatment and side effects. This included practical advice on how to maintain natural skin integrity during the treatment in order to prevent or minimize the onset of radiation-induced effects and to reduce irritation. The nurse provided contact with other health-care professionals- such as physiotherapists if needed during and after the treatment.

STANDARD CARE

In the radiation therapy department before treatment commences, patients are invited to a weekly group information session for general information about the treatment. Standard nursing care is organized according to the primary nursing system and includes an

information session with the nurse primarily responsible after simulation of the treatment. This session includes information about treatment, routines and side effects. There is no systematic assessment of the patient's nursing care needs. Radiation therapy and nursing care are primarily restricted to the daily treatment period, for about 15min for each patient. There is no follow-up of the care given in the radiation therapy department after the treatment is completed.

ETHICAL APPROVAL

The Ethical Committee at the Karolinska Hospital approved the research protocol (KS 95-326).

SAMPLES

Paper I

Eighteen of the 38 oncology nurses in the Radiation Therapy Department were invited to participate. All agreed to participate in the first phase of the study. For the second phase 17 nurses participated and for the third phase 16. The nurse who dropped out was unwilling to continue participation due to maternity leave.

Paper II-V

One hundred and thirty four of breast cancer patients attending the Radiation Therapy Department between January 1996-July1997 were randomized to either nursing care intervention (n=67) or standard care (n=67). Inclusion criteria included: patients with early breast cancer planned to receive curative radiation therapy over the chest wall and regional lymph nodes, patients able to speak and read Swedish and with no prior experience of radiation therapy treatment. (For clinical and demographic data see Table 2.)

Table 1. Clinical and demographic data of study sample.

	Intervention group n=67		Control group n=67		P value
	n=	%	n=	%	
Dose					
46 Gy	37	55%	52	77%	*
50 Gy	28	42%	14	21%	
Booster	2	3%	1	2%	
Mastectomy	37	55%	52	77%	
Breast conserving surg.	28	42%	14	21%	
Chemotherapy	34	51%	29	43%	
Endocrine therapy	38	57%	37	55%	ns
Employed	39	58%	32	47%	ns
Unemployed	3	5%	1	2%	ns
Retired	25	37%	34	52%	ns
Sick leave	31	46%	23	35%	ns
Education					
High School	37	56%	37	56%	ns
College	6	9%	7	11%	
University	24	35%	23	33%	
Family situation					
Living w.Family	42	63%	49	74%	ns
Single/widow	25	37%	18	26%	

ns = non significant, *p<0.05

QUESTIONNAIRES

The Delphi questionnaire

The Delphi method (Linstone and Turoff 1975), a structured communication process in three phases, was used to assess problems perceived. The communication process involves the design of an open-ended questionnaire. In the first phase the questionnaire contained two questions: “What nursing problems do you experience in the care of cancer patients?” and “What nursing problems do you experience in your work with other professionals?” In the second phase the questionnaire consisted of categorized replies to the initial two questions. The nurses were asked to rank the largest problems. Finally, in the third phase the questionnaire consisted of the ranked problems. A visual analogue scale (VAS) was added for subjective indication of the dimension of the problem. The scale ranged from “not at all a big problem” to “a very big problem”.

Impact of Event-scale (IES scale)

Distress reactions among the patients were studied using the IES scale. The instrument assesses current subjective distress caused by a specific life event (Horowitz, Wilner and Alvares 1979; Horowitz 1993), in this case radiation therapy treatment. The 15-item scale measures *intrusion*, intrusively experienced thoughts/images-ideas of the event and *avoidance*, consciously recognized avoidance of such feelings and ideas. The patient estimates the frequency of each item during the previous week by assigning each item one of four categories ranging from “never” to “often”. The categories are 0, 1, 3, 5 higher scores indicating a level of distress reaction. The IES scale has been used in previous studies in Sweden (Nordin and Glimelius 1997).

Oncology Treatment Toxicity Tool (OTTAT)

The Oncology Treatment Toxicity Assessment Tool (OTTAT) (Youngblood, Daus Williams, Eyles, Waring and Runyon 1994), a self-report instrument, was used to assess cancer-therapy-related symptoms. The instrument was originally used to measure outpatients symptoms in three settings: a radiation oncology clinic, a bone marrow transplant clinic and an adult medical oncology clinic. The original OTTAT consists of 37 items e.g. "skin changes", and “loss of appetite” and “pain”. Each item is rated for severity on a five-point scale ranging from 0 -none, to 4-intolerable. The higher the score, the greater degree of experienced side effects. The instrument was translated into Swedish by two of the researchers independently and then compared for consensus. As the instrument was used in this study only with radiation therapy patients the following nine items were omitted: cold sores, jaw pain, soreness in vein where chemotherapy was given, decreased interest in sexual activity, difficulty urinating and blood in the urine. Thus the Swedish version of the OTTAT contained 28 items.

Cancer Rehabilitation Evaluation System (CARES-sf)

A short form of a standardized, comprehensive quality of life questionnaire for cancer patients- the CARES-sf -was used to study quality of life. The instrument assesses the problems and behaviors affected by cancer and treatment. The 59 items are rated on a five-point scale (0-4) ranging from “does not apply at all ”- to “applies very much”- to me. Not all patients rate all the items, e.g. some subsections apply only to patients that have received chemotherapy. The instrument has been used in previous studies, and its validity, reliability

and internal consistency have been documented (Coscarelli and Shag 1991; Nordin and Glimelius 1997).

Wheel Questionnaire (WQ)

The Wheel Questionnaire is based on Lazarus and Folkman's (1991) model of appraisal. The questionnaire maps four aspects of perception that predict ability to cope with different types of stress. The aspects include ability of cognitive appraisal, degree of emotional involvement in our world, degree of emotional balance e.g. possibilities vs. obstacles and finally coping including perceived control of and influence on a situation. The WQ is an open-ended questionnaire and the investigator is present to guide the participant. A key sentence is used to guide the participant; in these studies "*What characterizes your daily life this week - how do you think and how do you feel?*" The participant's formulate the content of the WQ in their own words . The contents are ranked, and positive or negative loading and perceived possibility of influence are assessed. This instrument has previously been used in a Swedish study to investigate coping and social activity patterns in cancer patients relatives (Häggmark 1989).

Demographic data such as age, education, employment and family situation were asked for. Medical data including type of surgery, previous chemotherapy, endocrine therapy and radiation therapy dose was collected from the patient's medical records.

An overview of the questionnaires used in the different papers is presented in Table 3.

Table 3. Questionnaires used in each study.

Questionnaire	Paper
Delphi questionnaire	I
Impact of Event Scale, IES	II
Oncology Treatment Toxicity Tool, OTTAT	II, III
Cancer Rehabilitation Evaluation-short form, CARES-sf	II, III
Wheel Questionnaire, WQ	V, VI

PROCEDURE

Paper I

During a departmental morning meeting the investigators orally presented the purpose of the study and procedure to be followed. An introduction to the Delphi model, information on duration of the study (2 months) and statements of confidentiality, individuality of responses

and freedom to withdraw were also included in the instructions. The informants for this study were 19 of the 38 nurses in the Radiation Therapy Department. The Delphi process used, described structures group communication so that it is effective in allowing individuals as a group to deal with complex problems. In the first phase open-ended questions guided the communication. In the second phase an overview of the answers was presented and ranking of problems were performed. In the third phase, the subjective experience of the magnitude of the problem was asked for on a VAS-scale (Visual Analog Scale).

Paper II-V

Subjects were invited to participate in the study after undergoing computerized tomography (CT) in preparation for radiation therapy. The patients were given oral and written information about the study and ensured confidentiality, anonymity and freedom to withdraw. They were telephoned within three days to give their consent to participate. Consenting patients were immediately assigned at random to the experimental group or the control group. This was affected by opening a containing the information about which group the patient was to join. Intervention group patients were encouraged to call the nurse if any questions about the radiation therapy arose during the waiting period before the treatment started.

At the first visit to the radiation therapy department, before any preparations for treatment had started, the patients in the intervention group completed the questionnaires (approximately 20 min) and received the first intervention (45 min). The intervention was provided by an oncology nurse with post basic education in breast cancer nursing, patient education and body image.

During this time the patients had opportunities to talk about their personal fears or anxiety concerning the treatment or other issues. Patients in the control group also completed the questionnaires before any preparations for treatment had started. If questions about the treatment arose the researcher directed the patients to the appropriate staff at the treatment unit. Care was taken by the researcher not to disclose any intervention to the control group or department staff, so as to ensure that they would answer questions in their usual way.

During the treatment, the intervention consisted of one 30min session every week and two sessions of follow-up two weeks and three months after completion of the treatment.

Intervention group members were also encouraged to call the nurse if any problems arose during the treatment period or follow-up time. The control group completed the questionnaires at weeks three and five. During the follow-up period, questionnaires were

mailed to these patients at two weeks and three months. The treatment unit staff provided the required nursing care for this group.

STATISTICAL PROCEDURES

Parametric methods were used when the variables showed an approximately normal distribution (Polit 1996). Descriptive statistics were expressed as mean, Standard Deviation (SD) and percent. Statistical significance was accepted if $p < 0.05$. For nominal data, the Chi²-test (Polit 1996) was used. Student's T-test (Polit 1996) was used to determine differences in baseline data (Paper II, IV). ANOVA (repeated measure) analyses (Polit 1996) were performed to determine changes over time (Paper II, IV). A multiple regression analysis (Kleinbaum, Kupper and Muller 1987) was performed to test for the differences in treatment dose and type of surgery (Paper II). Relationships between variables were expressed using Pearson product moment correlation coefficients (Polit 1996) (Paper II, III). Internal consistency for the scales was measured using Cronbach's alpha test (Cronbach 1951).

QUALITATIVE ANALYSIS

Content analysis (Downe-Wambolt 1992; Morgan 1993) was used to provide knowledge and understanding of the data in Paper I and V. Sentences, words, and statements were systematically and objectively organized to be able to draw inferences from data to describe and quantify specific phenomena. Carney's Ladder of Analytical Abstraction (Miles and Huberman 1994) was used to guide the content analysis. Data was reconstructed into written material and read to gain an overview. A structured analysis identified themes. Finally, characteristics for coping were interpreted from the data (Paper V).

RESULTS

THE NURSE'S PERSPECTIVE

(Paper I)

The aim of this descriptive study was to investigate the problems the nurses perceived caring for cancer patients receiving radiation therapy. The nurses identified several areas of priority related to nursing care. "Poor follow-up of patients who have completed the course of radiation therapy" (76%) was perceived as the greatest nursing problem. This was followed by the problem of lack of time reported by more than half of the nurses.

The greatest problems among those related to collaboration with other health care professionals in delivering nursing care “lack of knowledge of what we are doing”, reported by 76% of the nurses. This was closely followed by “lack of communication” (71%). The nurses also indicated a discrepancy in knowledge and respect for their work among other health care professionals. This was also evident in the third Delphi phase where the most difficult problem was also “lack of communication”, followed by lack of knowledge, respect and comprehension of each other’s work.

In summary: the main findings concerning areas for development of the nursing care included; poor follow-up of patients after completion of treatment, lack of time to document nursing care given and lack of time to treat patients. Problems in working with other professionals included lack of communication, knowledge of competence, and comprehension of the profession.

THE NURSING INTERVENTION

(Papers II and IV)

The purpose of this randomized study was to investigate whether a structured nursing intervention using Orem’s self-care theory as a framework would affect subjective distress, side effects and quality of life (QoL) for women with breast cancer receiving curative radiation therapy. One hundred and thirty-four patients were assigned at random an experimental group (EG) or a control group (CG) each consisting of 67 patients.

Demographic and medical characteristics were similar in the two groups. Student’s t-test used to compare baseline measures of subjective distress, side effects and QoL showed a significant difference between the groups for QoL ($p < 0.05$), EG patients reporting a poorer QoL at baseline. The intervention proved to have a significant effect on subjective distress, the EG patients reporting fewer distress reactions than the CG ($p < 0.05$). The item endorsed by more than 50% of the total sample on the IES scale was “I thought about it when I didn’t mean to”.

For side effects no significant effects of the intervention were found. Fatigue (90%), difficulty in swallowing (70%) and dry mouth (55%) were the most common side effects. A multiple regression analysis showed that the difference in type of surgery and treatment dose could not explain the similarities of the perceived side effects between the two groups. As mentioned before, there was a baseline difference in global QoL between the two groups. The intervention did not have a measurable effect on QoL. Subjective distress, side effects and

QoL correlated significantly. A higher score indicated more perceived distress and side effects and a poorer QoL.

In summary, no measurable effect of the nursing intervention was found for side effects or QoL, but the nursing intervention proved to have a positive effect in minimizing distress reactions.

Paper V

The aim of paper V was to evaluate whether structured nursing intervention would affect the coping ability of the women with breast cancer who received it (EG) as compared to those who received standard nursing care (CG). The Wheel questionnaire (WQ) was used to map four critical aspects of perception. This instrument has been shown to predict the ability to cope with different types of stress (Häggmark 1989). Coping potential was assessed at baseline, at completion of treatment and at three months post treatment. The WQ showed a reliability of 0.73 for this study. The repeated measure analysis revealed that there was no effect of the intervention on patient's coping ability. To further analyze possible effects, the sample was divided into two age groups by the median age of the sample (59 years). The repeated measure analysis showed that the intervention had a significant effect on the Motivation index for the patients older than 59 years ($df=2$, $F=3.463$, $p<0.05$).

In summary, the results showed that the intervention provided patients older than 59 years (median age of sample) with a stronger motivation to be emotionally involved. Individual interventions aimed at enhancing coping potential are important, but different approaches are also needed to achieve this.

THE PATIENT'S PERSPECTIVE

(Papers III and V)

Paper III

The purpose of paper III was to describe symptoms experienced and QoL, including the severity of the most commonly reported symptoms during and after completion of treatment. The total sample was used to describe the pattern of side effects and QoL. Mean, standard deviation (SD) and percent of experienced symptoms and severity are given.

Symptoms

The results showed that fatigue (range 63-90%) was by far the most prevalent symptom at all points of measurement. Sleeping difficulties (41%) and depression (37%) was also mentioned most frequently at baseline. As the treatment progressed symptoms changed. By the third

week of treatment swallowing difficulties (58%) and difficulties in concentration (59%) were frequent. At completion of treatment skin changes (74%) and pain (49%) were reported.

During the first follow-up, skin changes remained at a high level (62%) and sleeping difficulties (53%) were prevalent. The sleeping difficulties remained high at three months (44%) and a new symptom cough was reported by 41% of the sample.

The severity ratings for fatigue peaked at week five where 30% of the sample rated it as a severe to intolerable symptom and 56% as a mild to moderate problem. The prevalence of fatigue had returned to pretreatment levels at three months post-treatment. Skin symptoms increased as treatment progressed from the third week to completion of treatment. Sixty-eight percent of the sample reported mild-to-moderate symptoms while 11% reported severe to intolerable symptoms. Skin changes had not returned to pretreatment levels at the three-month follow-up measurement. Dry mouth, sore throat and swallowing difficulties were reported by more than 50% of the sample. The majority of the patients indicated this as a mild to moderate symptom. The prevalence of pain increased as treatment progressed. At week five, 49% reported pain symptoms and of these patients 8% reported severe-to-intolerable pain. Nausea is rarely described as a symptom for this group of patients, but on completion of treatment 45% of the patients rated nausea as a mild to moderate symptom, 2% as a severe-to-intolerable problem. Four percent of the patients reported emetic episodes.

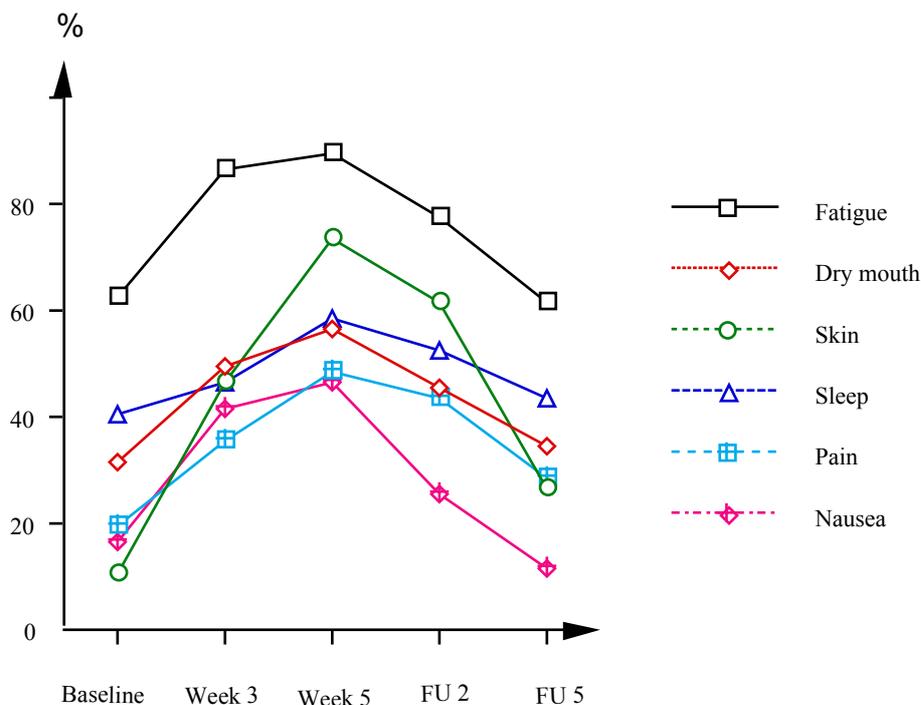


Figure 4. Patterns of the most commonly perceived symptoms for the total group.

Dyspnea and cough symptoms followed a different pattern. From the third week the symptoms increased, to remain at the same level during treatment. The cough pattern decreased at the second follow-up while the dyspnea increased. Forty percent reported moderate dyspnea and 12% severe-to-intolerable symptoms. Seventeen percent perceived the cough as a moderate symptom and 3% as a severe-to-intolerable symptom.

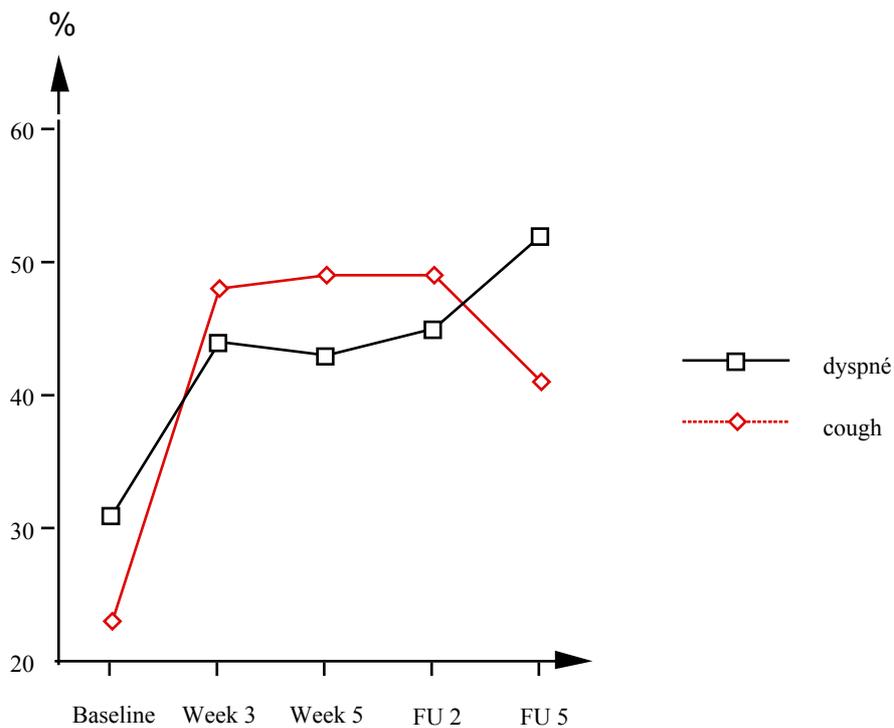


Figure 5. Patterns of pulmonary symptoms during and following radiation therapy.

Quality of life

The global QoL score showed an improvement as the treatment progressed. The poorest QoL was perceived before treatment had started. The pattern was somewhat different for the subscales. At start and completion of treatment psychosocial functioning and medical interaction problems were perceived as the poorest. Physical functioning increased as treatment progressed and problems of sexual function and marital interaction remained at the same level during treatment, decreasing at the last follow-up. The scales correlated positively and significantly over time, indicating that they were valid for measuring symptoms and QoL.

Summing up, the main findings indicated an increase in symptoms as the treatment progressed. Fatigue, sleep disturbances, skin symptoms, dry mouth, sore throat, pain, nausea

cough and dyspnea were the most commonly reported symptoms. QoL improved as treatment progressed.

Paper V

The purpose of paper V was to describe what coping strategies women with breast cancer use during and following radiation therapy. For this purpose the sample was analyzed as a whole. Content analysis was performed in three steps to explore the patients own accounts of coping strategies. Five major themes were identified through the three measuring points.

Characteristic for coping at baseline included trying to maintain a sense of normalcy in life by being involved in work and taking care of the family. At treatment end, activities directed towards self-care were central to coping. These also included social activities with friends and family. Despite experiencing symptoms, the women were trying to look forward at this time.

At three months post-treatment, the women seemed to have resumed their social life. A balance was then evident between depression, harmony and feeling well. Thoughts about the illness and possible recurrences were mixed with optimistic thoughts and a sense of hope.

In summary the main findings indicated that the women used several coping strategies that changed over time to handle the demands of treatment. This included family, friends, work and a broad spectrum of own activities to aid recovery.

DISCUSSION

The benefit of a combination of qualitative and quantitative research methods should be considered in relation to the research questions asked and the aims of the included studies (Ingersoll 1996). A qualitative approach was used to elucidate the nurse's perspective on nursing care problems (paper I) and also to describe different strategies used by the women with breast cancer to cope with the treatment (paper V). The quantitative approach was chosen to evaluate the effect of the intervention and to measure the degree and extent of different phenomena studied in the sample. The combination of methods may be useful to enhance or clarify results from different perspectives.

THE NURSE'S PERSPECTIVE

Caring for the individual with cancer provides a complex challenge to nurses and nursing. The challenge increases when the individual undergoes radiation therapy. Since this treatment modality often is combined with surgery, chemotherapy and at times even biotherapy it may be difficult to separate health promotion and maintenance in radiation therapy from those associated with cancer treatment in general. Oncology nurses in a radiation therapy department in Sweden are unique in that they have the education to give the technical treatment as well as having a degree in nursing. This affords an in depth knowledge of the effects of treatment and an excellent basis for promoting health care behaviors. For the oncology nurses in this study the perceived lack of time may indicate that there is a lack of organizational "fit" to provide optimal nursing care. The current health care emphasis on cost effectiveness does not encourage nurses to spend much time with patients. Spending more time with one patient may mean spending less time with another. Parle, Maguire and Heaven (1997) stress in their study that health professionals need sufficient time to interview and assess the needs and concerns of cancer patients. If nurses in radiation oncology are supposed to use their clinical expertise to thoughtfully identify and sympathetically use the individual patient's preferences, rights and needs in clinical decision-making an organization needs to be provided in which this can occur.

THE NURSING INTERVENTION

Nursing care interventions can minimize women's experience of subjective distress during treatment. The results showed that the intervention provided to the EG patients enhanced their distress-reducing capabilities. The fast-paced ambulatory care environment of a radiation oncology department where patients are seen today requires oncology nurses to perform very focused patient assessments. If this is not possible, the relevance of the care provided will suffer. The present nursing intervention proved the necessity for interventions and careful assessment in order to enhance psychological adjustment to diagnosis and treatment. An unexpected result was the lack of effect of the intervention on symptoms and quality of life. The measuring points for the intervention were selected in such a way as to provide the researchers with a picture of the patient's vulnerable periods and to study the effectiveness of the intervention. Unknown factors, such as life events, may influence patient's perceived quality of life. Unpublished data for the women in this study concerning life events suggests that this may be one explanation for the lack of effect on quality of life. Significantly more than the control group, the women in the intervention group perceived an increase in

responsibility at work and had also changed jobs more within the last year. This together with the fact that the randomization procedure failed to achieve two groups equal at baseline concerning QoL may to some extent explain the lack of effect of the intervention on QoL. The global scores on the CARES-sf can be seen as a measure of how the groups perceive their QoL. From the mean scores it is evident that a tendency towards higher scores is seen in the EG over time even if this never reaches statistically significant proportions it may well be a clinically important result.

Women who undergo surgery and receive adjuvant therapy for breast cancer perceive a poorer QoL than those undergoing surgery alone (Berglund, Bolund, Fornander, Rutqvist and Sjöden 1991; Ganz, Rowland, Meyerowitz and Desmond 1998; Woo, Dibble, Piper, Keating and Weiss 1998). The way the patient views the symptoms is also important for developing effective symptom management (Faithfull 1995; Longman, Braden and Mishel 1999). The perceived seriousness of a symptom and the patient's expectations about what can be achieved to alleviate it may also influence the perceived QoL.

Attempts to empower patients into becoming active partners in health care have been made in this study, and as the roles and expectations for practice shift such empowering should be a vital function of the health care system. The role as patient educator, support resource and problem facilitator should be attainable by oncology nurses. An oncology nurse with a background in patient education, communication and psychosocial support from a nursing care perspective would be the optimal solution. There exists a need for post-basic education options for nurses with patient education, communication skills and psychosocial support. The present intervention was easily implemented in the clinical setting, and the nurse's role was supported and accepted by oncology nurses, doctors and other clinical staff.

Further intervention studies are needed with different approaches to minimizing symptom burden and enhancing QoL. Also, a different type of approach is needed when offering participation in an intervention for patients that declined to participate in the present work. The patients were older (mean 73 years) and indicated as one of the main reasons for declining that it would be too emotionally burdensome to participate. They may well have been those patients that needed a nursing intervention most of all. This is also interesting as one effect of the intervention on coping abilities was a significant increase in the motivation index for women older than 59 years. It has been suggested that older women tend to perceive a poorer QoL. This may also be related to the fact that usually older people may have less social support than younger. Younger women live with significant others and work outside

the home to a larger extent than older (Maunsell, Brisson and Deschenes 1992; Cooper and Faragher 1993; Schnoll, Harlow, Stolbach and Brandt 1998).

Tradition and experience have dominated the clinical judgement and care of patients receiving radiation therapy. To provide care that is relevant to the patient's health care requirements, the nurse needs to define her nursing role and its relationship to the patient and other health care staff. The use of a nursing theory to aid practice helps to identify the focus, the means and the goals of practice. The use of common theories also enhances communication, increases autonomy and accountability for care. Several attempts have been made to define the paradigmatic origins of Orem's theory (Meleis 1997). To develop the theory, concepts have been used from systems theory, developmental theory and an interactional model. This includes defining health as a whole, the concept of personal integrity and the use of systems of nursing. These are, however, isolated concepts and a more appropriate paradigmatic origin may be the needs theory of Henderson (Kirkevold 1994). She defined 14 needs, and the universal self-care needs resemble these, the uniqueness of Orem's theory lies more in the expectation of the person's capability to engage in his own self-care. The theory demonstrates its own possible utility for nursing practice, especially when nurses attempt to shift from a medical model: the use of a needs and functional approach to care makes the shift more gentle and gradual. Orem's model incorporates the medical model, however, and also purports that nursing practice should build on it. The theory is developed around the ill person and the individual care of that person in institutional settings. The theory is about practice and for practice.

To define the role requires of the nurse to have knowledge of the patient's health care situation. Orem's (1995) definition of the seven groups of nursing situations provides the nurse with an effective tool to aid her role definition. This, together with the implementation of evidence based practice may offer nurses in radiation oncology a clear and well-defined role. It also provides a foundation to shed the previous ambivalence concerning the contribution made by radiation oncology nursing (Wengström and Häggmark 1998). The development of scientific knowledge related to radiation oncology nursing can explain why one event is related to another – how one thing affects another. In its final form, scientific knowledge may provide a set of interrelated causal processes, rather than one grand theory that explain everything.

EVIDENCE BASED NURSING

“Evidence based nursing practice” describes patient-centered clinical research that provides information on outcomes of nursing care interventions. Evidence based practice consists of the facts, experience and information offered to support the distinct claims that a clinical course of action is intelligible, truly effective, morally acceptable and sincerely intended. As a gold standard eliciting forth evidence, randomized controlled trials, systematic reviews and meta-analysis are accepted by the majority of the medical profession and also increasingly by the nursing profession. Other robust experimental or observational studies and expert opinions are also suitable to provide additional data. Quantitative as well as qualitative studies are needed to provide us with such evidence.

The review of the literature (Wengström and Forsberg 1999) proved the knowledge base available to be quite limited. The evidence presented should be seen as a basis providing a foundation on which further research should build. To continue development of oncology nursing as a science, the integration of the best scientific evidence from research with clinical practice and the patient’s choice is crucial and one way by which we can improve the quality of nursing practice. Evaluation of current clinical practice is needed since symptom management interventions in radiotherapy are unclear in many cases. Radiation therapy nurses need more information related to the specialty, since radiation therapy differs from medical oncology. Using medical oncology data to improve radiation oncology nursing practice is not always possible or appropriate.

Let us focus the evidence-based model on the nurse’s own experience and the practical context for a moment. This is particularly important if we are to minimize the gap between research and practice, as it suggests that the nurse’s own knowledge and experience has an important part to play in the process of determining relevant research. Medical and nursing journals needs to be read selectively by nurses as this contributes to an increased understanding of the health care needs of populations, individuals and families. This approach to research is determined by the nurse’s personal judgement regarding the aims, and feasibility of the research and its relevance to her own practice. Anecdotal evidence is also in line with this definition, suggesting that good practitioners combine their clinical expertise and best available evidence, recognizing that neither is sufficient alone. Without the expertise, practice may become overwhelmed by evidence that is inapplicable and inappropriate for the individual patient.

THE PATIENTS PERSPECTIVE

It is evident that despite progress in the development of linear accelerators, treatment planning and delivery, patients still suffer a variety of side effects related to the treatment. The present findings showed that the pattern of side effects was similar for all the patients whether they had received previous chemotherapy or not. How far this may have influenced the severity ratings of perceived symptoms has not been analyzed so far.

Some of the women's symptoms were associated with all or some of the adjuvant treatments (chemotherapy, endocrine therapy, and radiation therapy). Fatigue and lung symptoms were the most persistent physical effects. Fatigue is difficult to manage and has lately been worsened by the increased use of fatigue-inducing multi-modality treatments (Noll Hoskins 1997). Cancer-related fatigue differs from the fatigue that healthy individuals may experience, in that it persists despite adequate rest and sleep, and in that treatment compounds fatigue (Ream and Richardson 1999). For many patients, fatigue may be perceived as the most troublesome symptom related to treatment for cancer (Irvine, Vincent, Bubela, Thompson and Graydon 1991; Irvine, Vincent, Graydon and Bubela 1998; Smets, Visser, Garssen, Frijda, Oosterveld and De Haes 1998; Woo, Dibble, Piper, Keating and Weiss 1998). No effective management of fatigue has yet been developed, leaving nurses little guidance on how to deal with this distressing and persistent symptom. Hence, the management of fatigue is often left to the patient. Without guidance, patients often select common-sense strategies that would have been used before cancer affected them; yet these are often ineffective. Patients undergoing cancer treatment should be encouraged to employ strategies other than sleep and rest, such as light exercise (Mock, Hassey Dow, Meares, Grimm, Dienemann, Haisfield-Wolfe, Quitasol, Mitchell, Chakravarty and Gage 1997), hobbies, diverse activities, relaxation and visualization, sleep enhancement strategies and a balance between activity and rest. The women in this study were highly motivated to maintain their normal schedule and routines. At times this motivation may also have kept the women from seeking advice on how to interpret new symptoms after completion of treatment. Lung symptoms are a main complication after treatment with radiation therapy over the chest. If left untreated they may cause late effects such as increased fibrosis of the lung, and this may have great implications on the individual's future QoL. Adequate information on the nature of acute and late effects of treatment seems required to help the patient to interpret the meaning of new symptoms.

For most patients the cancer experience is not a single crisis, but a series of ups and downs that are at times triggered by a specific event such as cessation of treatment or recurrence of

disease. In this study, multiple coping strategies were found and the women were generally resourceful and optimistic. As they worked through their cancer experience, their perspectives changed. Family and friends were central to many of the women at the commencement of treatment, the families appear to have alleviated the women's burden with practical and emotional support. As treatment progressed, in an effort to adjust to the altered situation the women more commonly took part in social activities and saw friends. Contact with colleagues provided those who worked outside the home with a sense of normalcy. The women also used many forms of therapy outside medicine such as for example meditation to aid their recovery and to pamper themselves. It is evident that the impact of diagnosis and treatment for breast cancer unfolds over a period of time. Psychological responses to this are unique for each point in time for the individual. It also seems evident that individual assessments of coping strategies are required for meeting individual intervention needs.

METHODOLOGICAL CONSIDERATIONS

The fact that the intervention had no effect on the patient's QoL and symptoms may be explained by methodological shortcomings such as that the initial power estimation of 166 patients was impossible to attain. The treatment program for node-positive women with breast cancer at this clinic was revised to include chemotherapy before start of radiation therapy. Another explanation may be that the randomization procedure failed to achieve groups equal at baseline concerning QoL. Finally, the CARES-sf questionnaire is a general measure of cancer patient's QoL, and may not have covered the specific QoL issues relevant for women with breast cancer.

A challenge for researchers is also to design intervention studies with sensitivity sufficient to detect the treatment effects they are investigating. For an effective intervention, the stronger it is in relation to the control condition the greater the measured treatment effect will be.

Depending upon the choice of the control condition, the difference between the means for the EG and the CG will increase or decrease. Treatment integrity also needs to be included when discussing treatment effects. This means the uniform application of the intervention only to the patients in the experimental situation. In the present intervention study this may also explain the lack of significant differences in side effects and quality of life; the fact of the intervention may have provided nurses with an increased awareness of the needs for this patient group. This in turn may have altered their routine nursing for the control group.

If the results are to be relied on another explanation may be that this type of an intervention is not necessary for all patients, but should be directed to patients at risk for a poorer QoL and adjustment, such as older age groups.

When assessing the statistical significance of a nursing intervention based on group data, the results may not always include information of clear clinical relevance. The lack of statistically significant effects of the intervention may hide important clinical information. Adoption of the concept of *clinical significance* might yield more important information on the outcomes of the intervention. It has been argued (Hugdahl and Öst 1981; Lefort 1993) that the proportion of improved subjects is a more valid indicator of clinical significance than are statistically significant group level statistics such as mean, standard deviation and effect size. In addition, this type of information may be important for clinicians interested in individual performance, and also researchers, in that it may stimulate reflection on who does improve and who doesn't and why.

CONCLUSIONS

Patients with breast cancer listed for radiation therapy experience symptoms related to the treatment, alterations in health status, coping and psychological distress. Health care providers need to be aware of these potential experiences in order to provide effective care and to make necessary referrals.

Nursing care in radiation therapy should be organized in a way that provides nurses with sufficient time for the provision of nursing care.

Radiation oncology nurses need more information related to the specialty. Future intervention studies are needed to provide optimal clinical guidelines for nursing care.

The present nursing intervention had a positive effect in reducing subjective distress reactions.

There was a significant effect of the nursing intervention on the degree of emotional involvement for patients >59 years. This type of intervention should be directed towards patients risking poor adjustment, such as older age groups.

The persistent pattern of symptoms and side effects implies that the period from the second week of treatment up to two weeks following completion of treatment is critical for targeting interventions against symptoms and side effects of treatment.

Social support such as family, friends and working outside the home seemed important to the women in order to cope with the treatment. The identification of patients risking poor adjustment, such as single, widowed or unemployed women, is important.

IMPLICATIONS AND FUTURE RESEARCH

To develop nursing care in radiation oncology, new ways of organizing care may afford nurses and other health care providers a permissible basis to provide care.

A need exists to substantiate practice using the literature and to create contemporary, well-designed studies to enhance practice. Such studies may usefully investigate the impact of radiation therapy on sexuality, describe nausea and concomitant factors, and investigate pharmacological and non-pharmacological pain-relieving strategies for women with breast cancer. Theory-generating testing research is also needed to validate the evidence base in radiation oncology nursing.

Nursing research is needed regarding interventions based on findings from these studies and on other relevant research targeting the specific needs of patients with breast cancer during and following radiation therapy. These should cover health status, psychological distress and alterations in coping. Studies are also needed of prognostic factors for psychosocial distress in order to identify patients at risk. Further studies are needed which include the timing of interventions and other outcome measures, such as disease-specific questionnaires regarding common symptoms and QoL. Intervention studies involving patients at risk of poor adjustment may also provide researchers with more knowledge of what type of intervention is necessary to meet the individual.

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REFERENCES

- American Psychiatric Association, A. P. (1994). Diagnostic and statistic manual of mental disorders. Washington, DC.
- Baider, L. and A. Kaplan De-Nour (1997). "Psychological distress and intrusive thoughts in cancer patients." *J Nervous and Mental Disease* **185**(5): 346-348.
- Berglund, G., C. Bolund, U. Gustavsson and P. Sjöden (1994). "A randomized study of a rehabilitation program for cancer patients: The "starting again" group." *Psycho-Oncology* **3**: 109-120.
- Berglund, G., G. Bolund, T. Fornander, L. Rutqvist and P. Sjöden (1991). "Late effects of adjuvant chemotherapy and postoperative radiotherapy on quality of life among breast cancer patients." *European Journal of Cancer* **27**(9): 1075-1081.
- Bjoordahl, K. and S. Kaasa (1995). "Psychosocial distress in head and neck patients 7-11 years after curative treatment." *British Journal of Cancer* **71**: 592-597.
- Bowling, A. (1995). *Measuring disease. A review of disease-specific quality of life measurement scales.* Buckingham, Philadelphia, Open University Press.
- Brewin, C., M. Watson, S. McCarthy, P. Hyman and D. Dayson (1998). "Memory processes and the course of anxiety and depression in cancer patients." *Psychological Medicine*(28): 219-224.
- Carlsson, M. and E. Hamrin (1994). "Psychological and psychosocial aspects of breast cancer and breast cancer treatment." *Cancer Nursing* **17**: 418-428.
- Carpenter, J. and A. Andykowski (1999). "Menopausal symptoms in breast cancer survivors." *Oncology Nursing Forum* **26**(8): 1311-1317.
- Cartwright-Alcares, F. (1995). "Addressing sexual dysfunction following radiation therapy for a gynecological malignancy." *Oncology Nursing Forum* **22**(8): 1227-1232.
- Cella, D. F. and D. S. Tulsky (1990). "Measuring quality of life today: methodological aspects." *Oncology* **4**(5): 29-38.
- Chandra, P. S., S. K. Chaturvedi, S. M. Channabasvanna, N. Anantha, B. K. M. Reddy, S. Sharma and S. Rao (1998). "Psychological well-being among cancer patients receiving radiotherapy - a prospective study." *Quality of life research* **7**: 495-500.
- Chaplin, B. (1996). "Breast cancer - The role of the nurse." *Nursing Times* **92**(11): 5-8.
- Cooper, C. and B. Faragher (1993). "Psychosocial stress and breast cancer: the inter-relationship between stress events, coping strategies and personality." *Psychological Medicine* **23**: 653-662.
- Cordova, M. J., M. A. Andrykowski, D. E. Kenady, P. C. McGrath, D. A. Sloan and W. H. Redd (1995). "Frequency and Correlates of Posttraumatic-Stress-Disorder-Like symptoms after treatment for Breast cancer." *Journal of Consulting and Clinical Psychology* **63**(6): 981-986.

- Coscarelli, A. and A. Shag (1991). "Cancer rehabilitation evaluation system - short form (CARES-sf)." *Cancer* **68**: 1406-1413.
- Cronbach, L., J. (1951). "Coefficient alpha and the internal structure of tests." *Psychometrika* **16**: 297-334.
- Demark-Wahnefried, W., B. K. Rimer and E. P. Winer (1997). "Weight gain in women diagnosed with breast cancer." *Journal of American Diet Association*(97): 519-526.
- Downe-Wambolt, B. (1992). "Content analysis: Method, applications and issues." *Health Care for Women International*(13): 313-321.
- Downing, J. (1998). "Radiotherapy nursing: understanding the nurses role." *Nursing Standard* **12**(25): 42-43.
- Faithfull, S. (1995). "Just grin and bear it and hope that it will go away: coping with urinary symptoms from pelvic radiotherapy." *European Journal of Cancer Care* **4**: 158-165.
- Fawzy, N. W. (1995). "A psychoeducational nursing intervention to enhance coping and affective state in newly diagnosed malignant melanoma patients." *Cancer Nursing* **18**: 427-438.
- Ferrell, B. R., M. M. Grant, B. M. Funk, S. A. Otis-Green and N. J. Garcia (1998). "Quality of life in breast cancer survivors: Implications for developing support services." *Oncology Nursing Forum* **25**(5): 887-895.
- Forsberg, C. (1996). The sense of well-being in a group of patients with gastro- intestinal cancer. Department of medicine and surgery, Karolinska Hospital. Stockholm, Karolinska Institutet Thesis.
- Gagliardi, G. (1998). Modeling heart and lung complication data in radiotherapy of the breast. Department of Medical Radiation Physics. Stockholm, Stockholm University Thesis.
- Ganz, P., A. Coscarelli, C. Fred, B. Kahn, B. Polinsky and L. Petersen (1996). "Breast cancer survivors: psychological concerns and quality of life." *Breast Cancer Research and Treatment* **38**: 183-189.
- Ganz, P. A., K. Hirji, M. Sim, S., A. Coscarelli Shag, C. Fred and M. Polinsky (1993). "Predicting psychosocial risk in patients with breast cancer." *Medical Care* **31**(5): 419-431.
- Ganz, P. A., J. H. Rowland, B. E. Meyerowitz and K. A. Desmond (1998). "Impact of different adjuvant therapy strategies on quality of life in breast cancer survivors." *Resent Results in Cancer Research*(152): 396-411.
- Gordon, A. (1997). "The increasing efficacy in breast cancer treatment." *Clinical Oncology*(9): 338-342.
- Grahn, G. (1993). "Learning to cope: an intervention in cancer care." *Support Care Cancer* **1**(1993): 226-271.

- Green, B., J. Rowland, J. Krupnick, S. Epstein, P. Stockton, N. Stern, I. Spertus and C. Steakley (1998). "Prevalence of posttraumatic stress disorder in women with breast cancer." *Psychosomatics* **39**: 102-111.
- Hassey Dow, K. (1995). "A review of late effects of cancer in women." *Seminars in Oncology Nursing*(11): 272-278.
- Hassey, K. M. (1987). "Radiation therapy for rectal cancer and the implications for nursing." *Cancer Nursing* **10**: 311-318.
- Helgason, A. R., M. Fredrikson, J. Adolfsson and G. Steineck (1995). "Decreased sexual capacity after external radiation therapy for prostate cancer impairs quality of life." *International Journal of Biology & Physiology* **32**: 33-39.
- Holmes, S. (1997). "The maintenance of health during radiotherapy: a nursing perspective." *Journal of the Royal Society of Health* **117**(6): 393-399.
- Horowitz, M., Ed. (1993). "Stress response syndromes and their treatment". *Handbook of stress. Theoretical and clinical aspects*. New York, The Free Press.
- Horowitz, M., N. Wilner and W. Alvares (1979). "Impact of event scale: a measure of subjective stress." *Psychosomatic Medicine* **41**(3): 209-218.
- Horowitz, M. J. (1986). *Stress response syndromes*. New York, Jason Aronson.
- Hugdahl, K. and L.-G. Öst (1981). "On the difference between statistical and clinical significance." *Behavioral Assessment* **3**: 289-295.
- Häggmark, C. (1989). *Invitation to relatives to participate in the care of the cancer patient at the hospital- Effects of an activation programme*. Department of General Oncology. Stockholm, Karolinska Institutet Thesis.
- Ingersoll, G. (1996). "Evaluation Research." *Nursing Administration Quarterly* **20**(4): 28-40.
- Irvine, D. M., L. Vincent, J. E. Graydon and N. Bubela (1998). "Fatigue in women with breast cancer receiving radiation therapy." *Cancer Nursing* **21**(2): 127-135.
- Irvine, M., L. Vincent, N. Bubela, L. Thompson and J. Graydon (1991). "A critical appraisal of the research literature investigating fatigue in the individual with cancer." *Cancer Nursing* **14**: 188-199.
- Jaiyesimi, I., A. Buzdar, D. Decker and G. Hortobagyi (1995). "Use of Tamoxifen for breast cancer: Twenty-eight years later." *Journal of Clinical Oncology* **13**(2): 513-529.
- Johnson, J. E. (1996). "Coping with radiation therapy: Optimism and the effect of preparatory interventions." *Research in Nursing and Health*(19): 3-12.
- Kaasa, S., U. Malt, S. Hagen, E. Wist, T. Moum and A. Kvikstad (1993). "Psychological distress in cancer patients with advanced disease." *Radiotherapy and Oncology* **27**: 193-197.

King, C. R., M. Haberman, D. L. Berry, N. Bush, L. Butler, K. Hassey Dow, B. Ferrel, M. Grant, D. Gue, P. Hinds, J. Kreuer, G. Padilla and S. Underwood (1997). "Quality of life and the cancer experience: The-state-of-the knowledge." *Oncology Nursing Forum* **24**(1): 27-41.

Kirkevold, M. (1994). *Omvårdnadsteorier- analys och utvärdering*. Lund, Studentlitteratur.

Kleinbaum, D. G., L. L. Kupper and K. E. Muller (1987). *Applied regression analysis and other multivariable methods*. Belmont, California, Duxbury Press.

Kubricht, D. W. (1984). "Therapeutic self-care demands expressed by outpatients receiving external radiation therapy." *Cancer Nursing* **7**: 43-52.

Langius, A. (1995). *Quality of life in a group of patients with oral and pharyngeal cancer*. Department of medicine and the Department of Ear, Eye and Skin, Unit of Otorhinolaryngology. Stockholm, Karolinska Institutet Thesis.

Lazarus, R. S. and S. Folkman (1991). *Stress and coping*. New York, Columbia University Press.

Lefort, S. (1993). "The statistical versus clinical significance debate." *IMAGE: Journal of Nursing Scholarship* **25**(1): 57-62.

Leibel, S., A. and T. Phillips, L., Eds. (1998). *Textbook of radiation oncology*. Philadelphia, W.B. Saunders Company.

Lind, P., G. Gagliardi, B. Wennberg and T. Fornander (1997). "A descriptive study of pulmonary complications after postoperative radiation therapy in node-positive stage II breast cancer." *Acta Oncologica* **36**(5): 509-515.

Linstone, H. and M. Turoff (1975). *The Delphi method: Techniques and applications*. Reading, MA, Addison-Wesley.

Littbrand, B. and I. Turesson (1998). *Strålbehandling. Onkologi*. Eds. U. Ringborg, R. Henriksson and S. Friberg. Stockholm, Liber.

Longman, A. J., C. J. Braden and M. H. Mishel (1999). "Side-effects burden, psychological adjustment, and life quality in women with breast cancer: Pattern of association over time." *Oncology Nursing Forum* **26**(5): 909-915.

Maraste, R., L. Brandt, H. Olsson and B. Ryde-Brandt (1992). "Anxiety and depression in breast cancer patients at start of adjuvant radiotherapy." *Acta Oncologica* **6**: 641-643.

Maunsell, E., J. Brisson and L. Deschenes (1992). "Psychological distress after initial treatment for breast cancer. Assessment of potential risk factors." *Cancer* **70**(1): 120-125.

Meleis, A. I. (1997). *Theoretical Nursing: Development and progress*. Philadelphia, New York, Lippincott.

Miles, M. and M. Huberman (1994). *Qualitative Data Analysis*. Thousand Oaks, California, SAGE Publications.

- Mock, V., K. Hassey Dow, C. J. Meares, P. M. Grimm, J. A. Dienemann, M. Haisfield-Wolfe, W. Quitasol, S. Mitchell, A. Chakravarty and I. Gage (1997). "Effects of exercise on fatigue, physical functioning, and emotional distress during radiation therapy for breast cancer." *Oncology Nursing Forum* **24**(6).
- Morgan, D. L. (1993). "Qualitative content analysis: A guide to paths not taken." *Qualitative Health Research* **3**(1): 112-121.
- The National Board of Health and Welfare Stockholm, Sweden, Centre of epidemiology. (1999). *Cancer incidence in Sweden 1997*.
- Noll Hoskins, C. (1997). "Breast cancer treatment related patterns in side effects, psychological distress, and perceived health status." *Oncology Nursing Forum* **24**(9): 1575-1583.
- Nordensjöld, B. (1998). *Endokrin behandling. Onkologi*. Eds. U. Ringborg, R. Henriksson and S. Friberg. Stockholm, Liber.
- Nordin, K. and B. Glimelius (1997). "Psychological reactions in newly diagnosed gastrointestinal cancer patients." *Acta Oncologica* **36**(8): 803-810.
- Omne-Pontén, M., L. Holberg, T. Burns, H. Adami and R. Bergström (1992). "Determinants of the psychosocial outcome after operation for breast cancer. Results of a prospective comparative interview study following mastectomy and breast cancer." *European Journal of Surgery* **28A**: 1062-1067.
- Orem, D. E. (1995). *Nursing: concepts of practice*. Chicago, Mosby-Year Book.
- Overgaard, M., P. S. Hansen, J. Overgaard, C. Rose, M. Andersson, F. Bach, M. Kjaer, C. Gadeberg, H. Mouridsen, B.-M. Jensen and K. Zedler (1997). "Postoperative radiotherapy in high-risk premenopausal women with breast cancer who receive chemotherapy." *The New England Journal of Medicine* **337**(14): 949-955.
- Parle, M., P. Maguire and C. Heaven (1997). "The development of a training model to improve health professionals skills, self-efficacy and outcome expectancies when communicating with cancer patients." *Social Science and Medicine*(44): 231-240.
- Polit, D. F. (1996). *Data analysis & statistics for nursing research*. Stamford, Connecticut, Appelton & Lange.
- Poroch, D. (1995). "The effect of preparatory patient education on the anxiety and satisfaction of cancer patients receiving radiation therapy." *Cancer Nursing* **18**: 206-214.
- Pålsson, E. and A. Norberg (1995). "Breast cancer patients experiences of nursing care with the focus on emotional support: the implementation of a nursing intervention." *Journal of Advanced Nursing* **21**: 277-285.
- Ragaz, J., M. S. Jackson, N. Le, I. J. Plenderleith, J. J. Spinelli, V. E. Basco, K. S. Wilson, M. A. Knowling, C. M. L. Coppin, M. Paradis, A. J. Coldman and I. A. Olivotto (1997). "Adjuvant radiotherapy and chemotherapy in node-positive premenopausal women with breast cancer." *New England Journal of Medicine* **337**(14): 956-962.

- Ream, E. and A. Richardson (1996). "The role of information in patients adaptations to chemotherapy and radiotherapy: a review of the literature." *European Journal of Cancer Care* **5**: 132-138.
- Ream, E. and A. Richardson (1999). "From theory to practice: Designing interventions to reduce fatigue in patients with cancer." *Oncology Nursing Forum* **26**(8): 1295-1303.
- Redfern, L. (1998). "Breast cancer Part 3: Psychosocial care." *Professional Nurse Study* **13**(12): 875-883.
- Rose, J., C. L. Schrader-Bogen, G. Korlath, J. Priem and L. R. Larson (1996). "Identifying patients symptoms after radiotherapy using a nurse-managed telephone interview." *Oncology Nursing Forum* **23**: 99-102.
- Rutqvist, L. E. (1996). "Breast Cancer. In: Radiotherapy for cancer. Vol. 2. A critical review of the literature." *Acta Oncologica, Supplement*: 54-63.
- Rutqvist, L. E. and A. Wallgren (1998). *Bröstcancer. Onkologi*. Eds. U. Ringborg, R. Henriksson and S. Friberg. Stockholm, Liber.
- Sandelin, K., A. M. Billgren and M. Wickman (1998). "Management, Morbidity, and Oncologic aspects in 100 consecutive patients with immediate breast reconstruction." *Annals of Surgical Oncology* **5**(2): 159-165.
- Schnoll, R. A., L. L. Harlow, L. L. Stolbach and U. Brandt (1998). "A structural model of the relationships among stage of disease, age, coping, and psychological adjustment in women with breast cancer." *Psycho-Oncology* **7**: 69-77.
- Seeger, J. and T. Woodcock (1998). *Chemotherapy of Breast Cancer. Textbook of Radiation Oncology*. Eds. S. Liebel and T. Phillips. Philadelphia, W.B. Saunders Company.
- Sitton, E. (1992). "Clinical review. Early and late radiation-induced skin alterations. Part 1: Mechanisms of skin changes." *Oncology Nursing Forum* **19**: 801-807.
- Smets, E. M. A., M. R. M. Visser, D. Garssen, N. H. Frijda, P. Oosterveld and J. C. J. M. De Haes (1998). "Understanding the level of fatigue in cancer patients undergoing radiotherapy." *Journal of Psychosomatic Research* **45**(3): 277-293.
- Spiegel, D. (1997). "Psychosocial aspects of breast cancer treatment." *Seminars in Oncology* **24**(Supplement 1): 36-47.
- Spratt, J. S., W. L. Donegan and C. Sigdestad (1998). *Textbook of Radiation Oncology: Epidemiology and Etiology. Cancer of the breast*. Philadelphia, W.B. Saunders Company.
- Walker, B. L., L. M. Nail, L. Larsen, J. Magill and A. Schwartz (1996). "Concerns, affect and cognitive disruption following completion of radiation treatment for localized breast or prostate cancer." *Oncology Nursing Forum* **23**(8): 1181-1187.
- Watkins Bruner, D. (1993). "Radiation oncology nurses: Staffing patterns and role development." *Oncology Nursing Forum* **20**(4): 651-655.

Weintraub, F. and G. A. Hagopian (1990). "The effect of nursing consultation on anxiety, side effects and self-care of patients receiving radiation therapy." *Oncology Nursing Forum Supplement 3*: 32-38.

Wells, M. (1998). "What's so special about radiotherapy nursing?" *European Journal of Oncology Nursing 2*(3): 162-168.

Wengström, Y. and C. Forsberg (1999). "Justifying radiation oncology nursing practice - A literature review." *Oncology Nursing Forum 26*(4): 741-750.

Wengström, Y. and C. Häggmark (1998). "Assessing nursing problems of importance for the development of nursing care in a radiation therapy department." *Cancer Nursing 21*(1): 50-56.

Wengström, Y., C. Häggmark, H. Strander and C. Forsberg (1999). "Effects of a nursing intervention subjective distress, side effects and quality of life of breast cancer patients receiving curative radiation therapy - A randomized study." *Acta Oncologica 38*(6): 763-770.

Wettergren, L., A. Langius, M. Björkholm and H. Björvell (1999). "Post-traumatic stress symptoms in patients undergoing autologous stem cell transplantation." *Acta Oncologica 38*(4): 475-480.

Wickman, M., G. Jurell and K. Sandelin (1998). "Technical aspects of immediate breast reconstruction - two year follow-up of 100 patients treated consecutively." *Scandinavian Journal Plastic Reconstructive Hand Surgery 32*: 265-273.

Wittes, R. E. (1991). *Manual of oncologic therapeutics*. Philadelphia, Lippincott Company.

Woo, B., S. L. Dibble, B. F. Piper, S. B. Keating and M. C. Weiss (1998). "Differences in fatigue by treatment methods in women with breast cancer." *Oncology Nursing Forum 25*(5): 915-920.

Woods, M., M. Tobin and P. Mortimer (1995). "The psychosocial morbidity of breast cancer patients with lymphoedema." *Cancer Nursing 18*(6): 467-471.

Wyatt, G. K. and L. L. Friedman (1998). "Physical and psychosocial outcomes of midlife and older women following surgery and adjuvant therapy for breast cancer." *Oncology Nursing Forum 25*(4): 761-768.

Youngblood, M., P. Daus Williams, H. Eyles, J. Waring and S. Runyon (1994). "A comparison of two methods of assessing cancer therapy - related symptoms." *Cancer Nursing 17*: 37-44.