

*Health-Related Quality of Life  
in younger and older women treated for  
Breast Cancer in Norway*

**Article 1:** Aspects of breast cancer, Quality of Life (QoL) and Health-Related Quality of Life (HRQoL) - A theoretical background

**Article 2:** Differences in HRQoL between younger and older women treated for breast cancer: Associations between social function, future perspective, body image, sexual function and QoL

Master thesis in Health Science  
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Katrine Salberg Jensen



## **Summary of the master's thesis**

Improved survivor rates among breast cancer patients and increased amount of patients living with side-effects after treatment, have led to increased focus on quality of life (QoL). Aspects like body image, sexual function, future perspective and social function have been seen in association with QoL, in breast cancer patients. The relationship between QoL and aspects like body image, sexual function, social function and future perspective can be highlighted by theories like the biopsychosocial model of health and illness, and the identity theory. Age-differences in aspects of HRQoL are mentioned as essential, and are highlighted as an important suggestion for further research among breast cancer patients. The present master's thesis report significant lower body image in younger women ( $\leq 50$  years) than among older women ( $>50$  years) treated for breast cancer. Social function and sexual function were significantly associated with higher levels of QoL among younger women. In older women, social function, sexual function and future perspective were significantly associated to QoL. The results highlights the importance of enhancing social and sexual functioning among women treated for breast cancer.

## **Norsk sammendrag av masteroppgaven**

Økende overlevelsrate blant brystkreft pasienter og økt antall pasienter som lever med bivirkninger etter behandling, har ført til et økende fokus på livskvalitet. Aspekter som kroppsbilde, seksuell funksjon, fremtidsperspektiv og sosial funksjon har blitt relatert til livskvalitet blant brystkreft pasienter. Forholdet mellom livskvalitet og aspekter som kroppsbilde, seksuell funksjon, sosial funksjon og fremtidsperspektiv kan belyses av teorier som den biopsykososiale modellen for helse og sykdom og identitetsteorien. Aldersforskjell blant brystkreft pasienter nevnes som essensielt når det gjelder aspekter av helse- relatert livskvalitet, og har blitt foreslått som tema for fremtidig forskning. Den aktuelle masteroppgaven rapporterer at yngre kvinner ( $\leq 50$  år) har signifikant lavere kroppsbilde enn eldre kvinner ( $>50$  år) som har fått behandling mot brystkreft. Blant yngre kvinner var sosial og seksuell funksjon assosiert med signifikant bedre livskvalitet. Blant de eldre kvinnene, var det signifikante assosiasjoner mellom sosial funksjon, seksuell funksjon, fremtidsperspektiv og bedre livskvalitet. Disse resultatene belyser viktigheten av å bedre sosial og seksuell funksjon blant kvinner som har fått behandling mot brystkreft.

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## **Main introduction**

The present master's thesis, "*Health Related Quality of Life in younger and older women treated for breast cancer in Norway*," consists of two articles with different structures. The two articles are related to each other, and must be read in the given order. The APA (American Psychological Association) is the reference style in both articles.

The first article, "*Aspects of breast cancer, Quality of Life (QoL) and Health-Related Quality of Life (HRQoL) - A theoretical background*," provides the theoretical background of both articles. Since this article provides an introduction of the theoretical aspects and clarifies the concepts this article must be read first. Relevant articles and earlier research were mainly collected from databases such as Pub Med and Science Direct. The most commonly used key words to locate relevant material were breast cancer, quality of life, health-related quality of life, age-related differences, sexuality, body image, social function, future perspective, biopsychosocial model, identity theory and treatment in breast cancer. In short, the first article is chiefly a literature review and therefore provides the basis and background for the second article, which is empirical in nature.

The second article, "*Differences in HRQoL between younger and older women treated for breast cancer: Associations between social function, future perspective, body image, sexual function and QoL*," is an empirical study. This article is based upon data from a larger, prospective longitudinal study that investigates the side effects and health-related quality of life (HRQoL) after radiotherapy (RT) in breast cancer patients. The second article uses the structure and instructions from *Psycho-Oncology* as a guideline for its direction and approximate scope.

At the end of this paper are some appendixes. These are the EORTC QLQ-C30 Questionnaire (Appendix 1), the EORTC QLQ-BR23 Questionnaire (Appendix 2), Questionnaire for Background Information (Appendix 3) and a Certification from The Regional Committees for Medical Research Ethics (Appendix 4).



# **Aspects of breast cancer, Quality of Life (QoL) and Health-Related Quality of Life (HRQoL) - A theoretical background**

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## **Abstract:**

Today's improved survivor rates among breast cancer patients leads to several challenges. Many breast cancer survivors are living with different side effects which might affect their QoL. Several aspects like body image, sexual function, future perspective and social function have been seen in association with QoL. Previous research also indicates that body image and sexual problems are influenced by breast cancer treatments such as type of surgery and chemotherapy. The relationship between QoL and aspects like body image, sexual function, social function and future perspective can be highlighted by theories such as the biopsychosocial model of health and illness and the identity theory. Age differences in aspects of HRQoL are mentioned as essential and are highlighted as an important suggestion for further research among breast cancer patients.

**Key words:** Breast cancer, breast cancer treatment, Quality of Life, Health-related Quality of Life, body image, sexual function, social function, future perspective, age-related differences, biopsychosocial model, identity theory.

## **1. Breast cancer**

Today, breast cancer is the most common cancer in women worldwide (World Health Organization, 2012). In Norway, 2745 new cases of breast cancer were recorded in 2009 (Cancer Registry of Norway, 2011). About 80% of those 2745 affected by breast cancer are over 50 years of age, and the risk of getting this disease increase with age (The Norwegian Cancer Society, 2011). Rapid advancements in breast cancer treatments and mammography screening play an important role in the increasing rates of survival (Holleczek, Arndt, Stegmaier & Brenner, 2011). Nevertheless, women who do survive breast cancer meet medical, physical and psychosocial challenges (Dizon, 2009). The HRQoL includes the subjective impact of the disease as well as the disease's impairments and their treatments (Carr, Gibson and Robinson, 2001). The developments in treatments have consequently led to an increasing focus on quality of life issues among breast cancer patients and in research (Montazeri et al., 2008).

Breast cancer is a malignant tumor that originates from the breast tissue or lymph nodes around the breast. It is not known why some individuals develop breast cancer and some do not, but we do know that about 5% of all reported breast cancers are hereditary (The Norwegian Cancer Society, 2011). From the beginning of the year 2005 through the year 2009, the five-year survival rate among breast cancer patients in Norway was 88.3% in total (Cancer Registry of Norway, 2011).

The breasts mainly consist of fat tissue, and this fat surrounds twelve to twenty glandules in protective tissue (Kåresen, Schlichting & Wist, 1998). The breast tissue changes in the woman's mid-thirties, when the glandular tissue changes to fat tissue (The Norwegian Cancer Society, 2011; Kåresen et al., 1998). As a result, the breasts become less firm the older one grows (Kåresen et al., 1998). Some may fear this transformation, but it is a normal change. Similarly, not all tumors in the breast are malignant; some of them are part of the natural transformation and are benign (The Norwegian Cancer Society, 2011). The significance of the breasts is mainly to produce milk during pregnancy, but they are also meaningful for women's self-image and appear as a symbol of femininity and sexuality (Kåresen et al., 1998).

## **2. Treatment of breast cancer**

The standard treatment of breast cancer patients is surgery followed by different combinations of adjuvant (additional) treatments like chemotherapy, radiotherapy and hormone therapy (NBCG, 2012; Norwegian Directorate of Health, 2007). There are different kinds of surgery, and the most common are mastectomy or breast conserving surgery (King, Kenny, Shiell, Hall & Boyages, 2000). The aims of surgery are to eradicate the tumor and its prospective local extension, to control the disease and to increase the patient's survival rate. Breast conserving surgery removes only the tumor and a rim of normal breast tissue around the tumor. This type of surgery can be done if the mammography can locate clear margins around the tumor (NBCG, 2012). Mastectomy is a total excision of the breast parenchyma. This surgery is for patients with tumors in ill-defined margins, with tumors that widely extend within the breast or with tumors that involve the overlaying skin or nipple (NBCG, 2012; NHMRC, 2001).

Depending on the stage of the disease as well as the patient's age and the hormonal status of the tumor, some patients need additional (adjuvant) treatments with chemotherapy, radiotherapy and/or hormones (NBCG, 2012). Adjuvant treatments are shown to reduce the risk of recurrence and thereby improve survival in breast cancer patients (Montazeri, 2008).

Results show that every year in Norway, chemotherapy reduces the death rate by 38% among patients under 50 years old and 20% among those older than 50 years. The age of the patient, the hormone's status, the risk for recurrence, the side effects and the actability are important when assessing the need of systemic adjuvant treatment. Chemotherapy doses are calculated from the patient's body surface, and the treatment can be given every week or with three weeks spaces. The most common side effects of chemotherapy are hair loss and nausea, which stop after the end of the treatment (NBCG, 2012).

Radiotherapy usually starts about three to eight weeks after surgery, depending on whether the patient has been scheduled for chemotherapy treatment after the surgery. If chemotherapy treatment is not necessary, then radiotherapy should start about six to eight weeks after surgery. If chemotherapy is performed, then radiotherapy should start about three to four weeks after the end of the chemotherapy treatment. Radiotherapy is often administered five days per week and usually over a period of five weeks. The side effects of radiotherapy after breast radiation could be lymphoedema, impaired shoulder mobility and cardiac and lung damage, which may affect the patient's quality of life (Senkus-Konefka & Jassem, 2006).

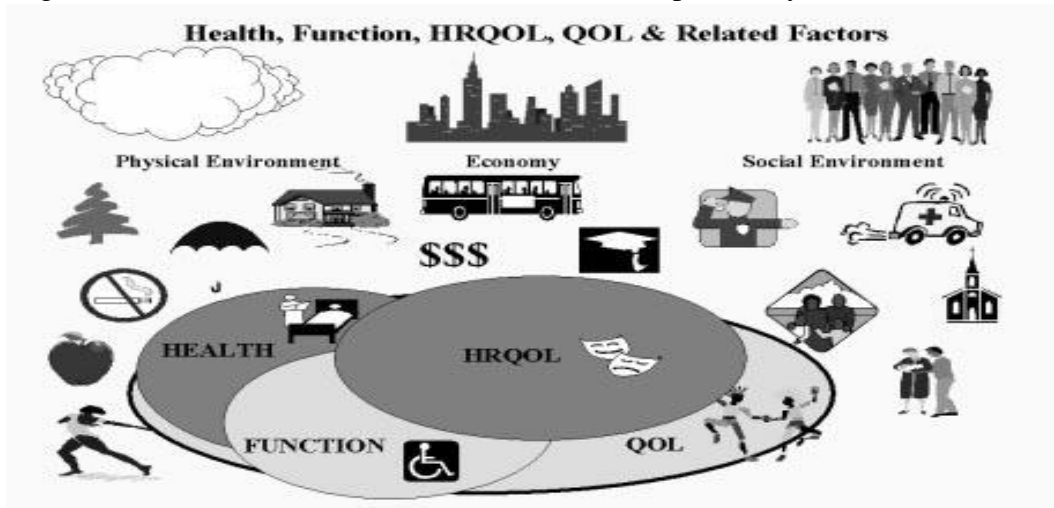
The function and growth of the breast tissue depends on the interaction between several hormones. A tumor is also sensitive to hormones, which is why hormone therapy is used as adjuvant treatment. In hormone treatment, the grade of the estrogen and progesterone receptors in the tumor predicts the tumor's response to the hormone treatment (NBCG, 2012). Hormone therapy may cause chemically induced menopause (Emilee, Ussher & Perz, 2010).

Treatment of breast cancer is associated with several side effects like fatigue, pain and those affecting quality of life (Montazeri, 2008). The most frequently reported side effect is fatigue. Fatigue is a nonspecific, multidimensional construct that involve tiredness, weakness and lack of energy, and can often last for years following the end of the treatment (Bower et al., 2000). Fatigue is known to influence many dimensions of life, including social function and sexual function (Bower et al., 2000; Henson, 2002). The choice of treatment and the type of diagnosis may affect a woman's body image, sexuality and well-being (Kissane, White, Cooper & Vitetta, 2004). The treatments may cause the patient to experience symptoms, even when the adjuvant treatments extend survival (Miaskowski et al., 2006). These experienced symptoms can lead to a lower score on quality of life (Ganz et al., 2002; Ganz et al., 2004).

### **3. Quality of Life (QoL)**

The World Health Organization defines Quality of life (QoL) as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 1997, p. 1). This definition enunciates that QoL is subjective, and can only be measured by the individual (Van der Steeg, De Vries & Roukema, 2004). QoL has no universal definition; instead, the concept is complex, broad and multidimensional (CDC, 2000; Eriksson, 2007). QoL conveys an overall sense of well-being, happiness and satisfaction with life as whole and includes subjective evaluations of both positive and negative aspects of life (CDC, 2000; The WHO QOL Group, 1998). It is challenging to measure QoL because the term has different meanings for nearly everyone. It includes diverse domains such as health, jobs, housing, schools, culture, spirituality and values (CDC, 2000). To illustrate the complexity of QoL, a figure is included (Figure 1).

Figure 1. Illustration of the multidimensional concept Quality of Life (QoL).



Reference: CDC, 2000, p.6

Figure 1 illustrates the complexity and the multidimensionality of the QoL concept. As shown in the illustration, QoL includes aspects such as health, function and health related quality of life (HRQoL), and these aspects include several sub-categories as well. The figure attempts to show that all these factors are separate aspects, but at the same time a part of the broad QoL term. This article will explain one of these aspects and its sub-categories; the health related quality of life (HRQoL), more thoroughly in the following section.

#### 4. Health-Related Quality of Life (HRQoL)

To handle the complexity of QoL, researchers have developed helpful techniques to conceptualize and measure its different domains. Health-related quality of life (HRQoL) encompasses aspects of overall QoL that can be apparently shown to affect both physical and mental health (CDC, 2000). To distinguish between the more general term QoL and the requirement of clinical medicine and clinical trials, the term HRQoL is used (Fayers & Machin, 2000). HRQoL is described as the space between a person's expectations of health and the person's experience of it, which varies among individuals. HRQoL concerns the subjective impact of the disease, its impairments and their treatments (Carr et al., 2001). The term HRQoL was meant to narrow the practitioners' focus on the effects of health, illness and treatment on QoL (Ferrans, Zerwic, Wilbur & Larson, 2005). HRQoL is an extensive concept, and includes factors like physical, emotional, sexual, social and cognitive functions, symptoms of disease and treatment, health risks, functional status, social support and socioeconomic status. All of these factors are considered by and from the perspective of the patient (Bottomley & Therasse, 2002). HRQoL measures have become important components of health observations both in the general population and among the ill (CDC, 2000).

## 5. Assessments of HRQoL

Although HRQoL is complex, diverse measuring instruments for this aspect exist, including questionnaires that are generic, disease-specific and domain-specific. Generic measures are broad measures of health status, and should encompass the dimensions of physical, mental and social health. Generic measures are often used to compare disease groups within and between specialties. The most popular generic measure is SF-36. However, generic measures are often supplemented with disease-specific measures (Bowling, 2001; CDC, 2000). Disease-specific measurements are clinically significant to specific conditions and diseases, so they are used when disease or condition-related attributes need to be assessed. A popular disease-specific measurement is the EORTC QLQ-C30. Finally, some researchers supplement their disease-specific measures with domain-specific measures. Domain-specific measures are used when the area is of particular interest to the researcher and when disease-specific or generic measurements selected for use, ignore the actual domain. Domain-specific measurements are specialized scales measuring specific domains, but the area of interest will vary according to how the condition and its treatment affect the patient (Bowling, 2001).

Several trends in health care have resulted in the development of pragmatic techniques that have helped to conceptualize and measure HRQoL more effectively (Fitzpatrick, Davey, Buxton & Jones, 1998). Information about HRQoL has become important and useful to both patients and physicians when they make decisions about treatments for serious diseases like cancer (Whelan & Pritchard, 2006). This article will delve into a closer look at the cancer-specific EORTC QLQ-C30 questionnaire.

The European Organization for Research and Treatment of Cancer (EORTC) was founded in 1962, and the aims of the organization are to conduct, develop, coordinate and stimulate cancer research in Europe. In 1980, the EORTC Quality of Life Group was created, which initiated a research program to develop and evaluate the QoL of patients participating in cancer trials. Further, this led to the development of the EORTC QLQ-C30, which is a QoL instrument for cancer patients (Aaronson et al., 1993). The EORTC questionnaires are used in several studies and are one of the most acceptable tools for measuring QoL in Europe. EORTC have operationalized the HRQoL in terms of functional status, cancer and treatment by pinpointing specific symptoms, the status of psychological, social and financial well-being and the global health status (Aaronson et al., 1993; Montazeri, 2008).

EORTC QLQ-C30 is a disease-specific self-assessment instrument and a core-questionnaire that contains of 30 items (Aaronson et al., 1993). QLQ-C30 is composed of



both multi-item scales and single-item measures. The questionnaire contains five functional scales (physical, role, emotional, cognitive and social functioning), three symptom scales (fatigue, pain and nausea and vomiting), six single items (dyspnoea, insomnia, appetite loss, constipation, diarrhoea, and financial difficulties) and a global health status/ QoL scale (Aaronson et al., 1993). Hereafter, this paper will refer to the *global health status/QoL scale* as just *QoL*.

One of the EORTC's essential functions has been the development and use of supplementary disease- or treatment specific questionnaire modules, which can provide relatively detailed information of specific patient groups. These modules are often used in addition to the EORTC QLQ-C30, and they cover general aspects of HRQoL in the cancer population. One of these specific patient groups is comprised of breast cancer patients.

EORTC have made a disease- specific module questionnaire for breast cancer, called the EORTC Quality of Life Questionnaire Breast Cancer 23 Items (QLQ-BR23), which asks 23 questions. These questions fall under five multi-item scales that assess systemic therapy side effects (surgery, chemotherapy, radiotherapy and hormonal treatment), arm symptoms, breast symptoms (symptom scales), body image and sexual functioning (function scales). In addition, three single items assess sexual enjoyment, hair loss and future perspective (Aaronson et al., 1993). The EORTC QLQ-C30 and QLQ-BR23 questionnaires are both validated in Norwegian (EORTC group for research into Quality of Life, 2011).

As explained, HRQoL refers to several aspects of health, both physical and mental (Bjornson & McLaughlin, 2001; CDC, 2000). To illustrate how EORTC have operationalized HRQoL in breast cancer patients, this article includes two figures (Figure 2 and Figure 3). These figures illustrate how this article understands and interprets the complexity of HRQoL according to EORTC's questionnaires (QLQ-C30 and QLQ-BR23).

Figure 2. General model with all variables. Associations between overall QoL and HRQoL aspects in accordance to EORTC questionnaires QLQ-C30 and QLQ-BR23

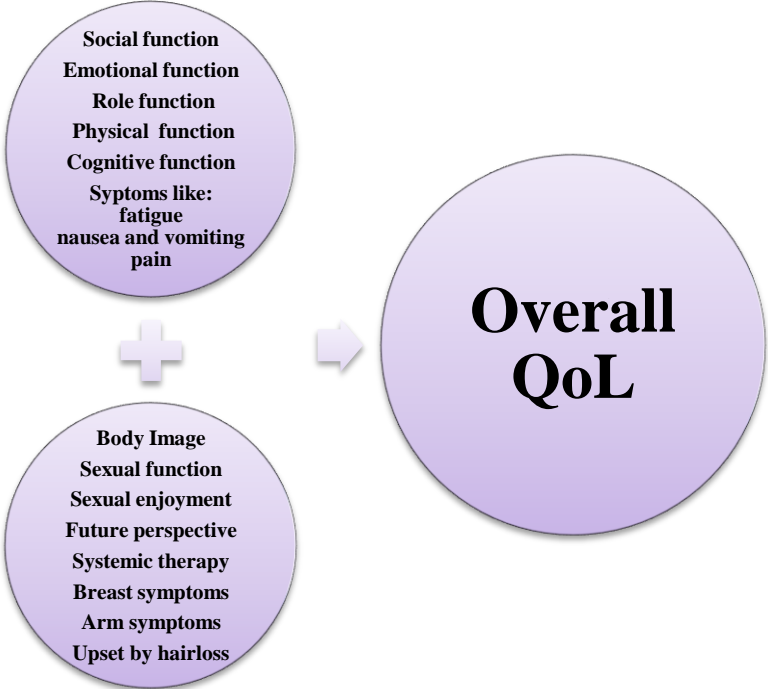


Figure 2 shows a general model with all EORTC-variables from both QLQ-C30 and QLQ-BR23. This model illustrates that all of the domains in the first circle from the QLQ-C30 questionnaire (social function, emotional function, role function, physical function, cognitive function, pain and symptoms like fatigue, nausea and vomiting) and the domains in the second circle from the QLQ-BR23 questionnaire (body image, sexual function, sexual enjoyment, future perspective, systemic therapy, breast symptoms, arm symptoms and feeling upset by hair loss) are independent domains that are separate from the overall QoL, yet they contribute to the larger concept, overall QoL.

These several aspects related to breast cancer and QoL can be interpreted and understood more thoroughly through theories. Among the extant theories, the biopsychosocial model of health and illness and the identity theory may explain some relations in breast cancer.

## **6. The biopsychosocial model for health and illness and breast cancer**

The biopsychosocial model for health and illness came as a development of the biomedical model in the 1970's. Numerous researchers criticized the biomedical model for its simplistic, causal thinking and for its other insufficiencies (Espnes & Smedslund, 2009). In response to these criticisms, Georg Engel created the new and developed biopsychosocial model. He claimed that the biomedical model is dualistic, as it assesses body and mind separately. In the biopsychosocial model, the dualistic aspect has been transformed, or is at least less visible, and a more holistic view comes through. Engel explained the biopsychosocial model as a dynamic and interactional model with a dualistic view of human experience in which mind and body have mutual influence (Borrell-Carriò, Suchman & Epstein, 2004).

The biopsychosocial model provides a holistic view of health and is influenced by biological, social and psychological factors. It relies on the assumption that every process in the body is affected by an interaction between biological, social and psychological factors. For example, when people become sick, their psychological and social factors are affected as well as the physical parts of their body (Espnes & Smedslund, 2009). Stress, attachment ability and performance and coping strategies, are portions of this biopsychosocial perspective. In addition, previous knowledge of social factors, work, status, economics, location, network and support affect the researcher's understanding of illness and behavior (Stubhaug, 2005).

One can understand and explain the different aspects of breast cancer by applying the biopsychosocial model and its view of health and illness (Wong-Kim & Bloom, 2004). Breast cancer survivors may face many concerns that span the areas of medicine, psychology, sexuality and physical status (Dizon, 2009). For example, surgical removal of the breast is invasive and has therefore been shown to affect the QoL. Specially, associations between having a mastectomy and psychological distress, depression, anxiety and diminished body image have been shown (Emilee et al., 2010; King et al., 2000; Moyer, 1997). The link between having a mastectomy and psychological distress, body image problems, depression and anxiety can indicate the essence of the biopsychosocial model (i.e., body and mind are connected). Also, sexual dysfunction after treatment for breast cancer includes physical, psychological, inter-relational and physiological aspects (Dizon, 2009), and can therefore be seen in light of the biopsychosocial model. Biological and physical changes in sexuality may depend on the woman's psychological health and how she perceives herself (Hordern, 2000). Research also found that self-esteem and body image problems significantly affect the QoL

among young women with breast cancer (Wong-Kim & Bloom, 2004). In accordance to this, a link between body image and this image's effect on QoL can be seen. The identity theory may be used as a framework to understand different processes among people and to see how illness-related identities like breast cancer may affect the self (Deimling, Bowman & Wagner, 2007).

## **7. Identity theory and breast cancer**

The identity theory, originally formulated by Stryker, is a micro-sociological theory that explains the individual's role-related behaviors. The theory explains a multifaceted and dynamic view of the self and of the relationship between the individual's behavior, the surrounding social structure and society. Society has an effect on one's social behavior and on one's very self when one is among people. The self is described as a social construct that emerges from one's multiple roles in society. The theory assumes that people occupy different roles, which are called role identities. These role identities may include the role of being a mother, a wife, a daughter, a blood donor and a social worker. In addition, people may occupy self-defining roles like gender, race and ethnicity while in society. Poor role performance may result in changes in the self and may produce symptoms of psychological distress (Hogg, Terry & White, 1995).

Identity theory may be used as a framework to understand different processes among people and to see how illness-related identities may affect the self. Stressors in life, such as life-threatening illness, may result in changes to personal identity. These changes can further alter aspects of a person's self. Different kinds of specific identities that people feel are important when they describe who they are may be disrupted if stressors like illness appear. The identity factors that can be disrupted include one's career, professional or family identities. Illness identities may replace the individual's real and specific identities (Deimling et al., 2007).

Cancer is one of these life-threatening illnesses that may appear at any point in a person's life. Cancer, as an illness-identity, can replace the original and primary identities of a person. One of the cancer types that might heavily affect identity is breast cancer. Breast cancer is called a sex-specific cancer, so it may affect important elements of the self that pertain to gender. The disease can have an impact on how a woman performs her roles, such as being a mother, performing parental care, engaging in spousal intimacy or meeting expectations at work (Deimling et al., 2007).

Social function and other aspects of QoL in breast cancer patients may be seen in accordance to the identity theory. The identity theory explains that there is a relationship between an individual's behavior and society's structure and members. Given this theory's assumption that society has an effect on social behavior and the self (Hogg et al., 1995), one can view social function among breast cancer patients as a part of the identity theory. Problems with social function among breast cancer patients may occur from the relationship between individual behavior and the social structure and society. Rosedale (2009) explains that women deal with various social challenges after breast cancer, such as the pressure to return to normal or the pressure to maintain a heroic survivor narrative. These problems and worries may explain why some women become less social after breast cancer treatment, and some even do not return to work. As the identity theory asserts, society's expectations are affecting social behavior (Hogg et al., 1995).

Aspects of body image and self-esteem may also be seen in accordance to the identity theory. In accordance to role identities, poor role performance may affect the self and some may produce symptoms of psychological distress (Hogg et al., 1995). Earlier research found that the breasts are significant to women's self-image, and are a symbol of femininity and sexuality (Kåresen et al., 1998); therefore, breast cancer may arouse feelings and behavior from women that can be explained with the identity theory. For example, a woman treated for breast cancer may feel different from her original identity, because the illness-identity has taken over as her main identity (Deimling et al., 2007). The cancer disease can make women feel less feminine when they lose one or both breasts. The cancer disease can also affect important elements of the self pertaining to gender and this disease can have an impact on how a woman performs her roles, such as being a mother, a spouse or a professional (Deimling et al., 2007). While coping with breast cancer and the side effects of treatment, women may feel that they cannot fill these roles any longer and too many problems are occurring in their lives. The identity theory can illustrate how the aspects of breast cancer may affect the life and daily roles of a woman.

The relationship among QoL and body image, sexuality, social function and other aspects in breast cancer, can be explained with the thoughts behind the biopsychosocial model of health and illness and the identity theory. Earlier research has documented that several aspects affects QoL after a breast cancer diagnosis. Changes in physical, psychological, functional, social and sexual aspects affect one's QoL (Henson, 2002). For an illustration of how the selected aspects from the EORTC questionnaires are related to QoL, see Figure 3.

Figure 3. Specific model for the chosen variables used in the next empirical article. Associations between overall QoL and HRQoL aspects in accordance to EORTC questionnaires QLQ-C30 and QLQ-BR23.

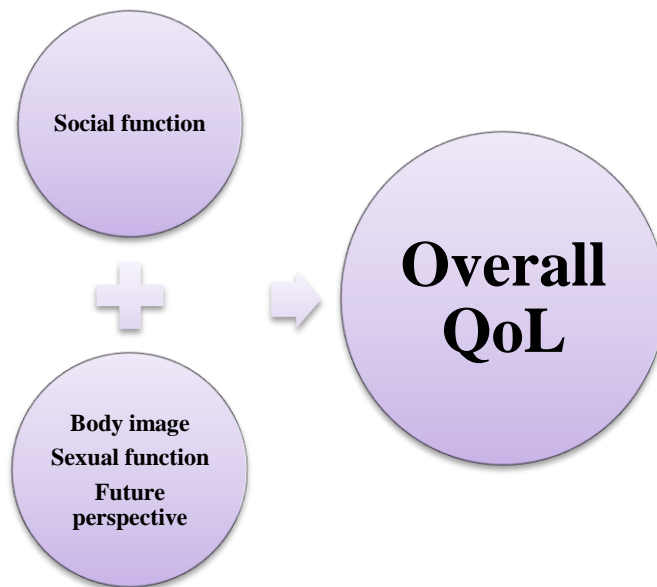


Figure 3 demonstrates that social function, body image, sexual function and future perspective are all independent domains separated from the overall QoL, but also makes a part of the larger overall QoL concept. The figure also illustrates how specific variables used and analyzed in this paper are related to overall QoL. Next, this paper provides the explanations and background information of each aspect.

## **8. Body image and sexuality in breast cancer**

Body image and sexuality are both aspects of the human behavior (Fobair et al., 2006), and breast cancer may affect them (Sheppard & Ely, 2008). Women's breasts play an important role in their feminine identity and have extensive meaning for their body (Montazeri, 2008; Pikler & Winterowd, 2003). Subjects related to the breasts are sexuality, motherhood, attractiveness, femininity and womanhood (Pikler & Winterowd, 2003).

Many definitions of the term *body image* have been presented, yet the term still lacks a clear definition (White, 2000). Body image is, for example, defined as "a person's perceptions, thoughts, and feelings about his or her body" (Grogan, 2008, p. 3). In the context of cancer, body image often refers to psychological aspects such as sexuality, self-esteem and stigma. How a woman experiences her body is subjective and is often a result of her thoughts, perceptions and feelings (White, 2000). For example, Pikler and Winterowd (2003) claim that women with better body image cope better with breast cancer.

Problems with body image and sexuality during the first year of survivorship appear to be influenced by the type of cancer treatment the patient underwent (Fobair et al., 2006) as well as the type of surgery. Women who received breast conserving surgery reported better body image than women treated with mastectomy (Curran et al., 1998; Figueiredo, Cullen, Hwang, Rowland & Mandelblatt, 2004; Ganz, Coscarelli Shag, Lee, Polinsky & Tan, 1992; Hopwood, Haviland, Mills, Sumo & Bliss, 2007; Kenny et al., 2000; King, Kenny, Shiell, Hall & Boyages, 2000; Montazeri, 2008). On the other hand, Shimosuma, Ganz, Petersen and Hirji (1999) found no relationship between type of surgery and QoL aspects. Thus, differences in research results do exist, and both surgery options have approximately the same survival rates (King et al., 2000). The practitioner's choice between mastectomy and breast conserving surgery may depend on differences in QoL and other elements of the patient's preferences (Kenny et al., 2000).

After diagnosis of breast cancer, the patient may undergo changes in sexuality and intimacy depending on the woman's psychological health, how she views herself, her sexuality before the diagnosis and where she is in her life cycle (Hordern, 2000). Sexuality encompasses biological, psychologic, physical, inter-relational and physiologic aspects, and sexual function is defined as "a range of solo and partnered forms of sexual expression" (Dizon, 2009; DeLamater & Karraker, 2009). Impaired sexual functioning is associated with reduced QoL among women with breast cancer (Montazeri, 2008). Sexual dysfunction affects about 90% of women diagnosed with and treated for breast cancer, and it can come in the form of physical, psychological, inter-relational and physiological dysfunction (Dizon, 2009).

Problems and physical changes in sexual function after breast cancer may concern disruption of sexual arousal, orgasm, sexual desire and pleasure. These changes could be related to the side effects of chemotherapy, hormonal therapy (chemically induced menopause) and breast surgery (Emilee et al., 2010). The types of sexual side effects and other problems related to breast cancer may depend on the age of the patient (Andt et al., 2004; King et al., 2000).

Research suggests that it's differences between younger and older women and their experience and scores in aspects like body image and sexual function (Andt et al., 2004; King et al., 2000). Interestingly, King et al. (2000), found that older women on average had better body image than younger women and that younger women were more afraid of disease recurrence than older women. They also presented that older women had a slightly better average QoL than younger women had and that the breasts were less important to the older women's feelings of attractiveness and femininity. Likewise, Hopwood et al. (2007) found that younger women (< 50 years) had worse body image than older women had. In contrast, Arndt et al. (2004) reported that younger women had better QoL than older women had. They also found that older breast cancer patients tended to report better role, emotional, cognitive and social functioning than younger women with breast cancer reported. According to Watters, Yau, O'Rourke, Tomiak & Gertler (2003), sexual function at baseline was significantly better among young women, and future perspective was significantly better among older women. The improvement in future perspective at follow-up was significantly greater in young women, and the decline in body image by the completion of chemotherapy tended to be more marked in young women. Furthermore, Montazeri (2008) explained that sexual function is an area that needs more attention, especially for younger breast cancer survivors. He also reported that younger women with breast cancer may need interventions that target their needs in problems with relationships, menopausal problems, sexual functioning and body image. Wenzel et al. (1999) presented results that showed no significant differences in sexual dysfunction or body image among younger and older breast cancer patients. As shown, there are several examples that can highlight age as an important aspect to be included in any discussion about QoL among women diagnosed with breast cancer. Arndt et al. (2004) add that social function and future perspective are two other aspects in QoL.



## **9. Social functioning and future perspective in breast cancer**

As the previous section mentioned, the term QoL refers to a multidimensional concept that includes dimensions like physical, emotional and social functioning (Arndt et al., 2004). Two of the most fundamental human motivations are the need to form interpersonal connections and the need to function in society (Preston, 2010). Among other explanations, has social function been explained as normative behavior in a social situation (Blakely & Dziadosz, 2007). Tyrer and Casey (1993) specifically define social function as “the level at which an individual functions in his or her social context, such function ranging between self preservation and basic living skills to the relationship with others in society” (p. 8).

Women have many roles in society that may include employer, parent, friend and spouse. When a woman discovers that she is ill, such as when she receives a breast cancer diagnosis, many experience impairment in several areas of her life, including social functioning. Women’s social functioning roles that may change after breast cancer diagnosis include household, family, social and community, self-care and occupational activities (Preston, 2010). Appearance-related breast cancer treatment can lead to social changes that are potentially disrupting. Visible problems among breast cancer patients may lead to avoidance of social situations, which can lead to other problems (Harcourt & Frith, 2008).

Earlier research has also found a connection between breast cancer and social function. According to Watters et al. (2003), physical, role and social functions may decrease during breast cancer treatments. A correlation between type of surgery and social function has also been shown. It is assumed that mastectomy patients will have an improved social function domain score (Munshi et al., 2010). The woman’s social function in terms of her partner can also be affected by breast cancer. The changes in sexuality that might result from breast cancer seem to influence the woman’s social function with her current partner. Sexuality is a main aspect when it comes to relationships between a women and her husband, and it can affect social function and QoL in connection with the disease and treatment (Manganiello, Hoga, Reberte, Miranda & Rocha, 2011). Furthermore, social function is linked to social support and integration in breast cancer. For example, women who were well integrated socially, before their breast cancer treatment tend to report better role function and vitality than less socially integrated women (Mandelblatt, Figueiredo & Cullen, 2003).

The future has always had a special place in the human mind. Numerous individuals desire a forecast of events that will occur. Cognitive abilities like abstract imagination, logical reasoning and induction can be necessary to forecast the future (McLean & Hurd, 2011). Future perspective can lead to considerations among breast cancer patients. Different kinds of

considerations may appear in accordance to thoughts about the future and the future perspective, such as fertility considerations. About 25% of diagnosed women worldwide will be diagnosed in their reproductive years, which make their choice of breast cancer treatment difficult to resolve (Dizon, 2009). Research has also shown that reported future perspective among breast cancer patients, can be seen in relationship with type of surgical treatment and adjuvant treatment. Future perspective domains are reported to be significantly better in patients treated with breast conserving surgery than in patients treated with mastectomy (Munshi et al., 2010). There are also other worries connected to the future perspectives of women with breast cancer, especially among younger women. These worries may be concerns about survival, concerns about premature menopause (which shorten the time of their fertility), concerns about an eventual pregnancy, risk of recurrence, concerns about work and career, body image concerns and sexuality concerns (Avis et al., 2005).

Studies have also mentioned that age is relevant to social functioning and future perspective. Watters et al. (2003) found that future perspective was significantly better among older women with breast cancer than younger women with breast cancer. King et al. (2000) reported that younger women were more afraid of disease recurrence than older women were. Arndt et al. (2004) found that older breast cancer patients tended to report better role, emotional, cognitive and social functioning than younger women with breast cancer reported.

## **10. Ethics**

When researchers work with data from human beings, they must know and follow all relevant ethical considerations (WMA, 1964). Thus, the present paper, discusses the ethics related to the empirical study that follows. First of all, I was not participating when collecting the data I used in this paper. Since I did not gain insight into the research protocol, I must trust that data was collected with the prescribed method. The treatment regimens were performed according to national guidelines (NBCG, 2012), so I have to trust that the sample is representative of the present group of patients in Norway. I obtained a copy of the certification from The Regional Committees for Medical Research Ethics (Appendix 4) which certifies that my research protocol and the plan used for data collection were approved. I also verified that all patients recruited for the main study had signed and given their written, informed consent before participating.

All researchers studying human materials and data must preserve patient anonymity (WMA, 1964). In the main study database, the social security number for each informant had

been replaced with a PID-number. This procedure de-identified the data to protect the confidentiality of the informants before researchers could perform any analysis on the data.

I would also like to reflect on the methodology I used for this master thesis. The analysis I chose for the next article might not be the most appropriate method for highlighting the aims of this study. Other analyses and methods that would clarify the aims of this study as well as I have done most likely exist. My lack of experience may influence the thoroughness of the chosen method as well as the paper in totality. Relevant findings and important factors in accordance to the aims of this study may have been overlooked. The findings of the present master thesis and a discussion appear toward the end of the empirical article.



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## **From Theory to Empiricism**



# **Differences in HRQoL between younger and older women treated for breast cancer: Associations between social function, future perspective, body image, sexual function and QoL**

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## **Abstract**

**Background:** Breast cancer is the most common type of cancer among women in Norway, and development in screening and treatments have led to increasing survival rate both in younger and older women. More women are living with side effects after breast cancer, which have led to increasing focus on quality of life (QoL). Age-differences in aspects associated with QoL are assumed. **Purpose:** Earlier research has suggested that differences in age affects QoL aspects. In accordance to this, the aims of this study were: 1) to explore differences in QoL, social function, future perspective, body image and sexual function between younger ( $\leq 50$  years) and older ( $>50$  years) women twelve months after treatment for breast cancer. 2) To identify associations between social function, future perspective, body image, sexual function and QoL among older and younger women treated for breast cancer. **Methods:** QoL and functional scales were measured by the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) and the breast module QLQ-BR23. Independent t-tests and multiple regression analysis were performed in separated age-groups (young  $\leq 50$  years, old  $> 50$  years). **Results:** Younger women reported significant lower body image than older women. Adjusted for comorbidity, surgery techniques and adjuvant treatments, social function ( $B= 0.66$ ,  $p < 0.001$ ) and sexual function ( $B= 0.20$ ,  $p=0.020$ ) were significantly associated with higher levels of QoL among younger women. In older women social function ( $B= 0.30$ ,  $p < 0.001$ ), sexual function ( $B= 0.19$ ,  $p= 0.003$ ) and future perspective ( $B= 0.27$ ,  $p < 0.001$ ) were significantly associated to QoL. **Conclusions:** The results highlight the importance of enhancing social and sexual functioning among women treated for breast cancer. Improvements in diagnosis and treatments have increased the rates of survival among breast cancer patients. Consequently, alternative approach to promote their health and QoL is highly essential.

**Key words:** Breast cancer, Quality of Life, Health-Related Quality of Life, age-related differences.





## 1. Introduction

Today, breast cancer is today the most common cancer in women worldwide (World Health Organization, 2012). In Norway, 2745 new breast cancer cases were recorded in 2009 (Cancer Registry of Norway, 2011). Improvements in breast cancer treatments and mammography screening play an important role in the increasing rates of survival (Holleczek, Arndt, Stegmaier & Brenner, 2011). Women who survive breast cancer meet medical, physical and psychosocial challenges (Dizon, 2009). The subjective impact of this disease and this disease's impairments and their treatments are the main concerns that the HRQoL addresses (Carr, Gibson & Robinson, 2001). Consequently, has this development led to increasing focus on quality of life (QoL) issues among breast cancer patients, and in research (Montazeri et al., 2008).

Several aspects will change after a breast cancer diagnosis, and this change will, in turn, affect QoL. Parker et al. (2007), as well as other researchers, have found that women treated with mastectomy had poorer QoL scores than patients treated with breast conserving surgery. It is also well documented that patients treated with mastectomy have poorer sexual function, sexual enjoyment, body image and future perspective than patients treated with breast conserving surgery (Fobair et al., 2006; Kenny et al., 2000; King, Kenny, Shiell, Hall & Boyages 2000; Manganiello, Hoga, Reberte, Miranda & Rocha, 2011; Montazeri, 2008; Moyer, 1997; Munshi et al., 2010). Body image seems to be the aspect that is most strongly affected by type of surgery. Namely, women who received breast conserving surgery reported better body image than women treated with mastectomy (Curran et al., 1998; Figueiredo, Cullen, Hwang, Rowland & Mandelblatt 2004; Ganz, Coscarelli Shag, Lee, Polinsky & Tan, 1992; Hopwood, Haviland, Mills, Sumo & Bliss, 2007; Kenny et al., 2000; King et al., 2000; Montazeri, 2008). Changes in sexuality and intimacy depend on the woman's psychological health and how she perceives herself (Hordern, 2000). In other words, body image may affect the sexuality of breast cancer patients.

A breast cancer diagnosis can lead to impairment in several areas of a woman's life, including social functioning (Preston, 2010). Visible problems may lead to avoidance of social situations (Harcourt & Frith, 2008). Watters, Yau, O'Rourke, Tomiak & Gertler (2003) found that physical, role and social functions decrease during breast cancer treatment such as chemotherapy. Further, improved social function has been shown in mastectomy patients (Munshi et al., 2010). A diagnose of cancer is likely to influence on future perspectives. Breast cancer patients may experience concerns about survival, risk of recurrence, premature menopause (which can lead to loss of fertility) and concerns about work, carrier, body image

and sexuality (Avis, Crawford & Manuel, 2005). Side effects after a breast cancer diagnosis can be numerous, so focusing on the aspects of health-related quality of life (HRQoL) seems essential.

HRQoL is a comprehensive concept that includes factors like physical, emotional, sexual, social and cognitive functions as well as the symptoms of the disease and treatments. All of these factors are considered by and from the perspective of the patients (Bottomley & Therasse, 2002). In the present paper, the impact of HRQoL aspects such as body image, sexual function, social function and future perspective on overall QoL are interpreted and illustrated in a model. The model illustrates that all of the chosen HRQoL domains (social function, body image, sexual function and future perspective) are independent domains that are separated from the overall QoL but also contribute to the larger concept overall QoL.

HRQoL in breast cancer patients has been shown to be dependent on age. Some found that older women (>50 years) tended to report better body image, social function, future perspective and overall QoL than younger women ( $\leq 50$  years) reported (Arndt et al., 2004; Hopwood et al., 2007; King et al., 2000; Watters et al., 2003). Interestingly, other studies found that younger women had better QoL and sexual function than older women had (Arndt et al., 2004; Watters et al., 2003). Yet another group of researchers reported no significant difference in sexual dysfunction or body image in younger and older breast cancer patients (Wenzel et al., 1999). The results of HRQoL research among younger and older breast cancer patients still diverge. Nevertheless, age seems to be an important aspect of QoL discussions among women diagnosed with breast cancer.

According this, the objective of this study was to explore HRQoL among younger and older women treated for breast cancer in Norway. The aims of the present study were:

- 1) To explore differences in QoL, social function, future perspective, body image and sexual function between younger women ( $\leq 50$  years) and older women (>50 years) twelve months after treatment for breast cancer; and

- 2) To identify associations between social function, future perspective, body image, sexual function and the overall QoL among younger and older women, twelve months after treatment for breast cancer.

## **2. Patients and methods**

### **2.1. Sample and settings**

This empirical article draws upon data from a larger, prospective longitudinal study that investigated the side effects and health-related quality of life (HRQoL) after radiotherapy (RT) in breast cancer patients. Consecutive breast cancer patients were referred for postoperative RT at St.Olavs University Hospital in Trondheim, Norway. They provided oral and written information during their first meeting at the outpatient clinic. Inclusion criteria were 1) no metastatic disease, 2) no physical or psychological disorders that would interfere with participation and 3) the ability to speak and understand Norwegian. Patients who developed metastatic diseases during follow-up were excluded. The recruitment period was from February 2007 to October 2008. Out of 261 eligible patients, 250 (96%) agreed to participate. The recruitment procedure for the longitudinal study is published in Reidunsdatter, Rannestad, Frengen, Frykholm & Lundgren's (2011) study. This main study's assessments were performed before starting radiotherapy (RT), after ending RT and at three, six and twelve months after RT. During follow-ups, 10 patients were excluded due to metastatic disease (n=4) and patient requests (n=6). At the 12-month assessment, a total of 9 patients were missing due to logistical problems (n=7) and unknown reasons (n=2). Hence, 231 patients were available for analyses at this time point.

### **2.2. Study design**

The present empirical work is based upon HRQoL data from the 12-month assessment, so this study's design is cross-sectional.

### **2.3. Measures**

All assessments were conducted as an outpatient follow-up at the hospital. Each patient's oncologist registered clinical and treatment information at the first consultation and recorded it in an electronic database. Sociodemographic information was collected by a self-report questionnaire when patients were included. "HRQoL measures" were assessed by the EORTC core QLQ-C30 questionnaire (Aaronson et al., 1993) and the breast module QLQ-BR23 (Sprangers et al., 1996) at the 12-month consultation at the hospital.

QoL was assessed by the two-item “global health status/QoL” scale of the QLQ-C30 core questionnaire. These two items address how patients rate their overall health and QoL during the past week on a 7-point response option from “very poor” (1) to “excellent” (7).

Social function was assessed by the two items under the “social functioning” scale of the QLQ-C30. These items inquired whether the patient’s medical treatment or physical condition has interfered with family life or social activities during the past week.

The functional scales of the breast module QLQ-BR23 were used to assess body image, sexual function and future perspective. The body image scale contains four items assessing whether the women have felt physically less attractive or less feminine as a result of their disease or treatment. In addition, the body image scale asked whether the women found it difficult to look at themselves naked and whether they had been dissatisfied with their body during the last week. Sexual functioning was assessed by two items asking to what degree the women have been sexually active and to what degree they have been interested in sexuality during the last four weeks. Future perspective is assessed by one item that asks to what degree the patients have been worried about their future health during the last week. The response options on all functional scales ranged from 1 to 4, where 1 represented “not at all”, 2 “a little”, 3 “quite a bit” and 4 “very much”. For detailed information regarding the wording of items, see the Norwegian questionnaires enclosed in Appendix 1-3.

Each scale was calculated for its average score and transformed to a percentile scale ranging from 0 – 100. Missing values were treated according to the scoring manual, which allows up to 50% missing observations per score. This means that the patient had to answer at least half of the items on the scale. In addition, the single-item measures were transformed into the same percentile scale. The transformation from raw score to percentile scale allowed the author to run more sophisticated analysis of the data. A high score represents a high level of functioning or high level of QoL (Aaronson et al., 1993).

### *Background variables*

This paper used the following socio-demographic and clinical variables as its background variables: age, marital status, type of surgery, chemotherapy, radiotherapy, hormone therapy and comorbidity. All of the control variables were dichotomized. Age was dichotomized as  $\leq 50$  years and  $>50$  years to serve as an approximate indicator of menopausal status. This cut-off point is used in several QoL breast cancer studies (Avis et al., 2005; Burwell, Case, Kaelin & Avis, 2006; Fehlauser, Tribius, Mehnert & Rades, 2005; Fobair et al., 2006; Kerr, Engel, Schlesinger-Raab, Sauer & Hölzer, 2003; Park, Lee, Lee, Lee & Hwang,

2011; Wenzel et al., 1999; Wong-Kim & Bloom, 2005) as well as epidemiologic literature (Morabia & Costanza, 1998).

Marital status was coded into “recluse” (0) or “married/cohabitant” (1), and type of surgery was coded into “breast conserving surgery” (0) or “mastectomy” (1). The different kinds of adjuvant therapies - chemotherapy, radiation therapy and hormone therapy - were all dichotomized into “no” (0) or “yes” (1). Comorbidity was defined as having one or more of these chronic conditions: cardiovascular disease, pulmonary disorders, diabetes or depression, and was dichotomized into “yes” and “no” (having non comorbidities).

#### **2.4. Statistical analyses**

Statistical analyses were carried out using IBM SPSS Statistics Data Editor 19.0 for Windows. Descriptive statistics were used to analyze the socio-demographic data and clinical characteristics of the study sample. Chi-square tests were used to identify significant differences in categorical socio-demographic and clinical characteristics between the two age groups. The internal consistency of the questionnaires was assessed by estimating the Cronbach’s alpha ( $\alpha$ ) values of the multi-item scales based on the recommendation of  $> 0.70$  (Ringdal, 2007).

Means and standard deviations (SDs) were calculated for the continuous variables of QoL, body image, sexual function, future perspective and social function. Further, the association between the independent variables’ scale score and QoL, socio-demographic and clinical variables, were analyzed by using Pearson’s correlations.

To test differences in the two age groups within the variables *body image*, *sexual function*, *future perspective*, *social function* and *QoL*, *t*-tests for independent samples were used. Statistical significance was set to  $p < 0.05$ .

A multiple regression analysis was used to assess the association between the dependent variable, QoL, and the independent variables of body image, sexual functioning, future perspective and social function. With QoL as the dependent variable, the independent variables were entered in blocks in the following order. In the first step, the background variables (marital status, surgery, chemotherapy, hormone therapy, radiotherapy and comorbidity) were entered. Thereafter, the continuous variables were entered. Body image was entered in step two, social function in step three, future perspective in step four and sexual function in step five. The multiple  $R^2$  coefficients were used to estimate the percentage

of variability of the dependent variable, accounted for all the independent variables in the regression models.

### **3. Ethics**

Every patient that the main study recruited had signed and given her written, informed consent. The institutional review board, The Regional Committees for Medical Research Ethics and The Data Inspectorate approved the main study. The author's application to carry out the present empirical work was approved by The Regional Committees for Medical Research Ethics (Appendix 4).

## 4. Results

### 4.1. Participants

The socio-demographic and clinical characteristics of the two age groups appear in Table 1. The patient's ages ranged from 28 years to 89 years, and the mean age was 58 years. 78.8% of the sample was >50 years old.

There was no significant difference in marital status between the two age groups ( $p = 0.417$ ). The majority of the women in both age groups were married/cohabitant: 81.3% of the younger women and 75.7% of the older women. A significantly larger proportion of younger women had removed the breast ( $p = 0.002$ ) and received chemotherapy ( $p < 0.001$ ) compared to the older women. Comorbidity was reported significantly more often among older women ( $p = 0.038$ ) than among younger women.

Table 1. Differences in socio-demographic and clinical characteristics in the two age-groups.

Demographic and clinical variables	Age		Total, n=231 n (%)
	≤ 50 years old, n=49 n (%)	>50 years old, n=182 n (%)	
Marital status			
Married/cohabitant	39 (81.3)	137 (75.7)	176 (76.9)
Recluse	9 (18.8)	44 (24.3)	53 (23.1)
Surgery **			
Mastectomy	22 (44.9)	42 (23.1)	64 (27.7)
Breast conservation	27 (55.1)	140 (76.9)	167 (72.3)
Radiotherapy	49 (100)	182 (100)	231 (100)
Chemotherapy ***	45 (91.8)	51 (28)	96 (41.6)
Hormone therapy	28 (57.1)	98 (53.8)	126 (54.5)
Comorbidity *	6 (12.2)	48 (26.4)	54 (23.4)

\* $p < 0.05$  (2- tailed)

\*\*  $p < 0.01$  (2-tailed)

\*\*\*  $p < 0.001$  (2-tailed)

## 4.2. Descriptive statistics

The internal consistency was good and significant for all scales: it was  $\alpha = 0.90$  for the QoL scale,  $\alpha = 0.90$  for the body image scale,  $\alpha = 0.91$  for the sexual function scale and  $\alpha = 0.85$  for the social function scale.

Tables 2 and 3 display the Pearson's correlation coefficients between the study variables separated by age group. Significant correlations were found between QoL and other variables in both age groups ( $\leq 50$  years and  $> 50$  years). Among younger women, QoL was significant ( $< 0.05$ ) and positively correlated with marital status, body image, sexual function and future perspective. All were medium-strong correlations. Furthermore, QoL was significant ( $< 0.01$ ) and positively correlated with social function (strong correlation) in this age group.

Among older women, QoL was significant ( $< 0.01$ ) and positively correlated with body image (medium-strong correlation), sexual function (medium-strong correlation), future perspective (strong correlation) and social function (strong correlation). QoL was also significant ( $< 0.01$ ) and negatively correlated with surgery (weak correlation), comorbidity (weak correlation). QoL significantly correlated ( $< 0.05$ ) with hormone therapy (weak correlation). Among the younger women, the strongest correlation was observed between QoL and social function; among older women, the strongest correlations were observed between QoL and future perspective, as well as QoL and social function.



Table 2. Pearson correlations coefficients of the study variables among younger ( $\leq 50$  years old) women (n= 49).

	1	2	3	4	5	6	7	8	9	10	11
<b>Age <math>\leq 50</math></b>											
1. Surgery	-										
2. Chemotherapy	0.27	-									
3. Hormone therapy	0.04	0.35*	-								
4. Radiotherapy	0.60**	0.32*	0.01	-							
5. Comorbidity	0.16	0.11	0.07	0.23	-						
6. Marital status	0.10	0.05	0.01	0.07	-0.14	-					
7. Quality of Life	0.05	-0.07	0.04	-0.11	-0.12	0.29*	-				
8. Body Image	-0.28*	-0.16	0.09	-0.37**	-0.16	0.38**	0.33*	-			
9. Sexual Function	0.16	0.03	0.03	0.06	0.01	0.36*	0.34*	0.12	-		
10. Future Perspective	-0.09	-0.03	0.15	-0.13	-0.05	0.26	0.28*	0.41**	0.01	-	
11. Social Function	-0.22	-0.08	0.08	-0.35*	-0.31*	0.39**	0.66**	0.44**	0.13	0.19	-

\*p < 0.05 (2- tailed)

\*\* p < 0.01 (2-tailed)

Table 3. Pearson correlations coefficients of the study variables among older (>50 years old) women (n= 182).

	1	2	3	4	5	6	7	8	9	10	11
<b>Age &gt;50</b>											
1. Surgery	-										
2. Chemotherapy	0.30**	-									
3. Hormone therapy	0.38**	0.16*	-								
4. Radiotherapy	0.49**	0.36**	0.49**	-							
5. Comorbidity	0.15*	0.02	0.10	0.01	-						
6. Marital status	-0.09	0.04	-0.11	-0.01	-0.07	-					
7. Quality of Life	-0.19**	-0.06	-0.17*	-0.11	-0.20**	0.04	-				
8. Body Image	-0.40**	-0.22**	-0.29**	-0.37**	-0.03	0.02	0.36**	-			
9. Sexual Function	-0.20*	0.03	-0.12	-0.11	-0.21**	0.33**	0.33**	0.21**	-		
10. Future Perspective	-0.19*	-0.16*	-0.19*	-0.19**	-0.18*	-0.07	0.56**	0.53**	0.21**	-	
11. Social Function	-0.11	-0.14	-0.13	-0.16*	-0.13	-0.01	0.55**	0.40**	0.11	0.54**	-

\*p < 0.05 (2- tailed)      \*\* p < 0.01 (2-tailed)

### 4.3. Age -specific scores

The independent-sample *t*-test showed a significant difference between younger and older women in body image,  $t(224) = 2.25, p < 0.05$ , but not in any of the other variables. Older women experienced more positive body image ( $M = 88.28, SD = 18.13$ ) than younger women ( $M = 81.12, SD = 24.58$ ).

Table 4 displays means and standard deviations (*SDs*). The mean values were quite similar between younger and older women, with the exception of the mean values for *future perspective*, *sexual function* and *body image*. On future perspective and body image, older women scored higher (future perspective  $M=71.98$ , body image  $M=88.28$ ) than younger women did (future perspective  $M=64.63$ , body image  $M=81.12$ ). On sexual function, younger women ( $M=35.71$ ) scored higher than older women did ( $M=28.74$ ). Body image and social function were the variables with the highest reported mean scores in both age groups. After calculating these values, there was interesting to see whether any of the independent variables were associated with the dependent variable, QoL.

Table 4. Comparison of mean scores between younger ( $\leq 50$  years) and older ( $>50$  years) women treated for breast cancer, twelve months after treatment.

Variables	$\leq 50$ years old	$>50$ years old
	n=49	n=182
	Mean ( <i>SD</i> )	Mean ( <i>SD</i> )
Quality of Life	79.42 (17.69)	75.23 (21.71)
Body image *	81.12 (24.58)	88.28 (18.13)
Sexual function	35.71 (25.23)	28.74 (23.26)
Future perspective	64.63 (24.91)	71.00 (27.06)
Social function	82.65 (19.53)	84.53 (23.11)

\*  $p < 0.05$

#### 4.4. Associations between independent variables and QoL

A linear hierarchical multiple regression analysis was used to explore whether any of the independent variables had any association with the dependent variable, QoL, separated in age groups ( $\leq 50$  years and  $> 50$  years). These results are shown in Table 5.

Table 5. Linear hierarchical multiple regression analysis. Associations to QoL in younger ( $\leq 50$  years old) and older ( $> 50$  years old) women treated for breast cancer in Norway.

Step and variable	Women $\leq 50$ years old (n=49)		Women $> 50$ years old (n=182)	
	B	$\Delta R^2$	B	$\Delta R^2$
Step 1				
Control variables:				
Marital status	13.02		0.21	
Surgery	5.60		-6.54	
Chemotherapy	-4.99		-0.79	
Hormone therapy	2.29		-2.64	
Radiotherapy	-6.85		-2.13	
Comorbidity	-3.19		-9.25	
		0.13		0.08
Step 2				
Body Image	0.04	0.04	-0.04	0.09
Step 3				
Social function	0.66 <sup>***</sup>	0.33 <sup>***</sup>	0.30 <sup>***</sup>	0.17 <sup>***</sup>
Step 4				
Future perspective	0.13	0.02	0.27 <sup>***</sup>	0.07 <sup>***</sup>
Step 5				
Sexual function	0.20 <sup>*</sup>	0.07 <sup>*</sup>	0.19 <sup>**</sup>	0.03 <sup>**</sup>

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ . Overall  $R^2 = 0.48$  (48%) in the age group  $\leq 50$  years old, and overall  $R^2 = 0.41$  (41%) in the age group  $> 50$  years old.  $\Delta R^2 = R^2$  Change.

According to the multiple regression analysis, none of the background variables (marital status, surgery, chemotherapy, hormone therapy, radiotherapy and comorbidity) emerged to be significantly associated with QoL. After adjusting for the background variables, social functioning ( $B= 0.66, p < 0.001$ ) and sexual functioning ( $B= 0.20, p=0.020$ ) were significantly associated with higher levels of QoL among younger women. In older women, social function ( $B= 0.30, p < 0.001$ ), sexual function ( $B= 0.19, p= 0.003$ ) and future perspective ( $B= 0.27, p < 0.001$ ) were significantly associated with QoL. Furthermore, future perspective ( $B= 0.13, p= 0.142$ ) was not significantly associated with QoL in younger women, and neither was body image ( $B= 0.04, p= 0.715$ ). Likewise, body image in older women ( $B= -0.4, p= 0.706$ ) was not significantly associated with QoL.

Among the older women, social function explained 33% of the variance in QoL, and sexual function explained 7% of the variance in QoL. In the younger age group, social function explained 17% of the variance in QoL, sexual function explained 3% of the variance and future perspective explained 7% of the variance in QoL. The overall  $R^2$  for the regression model among women aged  $\leq 50$  years old was 0.48 (48%), and the total  $R^2$  for women aged  $>50$  years old was 0.41 (41%). In other words, the regression models explain 48% and 41% of the variance in QoL among younger and older women respectively, at twelve months after treatment for breast cancer.



## 5. Discussion

HRQoL has become an essential outcome measure of the treatment of cancer patients (Arndt et al., 2004). Although treatment techniques and early detection have improved the survivor rates, breast cancer may still affect the QoL of women (Montazeri, 2008). The aims of this study were 1) to explore differences in QoL, social function, future perspective, body image and sexual function between younger ( $\leq 50$  years) and older ( $>50$  years) women twelve months after treatment for breast cancer and 2) to identify associations between social function, future perspective, body image, sexual function and the QoL among younger and older women treated for breast cancer.

The present study found that older women ( $>50$  years) experienced significantly better body image than younger women ( $\leq 50$  years). This means that breast cancer seems to affect body image among older women less than it affects body image among younger women. These findings are similar with the results presented by Hopwood et al. (2007) and King et al. (2000). They also found that older women ( $>50$  years) on average had better body image than younger women ( $\leq 50$  years) had. These findings suggest that practitioners should anticipate providing more support for body image to their younger patients than to their older ones. One potential explanation for the difference in body image can be type of surgery. Earlier reports have documented that women who underwent breast conserving surgery reported fewer problems with body image than those who had to remove the breast (Kenny et al., 2000). In our sample, only 22.8% of older women underwent mastectomy, while this proportion was the double (45.6%) in younger women, so this could be a plausible explanation of the difference in body image. The link between psychological distress, body image problems and having a mastectomy can indicate the essence of the biopsychosocial model, because the body and the mind are connected in this model (Dizon, 2009).

In the present sample, 91.8% of the younger women received chemotherapy, while only 28% of the older women underwent this type of adjuvant treatment. The breast cancer disease is often more aggressive in younger women than it is in older women. Consequently, younger women normally receive more intensive adjuvant treatment, and this greater intensity is likely to result in more side effects in younger patients (Wenzel et al., 1999). Fatigue is the most frequently reported side effect among breast cancer patients, and can often last for years after the end of treatment (Bower et al., 2000). Fatigue is known to influence many dimensions of life, such as social function and sexual function (Bower et al., 2000; Henson, 2002). Therefore, the poorer body image among the younger population could also be attributed to the more intensive treatment.

The identity theory might also throw light over the poorer body image experienced by younger women. The breasts mean a lot to women's self-image, and they are a symbol of femininity and sexuality (Kåresen, Schlichting & Wist, 1998). Loss of a breast and poorer body image can make women feel less feminine and thereby have a considerable impact on their identity. One might suppose that identity is stronger in older women, so younger women are more vulnerable to such loss.

Despite the difference in body image among younger and older women, neither of the age groups associates body image significantly with QoL. Therefore, it is possible that other dimensions of HRQoL are more important to the QoL among women in this study. This result might also be explained by the different number of informants in each age group. The small sample size in the group aged  $\leq 50$  years could have caused a lack of sufficient statistical power in this group, which may further affect the results.

The present study found no significant differences in QoL, sexual function, future perspective and social function between younger and older women twelve months after treatment for breast cancer. Earlier studies do not support the present findings, as differences between younger and older women have been found for these HRQoL aspects (Andt et al., 2004; King et al., 2000; Park et al., 2011; Watters et al., 2003; Wenzel et al., 1999). Some previous studies found that older women ( $>50$  years) tended to report better body image, social function, future perspective and overall QoL than younger women ( $\leq 50$  years) reported (Arndt et al., 2004; Hopwood et al., 2007; King et al., 2000; Watters et al., 2003). Others reported that younger women had better QoL and sexual function than older women had (Arndt et al., 2004; Watters et al., 2003). A third reported no significant difference in sexual dysfunction between the younger and older breast cancer patients (Wenzel et al., 1999), which supports the present findings in this study. These differing results could be explained by methodical aspects. The sample size in the group  $\leq 50$  years old was small compared to the sample size or the age group  $>50$  years. This might cause a lack of sufficient statistical power in the group younger group, which could have led to no significant differences between younger and older women in these HRQoL aspects.

Despite these findings, social function, sexual function and future perspective were significantly associated with QoL. Social function and sexual function were significantly associated with QoL among younger women, while social function, sexual function and future perspective were significantly associated with QoL among older women in this study. Social function seems to be an important aspect to one's QoL among both younger and older women in this sample. By focusing on, and offering good and confident social support to women



treated for breast cancer, health professional may help their patients to improve their social function and ultimately their QoL. Previous research offers mixed support for the present results. Some studies found that sexual function and social function are associated with QoL outcome in breast cancer patients (Mols et al., 2005; Montazeri et al., 2008; Pikler & Winterowd, 2003; Sammarco, 2009), whereas others did not find any association between social function, sexual function, future perspective and QoL (Safaei et al., 2008; Saleha et al., 2010).

Although social and sexual functions are associated with QoL in both younger and older women, they can differ in gradation. The social function seems to have less impact on the QoL of older women than it does on the QoL of younger women. Social function in younger women may be more important for their QoL than among older women, due to their family situations. Namely, younger women are likely to have young children, who still need support, help and care from their mother. The age of their family members may therefore present a plausible explanation for the difference. Nevertheless, both age groups reported that social function is the most important factor of QoL. Participating in social activities and intercourse with friends is probably essential to a human, regardless of age. One of the most fundamental human motivations is described as the need to form interpersonal connections and the need to serve a function in society (Preston, 2010). These fundamental human motivations may highlight why social function explains so much of the variance in QoL in the present sample.

The results presented in this paper also indicate that sexual function is significantly associated with QoL in both younger and older women. Sheppard and Ely (2008) have shown that sexuality is central to a person's sense of wellness and self-concept, so it may be an important aspect to follow, maintain and promote. Sexual function explains the variance in QoL among younger women better than it explains the variance among older women, which might be natural. It is reasonable to believe that younger women are more sexually active than older women. The other side of this assumption about younger women is the assumption that older women tend to lose interest in sexuality. As a result, society often ignores the sexual needs of older people (Hordern, 2000). Sexuality is described as a deep and integral aspect of the human personality and as an important aspect in a relationship (Sheppard & Ely, 2008). According to this, the majority of the present sample is married/recluse, which can be a plausible explanation for the significant association between sexual function and QoL. According to these findings, there is important focusing on sexuality among both younger and older breast cancer patients. Most oncologist and health personnel treating breast cancer patients probably need to

gain more knowledge about this aspect and then inform their patients. A wider dissemination of knowledge about the importance and the effects of sexual function would probably promote QoL in breast cancer patients.

Future perspective also appeared as significantly associated with QoL among older women in this sample but not among younger women. The reason for this might be age differences. Different kinds of considerations may appear in accordance with thoughts about the future and the future perspective, and age may influence which kind of considerations the patient will have (Dizon, 2009). The reason for this difference might also be methodical. Again, the sample size of each age group is not equal. The small sample size in the age group  $\leq 50$  years can cause a lack of sufficient statistical power to detect a possible association in this group. Further, the disparity in size might affect several results in this paper. Perhaps a different cut-off point in age would have been more pragmatic and led to other results. Despite the number of group members, the respective cut-off point was used to serve as an approximate indicator of menopausal status, and this cut-off point is used in several QoL breast cancer studies (Avis et al., 2005; Burwell et al., 2006; Fehlaer et al., 2005; Fobair et al., 2006; Kerr et al., 2003; Park et al., 2011; Wenzel et al., 1999; Wong-Kim & Bloom, 2005) as well as epidemiologic literature (Morabia & Costanza, 1998).

### **5.1. Strengths and limitations**

Interpretation and discussion of this data must consider some limitations. First of all, this study may be limited demographically, because it is based on a selective sample of patients from only one hospital in Norway. It can be difficult to generalize with this selective sample. This sample may not reflect differences in younger and older women and aspects associated with QoL in other areas of the country. The advantage of this sample is that it consists of breast cancer patients in different age groups, which makes this sample relatively varied.

Another aspect that can limit this study is the chosen time of measurement. Only one measurement time was explored, which was twelve months after breast cancer treatment. This cross-sectional design makes it impossible to explore cause- effect relationships. However, the choice to study only one time was made in accordance to the scope and the aims of this paper.

Despite these limitations, this study has several important strengths. It has a relatively large sample size (N=231), patients ranging from 28 to 89 years of age, and it looks at both

younger and older women with breast cancer. Women of all ages may get a breast cancer diagnosis, so research among both younger and older women is important. Further, a wide range of ages allows researchers to compare age groups and to run more analyses.

## **5.2. Conclusion**

In conclusion, improvements in diagnosis and treatments have increased the rates of survival among breast cancer patients. Consequently, alternative approaches to promoting their health and QoL are essential. This research suggests that younger breast cancer patients have greater difficulties with altered body image than older women do at twelve months after treatment for breast cancer. The impact of social function, sexual function and future perspective on QoL appears to be the most important factors among women in the present sample. The results highlight the importance of enhancing social and sexual functioning among both younger and older women. During breast cancer treatment as well as at follow-up, personnel should focus on helping the patient to maintain adequate social support. Encouraging the patient to participate in social activities and family life may likely be a good technique during the whole illness process for any woman, regardless of age. Health care professionals and clinicians treating breast cancer patients should be aware of the need for open discussion of sexual concerns and worries, from both younger and older patients. Furthermore, professionals should be prepared to offer support, guidance and counseling (Henson, 2002). In addition, good oral and written information about sexuality in breast cancer should probably be given before treatment and during treatment. In general, preparing both younger and older women for the age-related impact of breast cancer and helping them to deal with their problems may improve their QoL. However, there is a need for more research to complete the knowledge of this comprehensive field. Despite the enormous amount of literature already published for this field, none of the extant studies clarify exactly what factors affect QoL the most among breast cancer patients. More research should be performed, and data from comparable groups of women without breast cancer might be interesting to explore in comparison. Such a comparison could help us to investigate whether there exist any differences between breast cancer patients and healthy women according to the aspects associated with QoL.



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# **Appendixes**



## Appendix 1: EORTC QLQ-C30 Questionnaire

EORTC QLQ-C30

PIDnummer:

(Versjon 3.0)

Vi er interessert i forhold vedrørende deg og din helse. Vær så vennlig å besvare hvert spørsmål ved å sette et kryss x i den boksen som best beskriver din tilstand. Det er ingen «riktige» eller «gale» svar. Alle opplysningene vil bli behandlet konfidensielt.

Utfyll:  Før beh.  Siste beh.  3 mnd  6 mnd  12 mnd

	Ikke i det hele tatt	Litt	En del	Svært mye
1. Har du vanskeligheter med å utføre anstrengende aktiviteter, slik som å bære en tung handlekurv eller en koffert?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Har du vanskeligheter med å gå en lang tur?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Har du vanskeligheter med å gå en kort tur utendørs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Er du nødt til å ligge til sengs eller sitte i en stol i løpet av dagen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Trenger du hjelp til å spise, kle på deg, vaske deg eller gå på toalettet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b><u>I løpet av den siste uka:</u></b>	<b>Ikke i det hele tatt</b>	<b>Litt</b>	<b>En del</b>	<b>Svært mye</b>
6. Har du hatt redusert evne til å arbeide eller utføre andre daglige aktiviteter?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Har du hatt redusert evne til å utføre dine hobbyer eller andre fritidsaktiviteter?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Har du vært tung i pusten?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Har du hatt smerter?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Har du hatt behov for å hvile?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Har du hatt søvnproblemer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Har du følt deg slapp?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Har du hatt dårlig matlyst?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Har du vært kvalm?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

[Bla om til neste side](#)

24742



PIDnummer:

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I løpet av den siste uka:	Ikke i det hele tatt	Litt	En del	Svært mye
15. Har du kastet opp?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Har du hatt treg mage?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Har du hatt løs mage?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Har du følt deg trett?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Har smerter påvirket dine daglige aktiviteter?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Har du hatt problemer med å konsentrere deg, f.eks. med å lese en avis eller se på TV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Har du følt deg anspent?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Har du vært engstelig?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Har du følt deg irritable?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Har du følt deg deprimeret?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Har du hatt problemer med å huske ting?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Har din fysiske tilstand eller medisinske behandling påvirket ditt familjeliv?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Har din fysiske tilstand eller medisinske behandling påvirket dine sosiale aktiviteter?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Har din fysiske tilstand eller medisinske behandling gitt deg økonomiske problemer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Som svar på de neste spørsmålene, sett et kryss i den boksen fra 1 til 7 som best beskriver din tilstand.

29. Hvordan har din helse vært i løpet av den siste uka?

1     2     3     4     5     6     7

Svært dårlig

Helt utmerket

30. Hvordan har livskvaliteten din vært i løpet av den siste uka?

1     2     3     4     5     6     7

Svært dårlig

Helt utmerket

## Appendix 2: EORTC QLQ-BR23 Questionnaire

### EORTC QLQ-BR23

PID-nummer:

En del pasienter opplever av og til at de har noen av følgende symptomer eller problemer. Vær vennlig å angi i hvilken grad du har hatt disse symptomene eller problemene i løpet av den siste uka. Sett et kryss i den ruten som best beskriver din tilstand.

Utfylt:  Før beh.  Siste beh.  3 mnd  6 mnd  12 mnd

<u>I løpet av den siste uka:</u>	Ikke i det hele tatt	Litt	En del	Svært mye
31. Har du vært tørr i munnen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Har mat og drikke smakt annerledes enn vanlig?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Har du hatt såre, iriterte eller tårefylte øyne?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Har du hatt hårfall?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Dette spørsmålet skal bare besvares hvis du har hatt hårfall: Har du vært urolig p.g.a. hårfallet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Har du følt deg syk eller uvel?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Har du hatt hetetokter?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Har du hatt hodepine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Har du følt deg mindre fysisk tiltrekkende på grunn av din sykdom eller behandlingen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Har du følt deg mindre kvinnelig på grunn av din sykdom eller behandlingen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Har det vært vanskelig for deg å se deg selv naken?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Har du vært misfornøyd med kroppen din?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Har du vært bekymret for din framtidige helse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>I løpet av de siste <u>fire</u> ukene:</u>	Ikke i det hele tatt	Litt	En del	Svært mye
44. I hvilken grad har du vært interessert i seksualitet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. I hvilken grad har du vært seksuelt aktiv (med eller uten samleie)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Dette spørsmålet skal bare besvares hvis du har vært seksuelt aktiv: I hvilken grad har du hatt glede av din seksuelle aktivitet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Bla om til neste side

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PID-nummer:

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I løpet av den siste uka:

	Ikke i det hele tatt	Litt	En del	Svært mye
47. Har du hatt smerter i armen eller skulderen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Har du vært hoven i en arm eller hånd?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Har det vært vanskelig å løfte armen eller å bevege den ut til siden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. Har du hatt smerter i området ved det affiserte brystet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. Har du vært hoven i området ved det affiserte brystet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. Har du vært spesielt overfølsom i området ved det affiserte brystet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. Har du hatt hudproblemer på eller i området ved det affiserte brystet (f.eks. kløe, tørrhet, flass)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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### Appendix 3: Questionnaire for Background Information

PID-nummer:

**Bakgrunnsinformasjon om forhold som kan ha betydning for helse og livskvalitet.** Svar etter beste skjønn. Kryss av for bare en av svar-mulighetene.

Sivil status:  Gift/samboer  Skilt  Separert  Enslig  Enke

Antall barn:  Sett 0 hvis du ikke har barn Fødselsår eldste barn:

Hvilken utdanning har du? Kryss av for den høyeste utdannelsen du har

- Folkeskole/grunnskole/framhaldskol, 7-10 år
- Realskole/middelskole/yrkesskole/1-2 åring videregående skole
- Artium/øk. Gymnas/allmennfaglig retning/3-4 år skole/fagskole
- Høgskole/universitet, inntil 3 år
- Høgskole/universitet, mer enn 3 år

#### MOSJON

Med mosjon mener vi at du f.eks går tur, går på ski, svømmer eller driver trening/idrett. Hvor ofte driver du mosjon? (Ta et gjennomsnitt)

Aldri  Sjeldnere enn en gang i uka  En gang i uka  2-3 ganger i uka  Omtrent daglig

Dersom du driver slik mosjon så ofte som en eller flere ganger i uka: Hvor hardt mosjonerer du? (Ta et gjennomsnitt)

- Tar det rolig uten å bli andpusten eller svett
- Tar det så hardt at jeg blir andpusten og svett
- Tar meg nesten helt ut

Hvor lenge holder du på hver gang? (Ta et gjennomsnitt)

Mindre enn 15 minutter  16-30 minutter  30 minutter - 1 time  Mer enn 1 time

#### RØYKEVANER

Røyker du daglig for tiden?  Ja  Nei

Hvis du IKKE røyker daglig for tiden: Har du røykt daglig tidligere?  Ja  Nei

Hvis du svarte "JA", hvor lenge er det siden du sluttet å røyke daglig?

Mindre enn 3 måneder  3 måneder - 1 år  1-5 år  Mer enn 5 år

Hvis du røyker daglig nå, eller har gjort det tidligere: Hvor mange sigaretter røyker eller røykte du pr. dag?

Bevares av dem som røyker daglig nå eller har røykt daglig tidligere:

Hvor gammel var du da du begynte å røyke daglig?  år

Hvor mange år til sammen har du røykt daglig?  år

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PID-nummer:

### ALKOHOLBRUK

Er du total avholdskvinne?  Ja  Nei

Hvor mange ganger i måneden drikker du vanligvis alkohol? (Antall ganger)    
Regn ikke med lettøl. Sett 0 hvis mindre enn 1 gang i mnd.

Hvor mange glass øl, vin eller brennevin drikker du vanligvis i løpet av to uker?  
(Antall glass) Regn ikke med lettøl. Sett 0 hvis du ikke drikker alkohol.

### NÅVÆRENDE ARBEIDSFORHOLD

- |  |   |
|--|---|
| <input type="checkbox"/> I fullt arbeid          | <input type="checkbox"/> Helt sykemeldt   |
| <input type="checkbox"/> Delvis i arbeid         | <input type="checkbox"/> Attføring        |
| <input type="checkbox"/> Hjemmearbeidende        | <input type="checkbox"/> Uføretrygdet     |
| <input type="checkbox"/> Arbeidsledig/Permittert | <input type="checkbox"/> Alderspensjonist |
| <input type="checkbox"/> Delvis sykemeldt        | <input type="checkbox"/> Student          |

Hvis du er i arbeid (gjelder også heltids husarbeid) ber vi deg fylle ut de neste spørsmålene:

Hvordan trives du alt i alt med arbeidet ditt?

- Veldig godt  Ganske godt  Godt  Ikke særlig godt  Dårlig

Hva er husstandens årlige bruttoinntekt?

- |   |   |
|---|---|
| <input type="checkbox"/> Under 100 000 kr     | <input type="checkbox"/> 500 000 - 699 000 kr |
| <input type="checkbox"/> 100 000 - 299 000 kr | <input type="checkbox"/> 700 000 - 899 000 kr |
| <input type="checkbox"/> 300 000 - 499 000 kr | <input type="checkbox"/> 900 000 kr eller mer |

### VENNER

Hvor mange gode venner har du?

*Regn med de du kan snakke fortrolig med og som kan gi deg god hjelp når du trenger det. Tell ikke med dem du bor sammen med, men regn med andre slektninger og venner.*

Føler du at du har mange nok gode venner?  Ja  Nei

Hvor ofte tar du vanligvis del i foreningsvirksomhet som f.eks. syklubb, idrettslag, politiske lag, religiøse eller andre foreninger?

- Aldri, eller noen få ganger i året  
 1-2 ganger i måneden  
 Omtrent en gang i uka  
 Mer enn en gang i uka

Tusen takk for den hjelp du har gitt oss ved å fylle ut dette skjema.

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## Appendix 4: Certification from The Regional Committees for Medical Research Ethics

NTNU  
Norges teknisk-naturvitenskapelige  
universitet

Det medisinske fakultet  
Regional komite for medisinsk forskningsetikk  
Helseregion Midt-Norge



Høgskolelektor Randi Johansen Eide.

Saksbehandler  
Rådgiver Arild Hals  
Telefon 73 86 7152  
Fax 73 86 72 89  
Epost: arild.hals@ntnu.no  
rek-4@ntnu.no  
Postadresse: Det medisinske fakultet  
Medisinsk teknisk forskningssenter  
7489 Trondheim  
Besøksadr: Kreftbygget 5.etg  
St. Olavs Hospital

Vår dato:  
03.11.2006

Vår ref.:  
4.2006.2856

Deres dato:

Deres ref:

### **Strålebehandling av kreft. Sammenheng mellom behandling, bivirkninger og helserelatert livskvalitet.**

Komiteen vurderte prosjektet i sitt møte 20. oktober 2006 med følgende merknader og tilråding:

Formålet med studien er å kartlegge bivirkninger og objektive indikatorer på stråletoksisitet og studere sammenhenger mellom disse og gitte stråledoser/volum for de ulike subgrupper i kohorten. Med dette ønsker vi å estimere sannsynlighet for senskader og mulig identifisere risikopasienter som krever tettere oppfølging framover.

Studien lagt opp som en prospektiv oppfølging med kartlegging av en pasientkohort som får postoperativ strålebehandling av brystkreft. Prosjektet er tredelt; del 1 omhandler: behandlingsteknikk og registrering av dose-/volum til ulike organ. Del 2: objektive bivirkninger og indikatorer på stråletoksisitet. Del 3: helserelatert livskvalitet og opplevd helse. Alle kvinner som får postoperativ strålebehandling av bryst / brystvegg / operasjonsområde / regionale lymfeknuter ved kreftavdelingen på St. Olavs Hospital i et år (consecutive cases) inngår i studien. Stipulert antall er 200, og disse følges opp i denne studien i et år framover.

Komiteen har følgende merknader til prosjektet:

- Komiteen viser til prosjektprotokollen og har ingen merknader til målsetting eller plan for gjennomføring.
- Det skal tas biologisk materiale. I henhold til Biobankloven må det søkes spesielt om dette, jf. § 4 i loven, og dette skal vurderes av Regional komite for medisinsk forskningsetikk for det meldes til Sosial- og helsedirektoratet. Komiteens sekretariat vil oversende meldingen til direktoratet så snart den er oversendt komiteen og vurdert. Komiteen må forelegges en punkt for punkt redegjørelse for de momentene som skal svares på etter lovens § 4.

Postadresse  
N-7489 Trondheim

Besøksadresse  
Olav Kyrres g. 3  
Medisinsk Teknisk Forskningssenter

Telefon +47 73 59 88 59  
Telefaks +47 73 59 88 65  
Org. nr. 974 767 880

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Det må opplyses i informasjonsskrivet til forsøkspersonene at det blir opprettet en biobank.

- Komiteen viser til informasjonsskrivet og at data blir avidentifisert, jf. vedlagt veiledning pkt 9.
- Komiteen viser til at det blir vist til at prosjektet har en prosjektleder og en prosjektansvarlig. Komiteen er usikker på hva som ligger i dette, og ber om en skriftlig presisering av hva dette betyr. Når det gjelder ansvar for gjennomføring av prosjektet vil komiteen understreke at det er prosjektleder som er den ansvarlige for alle aspekter av gjennomføringen. Prosjektleder er også den person komiteen til enhver tid vil forholde seg til. Et eventuelt institusjonelt ansvar vil foreligge, men det må bli meget generelt og overordnet. Hvis det skal legges personlig ansvar på andre enn prosjektleder må det i så fall bli institusjonens øverste leder.
- Det må opplyses i informasjonsskrivet at prosjektet er godkjent av Regional komité for medisinsk forskningsetikk, Region Midt-Norge
- Prosjektleder må underskrive informasjonsskrivet.
- Komiteen ber om å få tilsendt revidert informasjonsskriv.

Komiteen ber om å få tilsendt artikkel/rapport når studien er fullført.

**Tilråding:**

**”Komiteen godkjenner at prosjektet gjennomføres med de merknader som er gitt.”**

Vi viser til dette og ønsker lykke til med prosjektet.

Med hilsen

Arne Sandvik  
Professor  
Leder i komiteen

Arild Hals  
Seniorrådgiver