Sexuality in the aftermath of breast and prostate cancer

Gendered experiences
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Till alla kvinnor och män som lever med en cancerdiagnos

Begrunda döden om du vill lära dig att leva
Yalom, 1980
Abstract

Sexuality is a sensitive topic in health care and is often interpreted through a natural scientific lens as just corresponding to sexual dysfunction and fertility problems. The purpose of this thesis was to describe sexuality and its outcomes in two cancer populations. Women with breast cancer and men with prostate cancer in all stages were invited to participate. In this thesis, these two populations are restricted to age groups between 45 and 65 years, since there are reasons to believe that younger people are more vulnerable to sexuality changes. Lifeworld, gender, and sexuality are three concepts of importance in this thesis and they are used from the viewpoint of nursing care. Phenomenological interviews (I, III) and focus group interviews (II, IV) were carried out with a total number of 46 informants. The EPP-method (Empirical Phenomenological Psychological) was used (I, III) in order to grasp the lived experience, and qualitative content analysis was used to analyse the seven focus groups (II, IV).

The lifeworld experiences of those women and men were comparable. The changes brought by the cancer and its treatment were a threat to their very existence, their existential base of knowledge had gone and alienation occurred (I, III). For the women, this was illustrated through the metaphor of a bird which is pinioned and unable to fly anymore. For the men it was expressed in the essential meaning “to lose the elixir of life”. Both women and men suffered, sexuality changed from one day to another and they handled it individually. Changed body appearance, and feeling old and unattractive were, for the women, the dominating features, whilst for the men changed desire and erection problems were their main concerns. The findings from the group discussions (II, IV) elucidate the gendered differences in these two contexts. The aim of the women was to look healthy and attractive and for the men the ability to have an erection was important. Neither of these two groups of people was able to meet their aims. On the other hand, being diagnosed with a life-threatening disease they were not in a position to claim preserved sexuality. This opens up existential questions that need to be confirmed in health care. To succeed in this, a change of perspective is required in health care. It should be possible to use human science to the same extent as natural science in health care.
Keywords: breast cancer, prostate cancer, sexuality, gender, lifeworld, psycho social oncology
List of Papers

THIS THESIS CONSISTS OF FOUR PAPERS; two have been published in international peer-reviewed scientific journals, and two others have been submitted. The papers will be referred to in the text by their roman numerals:


II. KLAESON K, SANDELL K & BERTERÖ C M: To feel like an outsider: focus group discussions regarding the influence on sexuality caused by breast cancer treatment. European Journal of Cancer Care. 2011; (20), 728-737.


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Introduction

Sexuality is an important and integral part of being human throughout life. It plays a central role in our personality and in how we meet existential threats throughout life. Breast cancer is the most frequent cancer in women; the same goes for prostate cancer among men. Cancer is more common in older age, but the thesis is restricted to age groups between 45 and 65 years, since there are reasons to believe that younger women and men are more vulnerable to the changes brought forward by diagnosis and treatment than the older population (Burwell, Case, Kaelin, & Avis, 2006; Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Lintz et al., 2003; Steginga et al., 2001).

Sexuality as such is gendered. The understanding of the sex differences based on the sexual organs different appearance and function, is shaped in part by the social aspects of being a woman or a man (Williams & Stein, 2002).

As an oncology nurse with a particular interest in the existential dimensions of nursing care, my initial question concerned how human beings experience changes in sexuality from a lifeworld perspective when they are diagnosed with breast or prostate cancer in middle-age. This investigation was then completed by an analysis based on a gender perspective.

A biomedical worldview predominates within health care. Sexuality is therefore often interpreted through a natural scientific lens as only corresponding to sexual dysfunction and fertility problems (White, 2010). In cancer care, where we work in inter-disciplinary teams, the possibility of taking a more holistic approach is present and relevant. For the majority of professionals, sexuality is still a sensitive topic to address, and we do not usually know when and how we should bring the topic up (Horden & Street, 2007; Katz, 2007; Saunamäki, Andersson, & Engström, 2009). By shedding light on the topic, letting the voices of men and women be heard, the professionals’ comprehension hopefully can develop. The findings in this thesis can contribute new and important knowledge to the biomedical perspective. If the professionals are comfortable bringing the topic up this may result in more individual meetings with patients, based on respect for universal human needs. Both patients and professionals can benefit from having printed guidelines, where issues of sexuality should have their given place.
Background

Breast cancer

The incidence and prevalence of breast cancer are high, and this is also the most frequent cancer group in Europe and North America (World Health Organisation & International Agency for Research on Cancer, 2008). Approximately 14% of females get this form of cancer during their life time. Breast cancer is seldom detected in younger ages and only 5% before 40 years of age and it is most common in the older population with a mean age of 64 years. The causes of breast cancer are still unclear. Different risk factors are discussed such as; late first full-term pregnancy, early menarche, late menopause, height, obesity, exogenous use of oestrogen, urban environment, high alcohol consumption, and hereditary factors (Swedish Cancer Society, 2009; World Health Organisation & International Agency for Research on Cancer, 2008).

Breast cancer treatment regimens have become more aggressive in the last few centuries and many women undergo surgery, radiation, and/or chemotherapy as well as approximately five years of hormone therapy. In later years immunotherapy treatment is also common (Swedish breast cancer group, 2011). Consequently today’s breast cancer survivors in developed countries have a relatively good prognosis, unlike those who have other forms of cancer. The highest five-year survival rates in Europe are in the north area, and in Sweden are as high as 87.8% (Swedish Cancer Society, 2009; World Health Organisation & International Agency for Research on Cancer, 2008). The treatment regimens are similar in most European countries and only small differences occur regionally or locally. Treatment for recurrent disease can lead to a longer life, but the need for chemotherapy and/or hormone therapy for several years can have an impact on quality of life (Swedish Cancer Society, 2009; World Health Organisation & International Agency for Research on Cancer, 2008).
Prostate cancer

For men living in Europe and North America, prostate cancer is the most common type of cancer. The incidence and prevalence during the three last decades has increased rapidly, and today one out of eight men will get the disease before the age of 75 (Swedish Cancer Society, 2009). Prostate cancer is seldom detected before the age of 50. However, diagnoses in the younger population, that is, those 65 or younger at the time of diagnosis, have increased in recent decades. This is probably due to increased awareness in this population, which has led to more frequent use of prostate-specific antigen (PSA) testing, in spite of scientific controversy over its value (Hogle, 2009; Krantz, 2008). The reasons for developing prostate cancer are similar to those associated with breast cancer. Age, ethnicity, and heredity are the most well known factors (National Cancer Institute, 2007). The five-year survival rate is high compared with other forms of cancer and is 87.3 % in Sweden (Swedish Cancer Society, 2009).

Unlike breast cancer treatment the standardised regimens for managing prostate cancer are vague. For men with prostate cancer, factors such as patient co-morbidities, personal preference, and potential side effect profiles as well as survival rate and life expectancy need to be considered in a different way than with females before the choice of treatment is made (Haas & Yenser Wood, 2009; The National Board of Health and Welfare, 2007). The treatment alternatives include active surveillance, surgery, radiation, or medical management. The forms of medical management are quite similar to those given to females, and during the last few years chemotherapy has also become a treatment alternative in this population (Haas & Yenser Wood, 2009; The National Board of Health and Welfare, 2007).

Sexuality

Sexuality is a complex phenomenon and research is not confined to one particular field (Robert, 1999). In this thesis the definition from the WHO (World Health Organisation) is central. “Sexuality refers to a core dimension of being human which includes sex, gender, sexual, and gender identity, sexual orientation, eroticism, emotional attachment/love, and reproduction. It is experienced or expressed in thoughts, fantasies, desires, beliefs, attitudes, values, activities,
practices, roles, relationships. Sexuality is a result of the interplay of biological, psychological, socio-economic, cultural, ethical, and religious/spiritual factors. While sexuality can include all of these aspects, not all of these dimensions need to be experienced or expressed. However, in sum, our sexuality is experienced and expressed in all that we are, what we feel, think, and do” (World Health Organization, Pan American Health Organization, & World Association for Sexology, 2000, p. 6).

Biology and physiology
The sexual response cycle was first described by the research team of Masters and Johnson during the middle of the 20th century. They described a series of physiological events that were the same for both females and males. This model of four defined events was later remodelled by Kaplan to include three events; 1) desire 2) excitement 3) orgasm. Later studies of female sexuality have been critical of this model, claiming it is more suitable to males than females. Instead, new models which take into consideration that in women arousal is often intimacy-based, have been developed (Pitkin, 2009). The human brain plays a crucial role in the sexual response cycle. At the base of the hypothalamus there is a desire centre. This centre is influenced by the gonad hormones from both sexes and is the centre for human libido (Lundberg, 2010). Testosterone is the most important hormone for males, and corresponds to oestradiol and progesterone for females. Both sexes have all these three different sex hormones in a fluctuating mix, but they decline during normal aging. The median age to reach menopause for women in Europe is 54 years. Geographical changes occur, with the lowest age at menopause in the Southern European region and the highest age in the Northern European region. In North America, the age at menopause is quite similar to the age in the south of Europe (Palacios, Henderson, Siseles, Tan, & Villaseca, 2010). After this period the woman only has a small amount of circulating hormones. The male’s declining testosterone levels are more individual and the question of whether there is a male menopause is still controversial (Kessenich & Cichon, 2001). Epidemiological studies on sexual functioning in the elderly have established that the patterns of sexual response change during aging. However, these studies have noted that older women and men are perfectly capable of excitement and orgasm well into their seventies and further on (Skoog, 2010). For older men, for instance, it takes a longer time to become aroused and they often require more direct genital stimulation. Since the introduction of pharmacological treatments for erectile dysfunction (ED) this is more of a medical problem than an aging problem in our modern societies (Marshall & Katz, 2002). Self-reported sexual activities and satisfaction of Swedish 70-year-olds have increased in both sexes during
the last three decades. This is not directly dependent on whether the person lives in a relationship or not. However, being sexually active for an elderly couple is strongly correlated to the men and their sexual abilities and interests. This trend has not changed over the years (Beckman, Waern, Gustavson, & Skoog, 2008).

Social norms and ideals
From the point of view of WHO’s (2000) definition of sexuality and the lifeworld approach central in this thesis, embodiment has a crucial meaning for sexuality. The human body is the physical location where sex, sexuality, race, class, and age intersect, are personified and practiced (Harding, 1998; Williams & Stein, 2002). The body image consists of four important parts; 1) perception, i.e. the way we construct our body 2) cognition, i.e. how we think about our body 3) social, i.e. our body image is something we share with other people 4) ecstatic, i.e. the experience of the body as something beautiful (Price, 1998). To look young, be successful, and have a slim body is an ideal for the middle-aged (Blood, 2005; Oberg & Tornstam, 2001). People diagnosed with cancer constitute one group out of many who face the danger of having their body image altered (Chamberlain Wilmoth 2001; De Frank, Bahn Mehta, Stein, & Baker, 2007; Price, 1998). When the body appearance is changed by injury, disease, disability, or social stigma and people’s individual coping strategies and social adjustments for dealing with these changes are insufficient, an altered body image exists (Price, 1998). This is well reported in all forms of adult cancer, and recent qualitative research studies have illustrated a particular connection with women’s sexuality (De Frank et al., 2007; Ganz et al., 2003; Pelusi, 2006; Rogers & Kristjanson, 2002). However, men’s sexuality seems to be less affected by the altered body image (De Frank et al., 2007). Men are instead more affected by disabilities. One explanation could be domination of the phallocentric model of sex in modern society. This ideal restricts men more than women from searching for new ways to be sexually active if they have a handicap (Lorber & Moore, 2002; Plummer, 2005). Women also have to cope with the menopausal transition in different ways than aging men (Kessenich & Cichon, 2001; Lorber & Moore, 2002). For many women, menopause is mediated by beliefs about femininity, desirability, and reproduction, and is therefore a sign of aging (Hinchlif, Gott, & Ingleton, 2010; Lorber & Moore, 2002; Pitkin, 2010).
Living with the aftermath of breast and prostate cancer

Treatments effects

The effects on sexuality of treatment for breast and prostate cancer are very individual and it has not been proven that they are related to age, relationship status, gender, or type of cancer (Tierney, 2008). However, the literature in this area suggests there is a tendency to mark the youngest people in those two cancer populations as the most vulnerable to physiological, psychological, and/or social changes (Ganz et al., 2003; Lintz et al., 2003; Tierney, 2008).

The first model for consideration about sexuality in health care, PLISSIT, was developed as early as the mid 70s. In the last decade another model called BETTER has been introduced. This model was specifically produced for oncology nurses, and unlike PLISSIT it contains the possibility of including the timing of the sexuality discussion with the patient and documenting that it took place. Hence, no perfect model for taking a sexual history exists (Kaplan & Pacelli, 2011; Katz, 2007).

Breast cancer is treated according to the stage of the cancer. For most women this means breast-conserving procedures followed by radiation therapy. However, some women need a more extensive type of surgery, namely mastectomy. In those cases the women are able to have a breast reconstruction, usually one year at the earliest after the mastectomy (Swedish breast cancer group, 2011). Less mutilating surgery results in a more positive body image but it has not had the direct positive impact on sexual functioning that had been hypothesised (Rogers & Kristjanson, 2002; Rowland et al., 2000). Lumpectomy can leave the affected breast looking very different from the other one and may cause a loss of sensation over the scar. This is particularly common during the first month after surgery and it has been reported to be a lifelong change for some women (Emilee, Ussher, & Perz, 2010; Hughes, 2008; Pelusi, 2006). Chemotherapy is probably the cancer treatment which has the most powerful effect on impaired sexuality. It can affect gonad function, causing menopause which can lead to decreased sexual arousal, libido, and orgasm. Further, it can affect sexual energy, inspiration, and erotic pleasure (Ganz et al., 2003; Hughes, 2008; Young-McCaughan, 1996). It has also been reported that the neuropathies that usually affect hand and feet during chemotherapy can have the same effect on the clitoris, resulting in decreased sexual arousal and pleasure in the aftermath. Chemotherapy also usually causes fatigue, alopecia, nausea, and bad breath as well as changes in taste. All these have potential negative
consequences for sexual well-being (Chamberlain Wilmoth, Coleman, & Smith, 2004; Pelusi, 2006; Tierney, 2008). Artificial menopause is another effect of chemotherapy. Besides its devastating outcome on fertility, it also leads to hot flushes, bodily changes in the form of weight gain and musculoskeletal problems, and also makes some women feel old and unattractive (Ganz et al., 2003; Katz, 2007; Young-McCaughan, 1996). Hormonal therapy usually has a less harmful outcome regarding sexual functioning, even if decreased lubrication and vaginal atrophy are probably underestimated problems. In this group of women, weight gain and body image disturbance are also common (Katz, 2007).

The negative effects of treatment on sexuality for men diagnosed with prostate cancer are quite well explored. Surgery as well as radiotherapy and brachytherapy can damage the nerves and blood vessels that are needed for an erection. Hormonal therapy reduces the levels of testosterone essential for sexual desire and erection (Galbraith & Chrighton, 2008; Moore, 2009; National Cancer Institute, 2007). However, even if sexual dysfunction and its negative effects have been well explored, a more holistic view of men’s sexuality is rare. The view that penis size reduces after surgery is an unexplored topic. Some quantitative studies suggest that this is not a problem, although in some qualitative studies the embodied impact of prostate cancer and its consequences on sexual well-being are elucidated (Fergus, Gray, & Fitch, 2002; Yu Ko, Degner, Hack, & Schroeder, 2010). Other neglected problems are fertility issues and experiences related to ejaculation and orgasm after treatment. Moreover, there is research related to how men respond to the impact of hormonal treatment. It seems that the average man is not prepared for the hormonal side effects, gynecomastia and hot flushes which are common. These two symptoms are typically associated with being a woman (Galbraith & Chrighton, 2008; Gray et al., 2005). Other negative side effects of hormonal therapy are; loss of bone mineral density, changes in body composition, moodiness, depression, and anxiety. The latter can result in hypertension, diabetes, and coronary artery disease (Higano, 2003; Kumar, Barqawi, & Crawford, 2005).

Cancer as a serious life event
To be diagnosed and treated with a life-threatening disease such as breast or prostate cancer will for most people open up existential questions and re-evaluations (Berterö & Chamberlai Wilmoth, 2007; Westman, Bergenmar, & Andersson, 2006). Existential concepts, in our secular society, are often vague and poorly defined (Salander, 2006; Strang, 2002). Since sexuality is often central for how a person views her/himself, but is also integrated into all other
life dimensions, cancer often has the potential to threaten the person’s identity (Tierney, 2008). To understand this it is important to notice the psychology behind a person’s self-image and her identity. Central to this is childhood and the theory that the connection between the new-born baby and its parents develops during the first three years of childhood. The quality of this can influence adult people’s sexuality in different ways during their lifetime (Tidefors, 2010). When talking about sexual identity this is most commonly connected with sexual orientation and self-identification with a particular group of people (Ridner, Topp, & Frost, 2007; Williams & Stein, 2002), which is not of relevance to this thesis. In this thesis, the lifeworld is central, meaning that identity is embodied. In a qualitative Nordic study, with 16 breast cancer women with a mean age of 49 years, the researchers tried to understand the meaning of suffering related to health care. The researchers drew the conclusion, in an ethical, existential, and ontological sense, that suffering related to health care is fundamentally a matter of neglect and lack of care. Existential suffering of women is not focused and they are therefore not seen as unique individuals. (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004). During the last few years, qualitative research on men living with prostate cancer in Sweden has been conducted. All these studies confirm that sexuality is important for these men and cannot be separated from other life experiences (Hedestig, 2006; Jonsson, Aus, & Berterö, 2009; Lindqvist, 2007). A fruitful way to understand the lifeworld and guide people during the cancer trajectory is probably to use the concept of VOL (Views Of Life), a concept studied in the Nordic countries since the beginning of the late 1960s (Kallenberg & Larsson, 2004; Lindfelt, 2003). The concept of VOL answers the question; how does it feel to be alive? VOL has three components including: 1) Theories of human beings and the world. This is influenced by scientific, religious, or philosophical theories as well as individual opinions. 2) A central value system demonstrating basic moral and logical norms and values. 3) A basic attitude towards life where a person’s deeper pattern of feeling of hope, happiness, and faith is represented (Kallenberg & Larsson, 2004; Lindfelt, 2003). This basic attitude towards life is central to the concept and has much in common with the perspective of salutogenesis described by Antonovsky (2005).
Aims of the thesis

The overall aim of this thesis was to describe sexuality from a lifeworld perspective among middle-aged women and men with breast or prostate cancer. In this study, the years from 45-65 are considered as middle-age. Another aim was to describe the gendered experiences in these people’s narratives.

The specific objectives were to:

- Describe the meaning structure and the constituent parts of sexual identity in the lifeworld of premenopausal women with breast cancer. (I)

- Explore how middle-aged women, who were still menstruating when diagnosed with breast cancer, experienced their sexuality through the changes brought about by breast cancer and its treatment. How did they express feelings connected to femaleness and bodily experiences? What gratification did they find in sexual life and closeness with partners and friends? (II)

- Explore how middle-aged men diagnosed with prostate cancer at all stages experienced their sexuality from a lifeworld perspective. (III)

- Explore how middle-aged men diagnosed with prostate cancer at all stages experienced and talked about changes in their sexuality due to cancer. (IV)
Conceptual Framework

Lifeworld, gender, and sexuality are the concepts of importance for the analysis in this thesis. These three concepts are used from the viewpoint of nursing care, and they have guided me through the whole process. In the context of nursing care the relevance of understanding narrative is central (Edwards, 2001). This attitude, a non-reductionist account of what it means to be a person, characterises respect for the patient’s dignity and worthiness, and meets the ethical demands of caring science (Dahlberg & Segesten, 2010; Eriksson, 2001). Narrative understanding in nursing involves an attempt to perceive the meaning of patients’ descriptions of illness in terms of a threat to their capacity to succeed in realising self-projects that have the goal of achieving health (Edwards, 2001)

Lifeworld theory and the lived body

The lifeworld is composed of the intersubjectivity and meaningful world which we take for granted. It was first developed by Husserl who claimed that no objective world exists, just a world that is subjectively experienced (Dahlberg & Segesten, 2010; Karlsson, 1995). Husserl’s theory was later advanced by Merleau-Ponty who developed the theory of body perception – the lived body which is the horizon for understanding and interpretation of the world. Merleau-Ponty claims that the body plays a crucial role, not only in our perception but in language, sexuality, and in our relations to others. We are our body – the body is the hub surrounded by the world but it is also the anchor which connects us to carnality (Merleau-Ponty, 1945/2002). From a phenomenological perspective there are four essential elements in the human existence: lived space – synonymous with spatiality, lived body – synonymous with corporality, lived time – synonymous with temporality, and finally lived human relations – synonymous with relationality (Van Manen, 1990). The immediate world is always grasped in terms of a concrete situation – a book to be read, etc. Bodily space is given an intention to take hold, which Merleau-Ponty called a matrix of bodily action (Merleau-Ponty, 1945/2002; Toombs, 1988). Central to the lived body is the concept of reversibility, which symbolises the dialectical relationship between the individual and the world. Human beings influence the world; at the same time the surrounding world influences them. The individual and the social dimension of reality cannot be separated: they are each other’s conditions (Araújo Sadala & Adorno, 2001;
Merleau-Ponty, 1945/2002; Sigurdson, 2006). This means that when people are affected by a disease the possibilities for interacting in the world change. An illustrative example is a woman who has lost part of the body such as a leg. Spatiality and corporality are perceived differently. The meaning of the floor for the woman has changed. She has to reflect about it, and therefore her lifeworld is different. It seems as if the body retains the potential for engaging in this type of action for which this body part would be the centrality if it were still there. This is, according to Merleau-Ponty (1945, 2002), because of the habitual intentions of the lived body. It means that the parts of the body can be implicit as “intentional threads” linking it to the objects (the world) which enclose it. Every identified object is consequently inseparably linked to the body since the body is the locus of all intentions. Time, temporality, is experienced differently than before she lost her leg. Suddenly she is dependent on other people to help her, and relationality is perceived differently than before.

When illness occurs, it is the body that experiences it. Activities, postures, and gestures change, and the adjustments are often experienced as foreign and unnatural.

**Gender**

Gender is the socially constructed meaning of the differences between females and males. It allocates unequal social power and privileges to women and men, and shapes their identities, perceptions, and interactional practice (West & Zimmerman, 1987). The concept of gender was first introduced in the mid-1970s by Rubin in the field of anthropology. Rubin stated that in all societies the sex/gender system can be understood as gender being the social and cultural interpretation of biological differences between the sexes. This interpretation is not the same in all cultures, but in our society we interpret it in a way that creates inequalities between genders. Rubin was also very clear about the importance of the reproductive role of women and their responsibility for children and childbirth in upholding the sex/gender system. These ideas also shaped the way she understood heterosexuality as a norm (Rubin, 1975).

Later on, Rubin’s theory was expanded and critically revised into the heterosexual matrix by Butler. In this matrix the representations of two separate sexes are the only possible positions. These two positions are each other’s opposites, in a bodily and biological way. At the same time desire is
understood as directed towards that which is different and other, and where humans are expected to feel mutual desire and a wish to be sexually intimate with each other (Butler, 1990). It is thus only possible to have desire for the opposite sex, which makes heterosexuality privileged. Even if gender is understood to be a cultural and social interpretation of sex, the matrix means that the only genders are femininity and masculinity. Butler further argues that gender is about performativity including bodily approaches and styles. Gender is an act with learned repetitions. Performing it wrongly initiates a set of punishments that are both self-evident and implicit, whereby the intimate link between sex, gender, and desire becomes evident. If a person feels desire for another person of the same sex, then that is commonly interpreted to mean something is wrong with that person’s sex. Therefore, gays are understood to be feminine and lesbians masculine, thus the normal form of desire is upheld, towards that which is different. On the other hand, performing gender roles properly provides the person with the feeling of a true essential identity. This is only possible if gender, body, and sexuality are in line with predominating discourses in the society; that is feminine women and masculine men with heterosexual desire (Butler, 1990). This means that heterosexuality becomes a privileged form of life in the society.

Connell is perhaps one of the most important persons for our understanding of masculinities. Connell describes four different types of masculinity; hegemonic, complicity, subordinated, and marginalised. These four forms should be interpreted as ideals, and for the individual man it is possible to adopt more than one form depending on the situation. Masculinities are therefore not fixed, but rather changeable, depending on different social situations. Hegemonic masculinity is characterised by traits such as strength, assertiveness, risk-taking, and aggressiveness, something that most men should strive for (Connell, 2008). For Connell, the main structures in the society can be understood through how labour, power, and cathexis are distributed. In the category about labour, Connell analyses the social structure which explains why the labour market is still segregated along gender lines. Women mainly work in caring domains and men in more technical professions. In the category about power, men’s violence against women and why the institutional influence on women is still to their disadvantage in many contexts are analysed. Connell draw our attention to the importance of distinguishing between the global or macro-relationship of power and the local or micro-situation. In the latter, individual women may have more influence than some men, although overall institutional power still tends to work in men’s favour as a group more than women’s. This third
category is different from the other two. In labour and power there is solidarity between the sexes but in cathexis this is instead built on reciprocity between the sexes. This means that cathexis presupposes sexual differences and these differences are what gives erotic flavour to the relationship (Connell, 2003). In this way his theory touches Butler’s theory which claims that it is not acceptable to feel desire for the same sex. However, in Connell’s concept, the relation of power is more visible than in Butler’s theory. Connell visualizes the differences between heterosexual couples as specifically asymmetrical. A heterosexual woman is sexualized as an object in a way that does not apply to heterosexual men. In that way the erotic reciprocity in hegemonic heterosexuality has its foundation in unequal exchange. These three structures depend on each other and work in a dynamic correlation, having different importance in diverse environments and settings (Connell, 2003).

**Gender, sexuality, and the lived body**
In this thesis I will combine the three concepts; gender, sexuality, and the lived body. The philosophy of body perception according to Merleau-Ponty is pre-reflective, and therefore can be compared with Butler’s theory of performative acts and Connell’s theory about cathexis. They can hopefully be the tools needed to understand the context in which the lived body has a central place.

The most prominent ideal in modern Western culture is perhaps the heterosexual romantic. In that, heterosexuality is institutional and shapes social practices in the family and workplaces, which is also in line with Butler’s and Connell’s theories (Butler, 1990; Connell, 2003; Williams & Stein, 2002). In these societies, male sexuality is more dominating and selfish than female sexuality. Hegemonic sexuality, with the phallus as a symbol, is a prominent ideal which generates power for those who can live up to it. This is also important for hegemonic masculinity. Therefore, it can produce fear and insecurity for those who cannot have an erection (Plummer, 2005). For most people the cultural meaning of sexuality and the person’s own experience is well implemented in their lifeworld. When conflicts exists, for example due to mastectomy or prostatectomy, they affect the person’s self identification and self esteem (Plummer, 2002). The concept of the lived body removes the dichotomy between sex and gender. Instead, it is the experience of being in a lived body that is important. The body is dependent on the sex, time, and place. The outcome of the lived experience can never be settled in advance (Moi, 1997).
Methods

Design

This thesis has a qualitative descriptive approach based on nursing care. Data triangulation was implemented, and existential phenomenology was used in studies I and III (Patton, 2002). The lived body with its most important features – being-in-the-world, and bodily intentionality – forms the basis of the knowledge in those studies. The theory of body perception is an epistemological starting point to examine empirical phenomena (Nortvedt, 2008). The focus group method analysed using qualitative content analysis was used in studies II and IV. This analysis is free and theoretically boundless (Graneheim & Lundman, 2004).

Setting and informants

The majority of the informants were recruited from associations for cancer patients. People who join voluntary organisations identify themselves with the ideas of the other members of that particular group. This was one of the reasons why I choose cancer associations – I wanted to be sure that the informants in the studies had identified themselves as people living with a cancer diagnosis. It has been reported that participation in voluntary organisations is correlated with high socioeconomic status. This position is also correlated with certain abilities, e.g. speaking in public and dealing with people (Söderholm Werkö, 2008). In cancer associations the motives for participation probably differ from other groups. In a Swedish survey of 1810 individuals belonging to cancer associations, the motives differed according to gender. For females the motives related to having cancer were most prominent (e.g. sorrow and fear about the future), whereas getting information and engaging in activities dominated in the group of men (Carlsson, 2005). Söderholm Werkö’s thesis established that active memberships in voluntary organisations provide the members with a collective identity related to the members’ sense of who they are and to mutual definition. This also contributes to the ability of the members to achieve empowerment (Söderholm Werkö, 2008).

The study sample comprised members of cancer associations for breast and/or prostate cancer in the middle and south region of Sweden. In two cases (study III) two men were patients in the same department as the researcher.
Those two were not members of a cancer association group. They joined voluntarily when they became aware of the study.

The inclusion criteria were:
- Swedish-speaking
- all stages of breast and/or prostate cancer
- 50 years old or younger and still menstruating (I, II), and approximately 65 years old or younger (III, IV), at the time of diagnosis and with six months or longer since the diagnosis.

The participants were recommended by the chairman of two different cancer associations (I, II). This chairperson sent information about the study to women that she felt might be interested and who fitted the criteria. If the woman said yes, a letter was sent containing a request for participation in an interview study. The letter also gave information about the purpose of the study and its voluntary nature. Women who showed their interest by signing the informed consent form were later contacted by me. Six women were interested in study I, and 12 were interested in study II.

In studies III and IV the design was different to the earlier studies. After a meeting with the board members of the prostate cancer association in Gothenburg I decided with the board members to place an advertisement in their own association magazine. This magazine is distributed to all members, not only in the south of Sweden but also in the middle. In the magazine there was some information about the study and my email address was provided. Eight persons contacted me directly and the other two joined voluntarily when they became aware of the study. In study IV it was difficult to recruit sufficient members. First, an advertisement about the study was placed in the same way as in study III. A handful of men showed interest and some of them were team leaders in local regional groups. Then I contacted a urological clinic in Gothenburg where two nurses composed a list of ten possible men. From this list two men were recruited and two others signed up by direct contact with me. The remaining 15 informants were recruited through snowball sampling. The snowball sampling was made possible by the group team leaders who first contacted me (Patton, 2002). Characteristics of the informants in the four different studies are presented in table 1.
Table 1. Overview of papers I-IV

<table>
<thead>
<tr>
<th>Paper</th>
<th>Participant’s demographic</th>
<th>Data collection</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Six women between 38-48 years with a mean age of 45 years. Five were married or lived in cohabiting relationships.</td>
<td>Phenomenological interviews</td>
<td>EPP-method</td>
</tr>
<tr>
<td>II</td>
<td>Twelve women (three groups) between 39-54 years with a mean age of 47 years. Eight women were married or lived in cohabiting relationships.</td>
<td>Focus group interviews</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>III</td>
<td>Ten men between 54-71 years with a mean age of 65 years. Nine were married or lived in cohabiting relationships.</td>
<td>Phenomenological interviews</td>
<td>EPP-method</td>
</tr>
<tr>
<td>IV</td>
<td>Nineteen men (four groups) between 53-76 years, with a mean age of 64 years. Fourteen were married or lived in cohabiting relationships.</td>
<td>Focus group interviews</td>
<td>Qualitative content analysis</td>
</tr>
</tbody>
</table>

Interviews
In studies I and III, phenomenological interviews were conducted by me. The interviews were carried out at a place of the informant’s choice. Four of the interviews in study I took place in the building where the cancer association usually had its meetings. The other two interviews were carried out outside in a park. In study III, five of the informants chose their home or their working place. The remaining five men chose the hospital in two cases, and three chose a room in the Swedish Cancer Society’s building. Before the interviews started there was some small talk while drinking coffee in order to develop a relaxed atmosphere (Kvale, 1996). Phenomenological interviews were carried out in order to achieve expressions of the women’s and the men’s lived experience (Kvale, 1996). They were asked to tell their story of being a woman/man diagnosed with breast/prostate cancer and how it had affected their sexuality. As an interviewer I tried to be as open and accommodative as possible to the informant’s narratives. Clarifications and exemplifications from daily life experiences were requested in order to deepen the understanding when it was needed. The interviews were tape-recorded and transcribed verbatim. They lasted 46-120 minutes and reflected the complexity and uniqueness of the phenomenon in rich narratives.
Focus group interviews

Focus group interviews were carried out in order to obtain data within the social context of the informants. I wanted the groups to be small, not more than four to six people in each group, because of the sensitive topic and the fact that I thought the informants really wanted to share their experiences with each other. In larger groups, it is difficult for everyone to speak because of the time limit (Krueger & Casey, 2009; Robinson, 1999). Seven focus group sessions were carried out at the same place that the cancer associations had their meetings, except for two groups (II, IV). One of them was conducted in one of the cancer association member’s own homes, and the other one in a Regional Oncological Centre in Sweden. Before the session started, I explained the purpose and the topic for the session. First, there was some small talk in order to bring the informants together and to help them to get to know each other. The group dynamics differed in each of the seven groups. During the session the women/men were encouraged to talk to one another, to ask questions, exchange anecdotes, and comment on each other’s experiences. I steered the focus of the group discussions and ensured that a dialogue occurred among the group members, rather than between me and them. As an inspiration to facilitate the talk about sexual intimacy, libido, and desire a series of picture-cards were used in the two first group discussions. In the remaining groups the film “Through Sorrow and Joy – a film about cancer and sexuality” was used before the interviews took place. This 45-minute-long film was produced for people living with cancer or having a close relationship with someone who has. The film is also intended to provide insight into issues of sexuality for health care professionals (Korst, 2004). This film had not been available for the first two group sessions. The picture-cards included about 50 pictures with different people, children, and animals in various situations, all with the purpose of helping the participants to reflect and imagine special situations or feelings connected to sexuality. The sessions lasted 110-130 minutes and were tape-recorded and transcribed verbatim.

During the first session with females and the first two with males an assistant researcher made notes about body language, gestures, and facial expressions during these sessions. Afterwards, there was a discussion about the substance of the different sessions.
Analysis

Existential phenomenology
The analysis of studies I and III used an existential phenomenological approach. In those two studies I chose the EPP-method (Empirical Phenomenological Psychological) which is based on Husserl’s phenomenological philosophy (Karlsson, 1995). The EPP-method was developed with a psychological perspective, which in those studies was substituted with a nursing perspective. The focus for me has been the informant’s daily life and concepts within nursing care.

The analysis consists of five steps where the different texts from the informant’s narratives are presented in different manuscripts. These manuscripts are not compared until the last step (Karlsson, 1995). In the first step, I tried to grasp the entirety of the text by reading the text several times until I reached an understanding and could continue the second step of the analysis.

In step 2, the texts were divided into meaning units (MU). Each unit contained one particular meaning of the phenomenon. New units were formed when I identified a shift of meaning. To illustrate step 2 some original text from study I is presented in the following quote:

“And I don’t have to worry about protecting myself against pregnancy. I don’t need to take pills and he doesn’t need to use a condom . . . and such things, which feels like a relief (MU 1) but of course I would prefer not being in this situation, but . . .” (MU 2). In this protocol I considered MU 1 as describing the situation after becoming menopausal. After MU 1 a temporal change occurred in the description to which I must pay attention.

During step 3, eidetic induction through interpretation took place, meaning that I tried to track out the meaning and possible relevance from the informants’ statements. In this step the informant’s everyday language was transformed into scientific nursing language, and in study III, Merleau-Ponty’s theory of perception was applied more substantially than in study I. In step 3 this quote from study I was transformed into the following statement: S thinks it is a relief to stop using contraceptives even if she thinks it is a high price. Step 3 is perhaps the most critical step in the analysis and in those two studies it was characterised by an intensive dialogue with the text. In study I, I collaborated with another researcher, and in study III with two other researchers. There were also several meetings involving all three to discuss the body perception of Merleau-Ponty’s theory, which was traceable in the informant’s narratives (III). The intention was to be sensitive to the whole as well as to the parts of the
data, aiming to capture the meaning structure of the phenomenon. To illustrate the work in study III, the following dialogue is presented: [In what situations do you weep? (I = interviewer)] “... I don’t know. I suppose it is when I think I’m not good enough.” [(I) No] “If it is masculine or not I don’t know.” [(I) No, but when you say you’re not good enough – for what?] “Well, sexually and emotionally.” [(I) Yes] “And then she says that you have so much more in common.” [(I) Yes] “And that it isn’t the main thing in a relationship.” [(I) No] “So it isn’t the sex life.” [(I) No] “Well... perhaps it isn’t but it is so deep-rooted in man’s nature that we must have it that way.” [(I) Yes] “I suppose it is what is gnawing at me a little.” This statement was rewritten: Jörgen cries when he feels sexual and emotional inadequacy. This situation is confusing and it seems as if Jörgen has difficulties with the implicit requirements of manhood. In step 3 the quote was transformed into the following statement: *Jörgen’s spatiality has changed since the matrix of his habitual action is no longer necessary and therefore his ability to interact in life is different than before. His bodily intentional threads are slack and he can no longer fulfil the implicit requirements of manhood.*

In step 4, the transformed meaning units were synthesised into a “situated structure” presented in the form of a synopsis. The quote above could fit with the idea of the constituent being in an existential vacuum (I) and the threat against manhood (III). In step 5, the documents from all of the interviews were compared and an “essential meaning structure” was formed. The movement between the whole and the parts plays a major role in the analysis. The interpretation in the EPP-method develops between the researchers’ pre-knowledge and endeavour of being as open as possible during the analysis (Karlsson, 1995). Karlsson suggests there are three important elements involved in validating the outcomes of the analysis; 1) The degree of success in the partial phenomenological reduction. 2) The horizontal consistency of interpretations. 3) The vertical consistency of interpretations. This means that I, as a researcher, must work with an open and curious mind, and as far as possible must not let my pre-understanding control the first steps of the analysis. I should also work with one document at a time and should not compare the documents until the last step (Karlsson, 1995).

**Qualitative content analysis**

The coding processes were used slightly differently during studies II and IV. The reason for this was that my pre-understanding was different between the studies. The differences between studies II and IV concerned the work which was done after a sense of the whole was obtained. In study II, meaning units were marked, the text masses were condensed, and depictions close to the text.
were made (Graneheim & Lundman, 2004). In study IV, open coding and creating categories were carried out instead (Elo & Kyngäs, 2008). The differences between these two approaches are small but the latter approach separates the findings from the text, which makes the statements easier to compare with the rest of the findings. However, by using latent qualitative analysis these approaches are inductive following the given direction interpreted in the text with similar outcomes. The outcomes depend on the dialogues which occur between me and the text masses. As in all qualitative studies I must be aware of the whole and the parts to successfully accomplish a new understanding of the whole. Finally, all the text masses were compared with each other and the text was abstracted to a higher level. By doing this the findings could be grouped into sub-themes which were prearranged in the same way in both studies (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). This work resulted in frameworks that depicted aspects of sexuality based on the groups’ collective experiences among this sample of informants. From these analysis processes, one theme finally emerged in study II and four themes in study IV. The different analyses of the text are illustrated in table 2.
### Table 2. Analysis of the text

Examples in step 2-4, study II

<table>
<thead>
<tr>
<th>Meaning Unit</th>
<th>Condensed meaning unit (description close to the text)</th>
<th>Condensed meaning unit (interpretation of the underlying meaning)</th>
<th>Sub-theme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a. No, it’s that I want – I want to be like all the others, a little. It isn’t me any longer, this woman with only one breast. She isn’t me, I don’t feel like that.</td>
<td>This informant is longing to look like a healthy woman. She does not feel like a woman because she has only one breast.</td>
<td>A feeling of being different from other women and a longing to be “normal” again.</td>
<td>Feeling different</td>
<td></td>
</tr>
<tr>
<td>1a. I have thought about the fact that when talking about breast cancer it is always the breast, its loss and the eventual loss of hair from the treatment but I feel that it is not these things that have changed me as a woman; rather it is the flushes.</td>
<td>Informants are discussing bodily changes since they stopped menstruating. They do not know why, but some believe that the hormones are causing the troubles.</td>
<td>Hormones cause bodily changes. One feels older, more bloated and one has flushes.</td>
<td>The unruly body</td>
<td>To feel like an outsider</td>
</tr>
</tbody>
</table>

Examples step 2-4, study IV

<table>
<thead>
<tr>
<th>Open coding</th>
<th>Grouping</th>
<th>Categorisation</th>
<th>Sub-theme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. One can find new ways?</td>
<td>Sexuality is different</td>
<td>Sexual needs</td>
<td>Redefining sexuality</td>
<td>When the body fails and feelings and relationships change</td>
</tr>
<tr>
<td>O. Yes that is what one has to do.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I. Mm.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>O. And then it is as said, it was like I said; it is all about the family. I rejoice just as much when I get the grandchildren home on a visit.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I. Yes.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>O. It is very pleasant.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I. Mm.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>O. To hold them and hug them, but there are absolutely no sexual thoughts.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I. No, but you can feel that your need is satisfied?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>O. Yes, sure, the intimacy and tenderness like that [pause] (One informant and the researcher (I) in focus group 3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| "And it must work in a better way because otherwise people will be tremendously disappointed about things. And this thing also leads to [pause] [sigh] bad relationships in the next phase."

| "And it must work in a better way because otherwise people will be tremendously disappointed about things. And this thing also leads to [pause] [sigh] bad relationships in the next phase." | Sexuality is different | Communication needs | Communication | Sex with technical aids and pills |
Ethical Considerations

Qualitative methods are highly personal and interpersonal. The responsibility for any inconvenience that may emerge for the informant is something I have to deal with, which can be difficult, especially in group discussions. However, there are several studies which confirm that sexuality issues are often fruitful to discuss with a focus group design (Kitzinger, 1995; Morgan, 1997; Robinson, 1999).

By choosing phenomenological interviews (I, III) the existential dimension of sexuality is elucidated. In earlier studies in similar populations, evaluations have indicated that it is possible to talk to patients about existential questions without negative effects. Many of those informants have stated that they felt relief when they were listened to (Andershed & Ternestedt, 1998; Berterö, 2001). By analysing these narratives, we may be able to help other people in similar situations. Hopefully, the analysis can also provide health care professionals with deeper knowledge of how sexuality can be experienced. By conducting focus group discussions (II, IV), people are able to talk and share their experiences with each other to provide mutual support in expressing feelings that are common in their group but perhaps not in society as whole. This will perhaps strengthen the informant’s confidence but it will also bring knowledge on a more general level.

As in all types of research with humans, the declaration of Helsinki forms the basis of the design (World Medical Association, 2008). Respect for the integrity, autonomy, and privacy of the informants is at the heart of the interviews. In the focus groups this was much harder. However, the informants and I decided to make an agreement for secrecy and confidentiality in each group. Several months before the different studies took place arrangements were made with the two largest cancer associations in the south of Sweden. In this way I was able to learn about the organisation, and how the interaction between the members took place. The cancer association members were able to get some information about me and the upcoming studies. Substantial efforts were made to design an information letter about the studies. In the letter, all participants were assured of confidentiality, and that participation would be voluntary throughout the process. All documents regarding the informant’s identity were separated from the hard copies and kept in a locked cabinet. All informants signed an informed consent form and whenever they felt they needed to talk to someone, for instance about feelings
arising because of the interview/focus group, they could call me, and I would give them support. They could also call the psycho-social department at a hospital in the region (I, II). Both before and after the interviews in studies I and III there was some correspondence through email and by telephone to make the informants feel secure and confident. During the phenomenological interviews I tried to be as sensitive and supportive as needed. The informants themselves chose how much they wished to tell me during the interviews. When I thought I wanted them to explain more in some special narratives I was careful not to compromise their integrity. The two informants, who voluntarily joined after finding out about the study (III), were not depending on me in some way as their clinical nurse.

By choosing cancer association members the inclusion criteria were narrowed to some extent since these members often have some special qualities (see also page 23). However, I calculated that the advantages outweighed the disadvantages. The four studies received ethical approval from the Regional Ethics Committee in Gothenburg (S 197-03) (I, II) and Linköping (Ö 164-07) (III, IV).
Findings

Study I. Sexual identity following breast cancer treatments in premenopausal women

To become menopausal due to breast cancer treatment was an attendant phenomenon and was not something the women could anticipate. After being diagnosed with a life-threatening disease this problem was secondary and they did not concern themselves with it. They seemed to be totally restricted in their ability to communicate their sexual feelings and needs associated with their sexuality and also in interaction with their partner.

The menopausal symptoms were the most common ones reported in this study. Loss of menstrual bleeding was both positive and negative for the participants. In a way it was kind of a relief to no longer have to take extra sanitary precautions. On the other hand, having a period is something you share with other females of the same age. Hot flushes were most troubling; making the women lose concentration and leaving them unable to interact in different social environments. This also forced them to change their way of dressing and they had to think about what to eat and drink. For some women all these changes made them feel like and identify themselves with their mothers. This was in some cases very stressful, making them feel old and unattractive.

At the same time they felt that their body had changed in a dramatic way. They did not recognise themselves, which in turn affected their capacity to interact in all sorts of social contexts such as responding to advertisements with sexual messages in the media, going to public baths etc. Becoming menopausal at their age was unnatural and most troublesome since they did not know how the medical treatment affected them and what the consequences would be in the long run.

It was as they had been forced into an existential vacuum which ruled out the possibility of creating an identity which was familiar and secure. After chemotherapy treatment, the women expected to be healthy and strong again, to be re-established as normal. They struggled to live up to these expectations while feeling that nobody understood what they were going through. The partner or other close friends and the cancer association members played a major role in maintaining the women’s well-being. By meeting with the members of the cancer association the women felt confirmed in their perceived uniqueness and loss of femininity.
Their love life, with regular sexual intercourse was suddenly gone; however for these women this was secondary and they hardly reflected upon it. Later on, four of the six women became sexually active again, and discovered that they had now become more passive. It was as if they had to surmount obstacles to get aroused. The women’s need for hugging and closeness to their partner increased, and this improved their intimacy. At the same time the women also could appreciate other things the partner did for them in other ways than before, and this also gave them new strength in intimate relationships.

**Study II. To feel like an outsider: focus group discussions regarding the influence on sexuality caused by breast cancer treatment**

During the three focus group sessions four sub-themes were identified: To feel different, the unruly body, eroticism is not what it used to be, and re-evaluating. The women appeared to have difficulty verbalising positive feelings connected to the female body. Instead, they expressed an overwhelming feeling of not recognising themselves and not knowing whom to identify themselves with.

The two first themes; to feel different and the unruly body symbolise the body changes due to their menopausal symptoms. Emotional and bodily changes such as: feeling old, feeling unattractive, and experiencing many ambiguous physical symptoms such as pain, stiffness, hot flushes, fatigue, and dizziness were all mentioned and coped with in the same way as in the individual interviews observed in study I.

On the other hand, discussions about eroticism with attraction, desire, and lovemaking as natural features were explicitly mentioned during the different sessions. This was particularly evident in focus group 3. The theme Eroticism is not what it used to be illustrates that the women withdrew from their partners, attraction to the opposite sex was gone, and it took a long time to become aroused when having sexual intercourse. Sometimes lubrication of the vagina was inadequate, resulting in pain, and dissatisfaction instead of joy and pleasure. It was as if they could no longer devote themselves totally to erotic feelings. If they tried to watch an erotic film for example they just felt disgusted. The majority of the women seemed to live in harmonious relationships with their partners, which enabled love and appreciation anyway. They felt great understanding from their partners, which increased intimacy and strengthened love, albeit not in an erotic way.

The 12 informants were in different stages of their disease and for those who were in a chronic situation or suffered from physical adjustment a re-evaluation about the meaning of life had occurred. As a consequence of the re-evaluation the women seemed to take more time for themselves, dictating their own wishes in a more mature way than before. This could result in the
breaking up of relationships with people whom they no longer felt mutual interaction with. At the same time they could confirm and appreciate other people’s engagement with them in completely new ways. During the transition their femininity was transformed and their ego was changed, now focusing more on quality of life in terms of self respect. For some this resulted in a more relaxed and flexible female role. To be confirmed as a woman was essential for well-being and femininity. Closeness to their children, close friends, and/or their partner and the other women in the cancer associations offered them confirmation without the need for words. These intimate relations compensated to some degree for the losses connected to their own lack of attractiveness.

The bridge theme for these three sessions, *to feel like an outsider*, has a dual meaning in this population. The first meaning is connected to the embodiment of experiences due to the cancer diagnosis and not least the cancer treatments. The second is connected to the re-evaluation of the women’s ego as they focused and concentrated on themselves.

**Study III. Losing the elixir of life – sexuality in the context of prostate cancer narratives**

The essential meaning, *Losing the Elixir of Life*, is closely connected with the experience of the otherness of the body. The changed body made access to the world different for the informants. Sexual ability was seen as an isolated issue for the subjects; when it failed it was a threat to their very existence. This threat made them more vulnerable and deprived them of some of their autonomy, leading to shame. These were indeed private and embodied experiences which affected the informant’s sense of themselves. The lifeworld for these men comprised the dynamic interaction between the deprivation of their “elixir of life” and their opportunity to achieve intimacy.

The essential meaning in this study has four general constituents; *something which no longer exists*, the threat to manhood, intimacy, and staged manhood, reflecting the variance in the essential structure.

In the theme, *something which no longer exists*, the informant’s experiences of diminished libido and/or impotence were elucidated. For those who could incorporate technical aids and/or pills into their lifeworld, these could have tremendously positive effects on their sexuality. In the same way as other equipment used in cases of handicap, technical aids could make men comfortable when they were incorporated in the men’s lifeworld. Unfortunately, only a handful of the informants found it possible to incorporate these kinds of aids into their lifeworld. The others expressed fear of negative side-effects and discomfort because they had to arrange everything
beforehand, reducing their motivation to have sexual intercourse. If, added to this, their partner did not encourage the use of technical aids the participants tended to give up. For these men, bodily temporality differed from their previous bodily temporality. At the same time past, present, and future were present in an overwhelming mix. For instance memories often had a central place in their lifeworld experiences – “the good days” sustained their spirits in the present. In this population the body image was affected for various reasons: changed bodies, developing breasts, regression of genital organs and muscles, gaining weight, and being forced to wear diapers because of leaking urine and/or faeces. This means, according to Merleau-Ponty’s theory, that the body appears as an attitude directed towards certain active or potential tasks. This is an intuitive sense of the body which forms the corporeal identity that is essential as the basis for existence.

In the threat to manhood the usual body representation of the informants was gone, resulting in loss of the habitual intentions of the lived body. For a while they were paralysed, not knowing how long they would be alive. Eventually they accepted the situation, realising that they might live a little longer, resulting in a feeling of being cheated by the loss of sexual ability. This also brought the feeling of mutilation and of being only half the man they used to be. In a way they found some comfort from being a man who had reached middle-age and had accepted that sexual ability diminished through normal aging. For these men their cancer was mystifying, hence they were incapable of understanding the biological and practical functions of the prostate gland. They were also not encouraged by the health care professionals to ask questions about it.

The constituent, Intimacy, symbolises the erotic part of the informants’ lifeworld. Before the diagnosis, sexual intercourse with a partner had been a way to achieve intimacy for the men. When the ability to have sexual intercourse declined, they either developed new ways to gain sexual satisfaction or they became less sexually active. When the possibilities of achieving common sexual satisfaction through intercourse diminished, men could exhibit sensuality and appreciation in other ways than before, which could enable closeness and intimacy. Intimacy could also be expressed through the daily caring attention the couples showed each other.

The last constituent, staged manhood, symbolises the changed intentionality and its consequences for the informant’s lifeworld. Virility was a matrix of bodily action for the participants before the diagnosis and when it failed the men continued to act as if it remained. (According to Merleau-Ponty this means that bodily space is given an intention to act in a way which is
embodied and not reflected). Virility was connected to the ideal of youthfulness. This was difficult for the men to maintain and it affected their quality of life a great deal. For those men who could still feel attraction to women this compensated in a way for the changes, even if they became impotent and were unable to penetrate.

One man differed from the others with respect to his experience connected with sexuality. His sexuality was somewhat enhanced after he completed the seed implantation. This made him feel satisfied and grateful for not being in the same situation as the other fellow suffers. This was the only reason he wanted to participate in the study.

**Study IV. Talking about sexuality: desire, virility, and intimacy in the context of prostate cancer associations**

The findings from the four different focus group discussions suggest that being diagnosed with prostate cancer and undergoing treatments were threats to male identity. During the transition period of illness, the men acquired a new identity to generate self-confidence. This process was not in any way linear and, although the men had many similar experiences, they interpreted them in different ways. The men were occupied with unfamiliar feelings and their body had failed them. Their sexuality was subsumed in their illness experiences and connected with silence and sorrow. However, the focus groups provided a space to share experiences. The following four themes represent an abstraction of all the statements in the four groups: *when the body fails and feelings and relationships change; prostate cancer’s effect on masculinity; sex with technical aids and pills; to lead the way and have the courage to talk.*

In the first theme, *when the body fails and feelings and relationships change*, the emotional dimensions, particularly fear, anger and frustration, and the informants’ close relations are discussed. The majority of the informants in this study were married or lived in long-term cohabiting relationships with females. The different sexual patterns that the couples had developed during these years were suddenly gone and a mutual acceptance of silence between the couples appeared. Sexual needs were suppressed when the ability to perform was the main stressor. Some of the couples came closer to each other, and for them their intimate relationships changed character. On the other hand, the different discussions elucidated the great losses connected to the informants’ new life situation. Although the men shared the same experiences, they interpreted them in many different ways, some of them contradictory. The participants expressed in words that they felt different from before and it seemed that they were all very sure that this was because something psychological was going on in their mind. In the different group discussions, it
was noticeable that, during the sickness process, some men re-evaluated their sexual life and a new definition of the “self” emerged. This process was closely connected to their life situation overall. The friendship between the active members in the groups was strong. All the contradictory feelings that the new life situation had brought and the frustration it caused were shared and discussed during the sessions, which deepened the male friendship.

Through the theme, prostate cancer’s effect on masculinity, the informants’ self-identity was visible. This theme dominated among all the changes connected to potency, and was something which seemed to be difficult to verbalise. Collectively, in all these different experiences, there was the feeling of being deprived of masculinity. The informants’ new life situation implied that their usual sexual habits, with regular intercourse, had diminished. This affected the informants in different ways. For a majority it was evident that it was a greater loss for them than for their partner. Most of the men described having received great support from their partners, who seemed to deny their own sexual needs. The decreased virility and desire was for most the greatest change after treatment and therefore some of them felt that their mutual sex life with their partner had become a duty.

The theme, sex with technical aids and pills symbolises how the informants deal with the possibilities for bringing technical aids and/or pills into their life. In the four different groups, there was an abundance of experiences and knowledge about different technical aids and how to use them, which the informants eagerly shared with each other. Urinary incontinence, which was a common side effect of operations and radiotherapy, seemed to be the main problem in terms of attractiveness and having an acceptable love life. For the average man in this study, this was a substantial obstacle during the period soon after treatment. In spite of this, the discussions indicated that the participants did not link urinary incontinence and its aftermath to sexuality as a whole. If the men lived in a trusting and caring relationship and with the help of pelvic floor exercises, it was possible to overcome this obstacle over time for most of the informants.

The last constituent, to lead the way and have the courage to talk, explicated all negative images surrounding prostate cancer in the societies. Especially prominent were discussions in which urinary incontinence and its negative consequences were mentioned. In these groups a majority were convinced it was important to talk and shed light on the problems associated with their situation.
Reflective summary of findings

Reflective summary of the gendered experiences in studies I and III

The informants’ “intentional threads” were slack and their usual matrix of bodily action was gone. This meant that their usual sexuality, which previously was habitual and functional, irrespective of whether the origin for the changes was biological, physiological, or emotional, now presented itself as “an obstacle” to the body. For the informants, this meant that their existential base of knowledge was gone. For the women this fact was characterised by the metaphor of a bird that is pinioned and unable to fly anymore. For the men it was expressed in the essential meaning, to lose the elixir of life. Both women and men suffered tremendously. Sexuality changed from one day to another, and they all handled it individually. All these personal and sometimes very private experiences were captured in the different constituents which symbolised the variety and the structures of the existential meaning under study. However, although the existential meaning for the sexes was quite similar, the way of responding to it was different. Changed body appearance, feeling old, and feeling unattractive were most dominant for the women. The informant’s body image, described by Price in the background, seemed to be affected, and was probably the most important factor in how the women viewed themselves sexually. According to Butler’s theory about performance this is symbolised in the practical arrangements the women made with wigs, makeup, and clothes. For women who have gone through a breast reconstruction some improved bodily appearance was evident. They got a firm new breast, and the other breast was rebuilt as well to obtain symmetry. In that way they gained a more attractive appearance which according to Butler’s and Connell’s theories fitted well into the heterosexual matrix and the structure of cathexis in the society.

Hegemonic sexuality, where male sexuality is more dominating and selfish than women’s sexuality, affected the male informants’ views about themselves. For the men their bodily appearance was not as important as it was for the females. Instead it was their ability to have an erection that was important. This also affected their masculinity from the viewpoint of the hegemonic ideal. Their changed body with reduced virility, impotence, urinary, and faeces incontinence, were embodied, and they could no longer live up to their ideal of masculinity.

Those two studies are phenomenological, built on the informants’ lifeworld, which shows the habitual intentions of the lived body. The lived body is a “situation” dependent on the sex, time, and place, and therefore both women
and men have completely different options for acting and coping, depending on the unique circumstances. However, modern societies have forgotten the original phenomenal body and people are used to valuing and objectifying their bodies in interaction with other bodies. For the informants in these two studies, the existential base for knowledge had been injured, resulting in reduced autonomy, and leading to silence, sorrow, and shame to different degrees. It seems as if men on the whole were more vulnerable than women.

Reflective summery of gendered experiences studies II and IV

During the focus group discussions (II, IV) the norms which control sexuality issues were captured. Looking healthy and attractive was dominating for the women, but was an ideal they could no longer live up to. Instead they felt that they made other people uncomfortable and embarrassed e.g. if they showed themselves nude in public physical exercise facilities. In these public facilities the women were incapable of performing based on prevailing expectations as women. Vasomotor symptoms made them feel less feminine due to the fact that they did not feel attractive when they were dripping with sweat and their face was flushed. At the same time, they had difficulty concentrating in this situation. This made them feel uncomfortable among people. They felt like an outsider, nobody could understand what they were going through. Again you can see how Butler’s performative theory was noticeable in these groups of women. To appear as a woman, a woman’s body is necessary and you should also behave according to the society’s expectations. The intimacy with other women in the cancer associations was a great support for them. On the other hand, many women in this study re-evaluated their ego, now focusing more on their own needs and allocating more spare time for themselves. Here you can see the potential for change. According to Butler, gender is structured through a series of imitations and repetitions. There are no original sexes and this is why change is possible.

For the men the stigma was slightly different. During the four group discussions the issue of hegemonic sexuality dominated. The symbolism of the phallus in society was discussed, both explicitly and implicitly. This seemed to have a dual meaning for the participants. Dual in the sense that they were convinced that the ability to have an erection is a man’s right, in line with hegemonic sexuality. Then again they felt they should be grateful for their treatment and happy to be alive. These men had lost some power according to the ideal of hegemonic masculinity. All the men were heterosexual and were used to interpreting women in general as sexual objects, important for their sexual well-being. Therefore, it seemed as if the men suffered in their superficial contact with women in the society. However, even the women
expressed dissatisfaction with this, though not to the same degree as the men. On the other hand, excluded sexual function vasomotor symptoms and bodily changes were not a major concern for the male informants. Both women and men described decreased desire and problems getting aroused. This was something they really missed, but it seemed that the males, on average, were more comfortable talking about it. In their close relations it appeared there was a silent agreement about the new intimacy situation. Sexual intercourse was not something they just could assume. These experiences seemed to be comparable in both studies. The feeling of shame was in some way deeper for the men because their potency had changed. This was something they had not experienced before, and was impossible to put into words. The focus group sessions filled a vacuum and were most beneficial for male friendship.
Reflections on the method

Reflection on the research process
During the period from summer 2003 until winter 2008, my understanding of the phenomenological method developed through this project. Before that time I was unaware of its philosophical implications. I was conditioned by my 25 years in a surgical clinic and therefore used to be thinking rationally; instead I had to learn to be open minded about subjective experiences in a new way. Rather than hunting the phenomenological researcher compares itself to fruit picking. The ones looking for fruit must observe with patients and move with slow gestures, so that the fruit can be gathered without changing its essence (Mortari, 2008, p. 11).

The phenomenological approach is not the opposite of the biomedical approach; it is just another way to understand what the latter may actually mean philosophically (Araújo Sadala & Adorno, 2001). The approach is not something which is possible to develop in a short time period. However, during these last few years I have felt that the nursing skills I gained from my long-term profession have helped me. As an interviewer I have felt secure, confident, and sensitive to the unknown while carrying out my mission. Since the design was framed in such a way that the same method was used twice, it has been most educating. I also wrote a research diary on a regular basis during these years. All thoughts, theories, and new approaches are documented in this diary and it is habitually checked. By doing this, I feel I have provided knowledge to the benefit of the phenomenological perspective, but perhaps to qualitative methods particularly.

The EPP-method, which was developed in psychology, was used. This method permits interpretation and has some common ground with the hermeneutic scientific approach which I found appropriate. At the beginning of the project I had difficulty being open about sexuality. It was not until the analysis in study III I felt that I could be totally open to the phenomenon under study. I think that my identification with the women, because we were in the same age group, made it more difficult to be open and curious. Also, the fact that this was my first study was another obstacle. In study III I was an outsider getting inside information. The men were therefore forced to explain what they really meant during the interviews. Hedestig points out the advantage of being the same sex as the informants to ensure trustworthiness (Hedestig, 2006). It can probably make the informants feel more relaxed, above
all when discussing a sensitive topic such as sexuality. On the other hand it is more difficult to be open-minded and not let pre-understanding take control (Trost, 2005). In an interview study about sexuality among 52 men with prostate cancer, the men themselves were able to pick the sex of the interviewer. Only one preferred another man (Chappel & Ziebland, 2002).

By carrying out focus group interviews, data triangulation was implemented in the project (Patton, 2002). In study II the first two group discussions took part in a time period of 16 months. The third group interview was planned and performed two years later. The reason for this was that during the analysis process I realised that there was not enough strength in the material. At this time the film “Through Sorrow and Joy – a film about cancer and sexuality” was distributed. I thought it would be an advantage to use it as a trigger. However, the group dynamics were so safe and creative that the film was probably redundant. In group 2 in study II the interview took place in one of the informants’ homes. She was well known in this group so this was not a big disadvantage. In this group, two friends took part, which affected the outcome to some extent. The friendship of these two women limited the opportunities for the other two women to participate in the discussions. In the last focus group in study IV the informants were slightly more unwilling to debate than in the other groups. I was more of a participant than a moderator. Afterwards, I felt that the informants really were grateful for their new insights into the phenomenon under study.

The coding system in the analysis was used differently in study II compared to study IV. During the time period between study II and study IV I progressed as a researcher. This progress and the fact that I was of a different sex to the informants in study IV affected the findings. I felt comfortable steering the group discussions due to my experiences in group processes over a number of years in a cancer rehabilitation program. An assistant researcher was used in three of the seven group discussions. It has been interesting working with the groups in different ways though I cannot say that it was a benefit in this project. The literature proposes using an assistant in each group, but this is probably more important in bigger groups than these (Krueger & Casey, 2009).

During this project I have worked in a close relationship with a sociologist and a nurse professor. This has been a great advantage for me during the analysis processes and has probably improved the quality of the results. This has also been observed by other researchers (Perry, Thurston, & Green, 2004).
**Trustworthiness**

The audit trail during these four studies has been illustrated throughout the thesis. Research is both an inspired and a harsh process and by using interpretation the researcher always takes the risk of losing some important information (Sandelovski, 1993).

In these four studies there are two critical aspects. First and foremost is the translation of the transcription from Swedish to English, and secondly there is the phenomenon under study. Every word and quotation was carefully dissected to ensure it articulated the right tone. This demanding work was done in collaboration with a native English speaker. Sexuality can never be an isolated phenomenon but as the two phenomenological studies (I, III) were carried out, some possible constituents were illustrated and some possible meanings were described.

In this project, purposeful sampling in cancer associations with an element of the snowball method was used (Patton, 2002). These samples, with some exceptions, included people who were heterosexual, ethnic Swedes. Also, the samples were dominated by middle class people. This may have limited the findings. However, the informants were people who probably valued sexuality highly and wanted to share their experiences with me. In that way, reciprocity between me and the informants was reached during the project.

The time limit may have been a limitation since it permitted only one interview with each informant. This can be a disadvantage when doing phenomenological studies (Patton, 2002). However, there were follow-ups of all interviews, and in studies I and II some information sessions in the cancer associations were held in order to report the findings.
Discussion

Modern societies can offer their citizens great medical treatment for various forms of cancer. The improvements during the last two centuries are unique in many ways. However, research has suggested that many of the bodily changes and sexual consequences can be difficult to cope with, and this can be devastating for self-identity and quality of life (Galbraith & Chrighton, 2008; Hughes, 2008; Tierney, 2008). In this thesis, the lifeworld analytical approach was used. In this way I could go beyond the natural science perspective and seek the experiences of sexuality. With the help of Butler’s and Connell’s theories it was possible to identify gender differences in these two groups of people.

The studies with women (I, II) were dominated by issues such as rapid body changes with loss of menstrual bleeding, hot flushes, feeling old and unattractive. The men (III, IV) were more affected by diminished desire and impaired or lost ability to achieved erection. This led to quite different coping strategies even if their losses and their difficulties interacting in the society were comparable. An earlier qualitative study describing premature menopause in a healthy population, younger than 40 years, suggested that there are multiple disruptions in the lives of women. In that study the women’s experiences of being out of synchrony, were comparable with the experiences of the informants in this thesis. Their being-in-the-world was ruptured, forcing them to become aware of their problematic body, leading to a sense of alienation (Boughton, 2001). In another study, exploring the experiences of hot flushes after breast cancer, the women spoke emotionally about being out of control. In both these studies, as well as in this thesis, the women expressed difficulties about interaction in the society as a whole (Fenlon & Rogers, 2007). The psycho-social consequences in this population are understandably heavy and the emotional components dominate. The initial period after diagnosis is dramatic and all the women’s efforts are concentrated on the cancer treatments. In this thesis this situation could be symbolised as a bird that is pinioned and unable to fly anymore. This is in line with two other qualitative studies on breast and gynaecologic cancer (Ekwall, Ternstedt, & Sorbe, 2007; Elmir, Jackson, Beale, & Schmied, 2010). In this thesis, to feel like an outsider (II) had a dual meaning for the informants. The positive consequences were personal maturity and re-evaluation of the “self”. This is often a positive result in the cancer trajectory for women (Berterö &
Chamberlain Wilmoth, 2007). In the context of heterosexuality, which is the setting in this thesis, women are used to being viewed from the male glance. Therefore, it is not strange that they do everything in their power to continue to act as before. But all these efforts are quite difficult to continue and the women need a well-functioning support network. For most women the erotic part of life had a rather obscure place in their life during the first transition period. Instead their needs for intimacy were satisfied by their children, pets, partners, and close friends. In a way, women are more privileged to have this form of intimacy than perhaps men are. One explanation for this may be the gender structures in the society, where women are expected to have a more caring role than men. This can also explain the fact that female partners of men with prostate cancer often take a more active and supporting role than vice versa.

For the men, the embodied experiences were quite different than in the group of women. The threat to their very existence, which was a result of the sexuality changes, made them sorrowful and silent. Qualitative studies about sexuality in prostate cancer are not as common as among women. However, there are some studies which confirm the findings of this thesis (III, IV) (Fergus et al., 2002; Gray, Fitch, Fergus, Mykhalovskiy, & Church, 2002; Oliffe, 2005). In a grounded theory study with 18 men (median age 65), of which four were homosexual, the stigma was evident. This was above all expressed by the homosexual men (Fergus et al., 2002). A very interesting finding in this thesis is how the men express and comprehend urinary incontinence. This is something they do not interpret as part of their sexuality. This seems to be an unexplored topic and, for me as a female researcher, quite strange. However, if I use the hegemonic sexuality with the phallus as an important symbol to seek an explanation for this I can understand it. People are often unaware of norms and ideals as long as they are healthy. The informants did not have to question the standards until they had sexual concerns of their own. The findings made it clear that some men actually could or had re-assessed their sexuality and had taken a more holistic view. A future challenge for those of us working in health care is therefore to invite men to discuss sexuality from a more holistic perspective.

Married and/or cohabiting couples were dominant in this thesis. It also seemed that the majority lived in harmonious relationships. Generally, it is an advantage for both women and men to have a partner who can support them during the cancer trajectory (Katz, 2007). A common opinion is that prostate cancer affects both sexes in a relationship in a different way to breast cancer (Katz, 2007). Perhaps the female partners play another role in their support for
the sexual consequences than male partners do in the reverse situation. The trend that elderly couples’ sexual activities strongly correlate to the men’s ability and interest has not changed during the last three decades (Beckman et al., 2008). Qualitative studies with men have explored the important role a female partner sometimes has in enabling the man to renegotiate his sexuality (Berterö, 2001; Charmaz, 1995; Fergus et al., 2002). This was also observed in my studies (III, IV), and it seemed to be very difficult for the couples to talk about it. According to hegemonic sexuality the sexual needs of women on the whole are toned down and they are not used to proclaiming them. This can be one explanation for why it is so difficult to talk about mutual sexuality in relationships.

The film used as a trigger in the focus groups (II, IV), resulted in an increased awareness for the men about the women’s situation. The discussions confirmed that men usually do not think that decreased desire for women is an obstacle for intercourse between couples. In all the four studies, the couples’ difficulty in talking, really talking, about their mutual sexual life was apparent. This is still a rather unexplored topic which is probably an underestimated problem in health care. A researcher in a focus group study, exploring the meaning of erectile dysfunction, identified quite similar experiences as were noticeable in this thesis. The intimacy, which earlier had been a way to accomplish closeness, was gone and some men had tremendous difficulty talking about it with their partner. This was due to embarrassment and performance anxiety, which were also expressed in this thesis (Bokhour, Clark, Inui, Silliman, & Talcott, 2001). Perhaps the ideal of hegemonic masculinity is an obstacle for men in this case. They are not used to expressing themselves emotionally but they usually do not have difficulty expressing themselves in other domains, such as workplaces etc (Johansson, 2001). In this thesis, having close relations was important for quality of life. In lifeworld research on women who have suffered heart attacks, this was compared to having a safety net. (This safety net should prevent the women from further suffering (Johansson Sundler, Dahlberg, & Ekenstam, 2009). This may also be the case in my studies.

Since sexuality is an integrated component of all other aspects of life the most important approach should be to offer symmetrical encounters in health care. Encounters usually establish a meeting between two persons with different lifeworlds and separate horizons. This means that a patient with all her/his expectations and alienation, which Swenaeus calls unhomelikeness, meets a professional who represents the medical perspective and symbolises some sort of an expert. If the encounter is to be mutual the professional must
be able to put himself in the patient’s situation. The patient also has to see things from the medical viewpoint of the professional (Svenaeus, 1999). This is a great opportunity for nurses who want their patients to cope and take responsibility for their life in the new situation. The learning process starts with giving the patient the opportunity to reflect. Thoughts, feelings and actions become more conscious by reflecting on experiences. Genuine learning is something that differs from the learning of information and therefore must be supported at an existential level based on the unique situation and must continue coherently for a long time (Berglund, 2011). Berglund’s essay points out the importance of the lifeworld and caring on an existential basis. This was also something which Källerwald explored in her thesis four years ago (Källerwald, 2007). It is also in line with dialogues aiming to strengthen the patients’ autonomy. Changed autonomy is perhaps the most important finding of this thesis. It was more evident in the group of men and can be explained by the theory of hegemonic masculinity and sexuality. The changed autonomy is invisible, but silence, sorrow, and shame are its outcomes. Nordenfelt highlights the importance of creating autonomy. Theoretically, it is about two things; the ability and the opportunity to govern oneself (Nordenfelt, 2000). Autonomy can be improved by using the theory of VOL in dialogues with patients, (Andersson, 2006). This is only possible if we have health care that is more individual and more focused on the lifeworld. Nursing care can be developed by using gender sensitive care where we consider the different conditions for health and well-being. These depend on the different gender characteristics and opportunities that are based on the lifeworld and the lived body (Miers, 2002). Thus, we have to use both perspectives; natural science and human science. This work has been started but we have already experienced difficulties. A qualitative study with nurses working as psychosocial nurses in cancer care revealed that the nurses did not understand their role or responsibilities (Arving & Holmström, 2011).
Conclusions and clinical implications

This thesis brings new and different perspectives on sexuality obtained from a group of middle-aged women and men diagnosed with breast and prostate cancer. Sexuality cannot be separated from other life dimensions, and therefore these people’s experiences are not unique to this group; they are universal. However, the complexity of the phenomenon makes this topic sensitive to address for professionals. In the same way, those who are affected tend to be silent and passive during the encounters. This thesis shows that although patients are not unwilling to discuss sexuality, they are silent in the cancer organisations. To address this topic is perhaps for future generations which will probably be brought up in a more liberated way. But we cannot wait; we must hurry. The great medical improvements during the last few centuries shall not be at the expense of human suffering.

First of all we have to change our perspective in health care and let caring science have as much space as the biomedical perspective. Even in health care, we have hegemonic ideals. Connell highlights the importance of awareness of all the different power relations in the society, and I can see that this is also true in health care. The concepts of curing, nursing, and caring are unfortunately asymmetrical and this is strongly reflected in caring science and how we treat our patients (Strömberg & Eriksson, 2010; Wijma, Smirthwaite, & Swahnberg, 2010).

Inspired by the lifeworld, we can interact with the patient and her/his partner, inviting them to talk and discuss with us. Using the whole professional team we can educate and guide them through their cancer trajectory. By inviting partners and/or other close friends of people in these populations, the conditions for improved sexual health can hopefully increase. Educating resources including booklets, websites, and other informative materials increase the opportunities for the patient to obtain knowledge about her/his body and the sexual consequences of the disease. In that way she/he or the couple can incorporate valuable knowledge into their lifeworld. It should be natural to offer regular patient education sessions which will complement the care. Then the patient alone can decide when and whether or not to learn about cancer and its outcomes.

Psychosocial oncology where sexuality has a place, should be of higher priority in the health care organisations. The professionals have to be mature and safe in their own sexuality to manage this priority. By letting regular
preceptorships and other tutorials play an important part in the health care organisations, the professional skills will develop. In the future, nursing care has to be more flexible and reflective. We have to ask: is this person in need of factual knowledge or is she/he more in need of emotional support? This is indeed a major challenge for future health care organisations.

It is tempting to suggest some assessment tools beyond PLISSIT and BETTER, which already exists. However, by focusing on the lifeworld perspective this is unnecessary. The most important thing is that patients should feel trust and faith in us as nurses, and should feel we treat them as whole human beings. The erotic part of sexuality and support with medical and technical advice could usefully be captured by implementing regular questionnaires. It should be evident from the medical records if the patients wish to fill in such questionnaires, and if they do, follow-ups are most important.

More research from a lifeworld approach is desirable. The relationship between couples is one important but undeveloped area. Ethnicity, homosexuality, and disabilities in these populations are other interesting and unexplored research fields connected with sexuality.
Kvinnors och mäns upplevelser av sin sexualitet efter behandling av bröst- och prostatacancer


Denna sammanfattning beskriver kort avhandlingen och resultatet av de olika studierna men däremot inte de diskussioner utifrån olika teorier som förs i avhandlingen.

Om bröst- och prostatacancer
Nära 14 procent av alla kvinnor riskerar att få bröstcancer under sin livstid. Denna cancerform upptäcks sällan hos yngre kvinnor, endast fem procent är yngre än 40 år. De flesta är äldre kvinnor och medelålders vid diagnostillfället är 64 år.

Tidigare upptäckt och allt bättre behandlingsmetoder har lett till att allt fler kvinnor överlevt allt längre och prognosen är relativt god jämfört med andra cancerformer. Kvinnor i norra Europa och Sverige har de högsta överlevnadsvärdena för bröstcancer med 87,8 procent efter fem år.

Behandlingen av bröstcancer kan bestå av operation, strålning, cytostatika och/eller antihormonmedel. Cytostatika är antagligen det som har störst negativ påverkan på sexualiteten. Denna behandling kan leda till minskad sexuell lust och svårighet att få orgasm. En effekt är att kvinnan kommer in i klimakteriet för tidigt vilket kan leda till olika besvär som vallningar,
muskelproblem och framförallt ett förändrat utseende, som gör att kvinnorna känner sig oattraktiva vilket i förlängningen kan påverka deras sexualitet.

Prostatacancer som är något vanligare (17 %) än bröstcancer drabbar en av åtta män innan de har fyllt 75 år. Överlevnaden är lika god efter fem år som vid bröstcancer. Cancern upptäcks sällan före 50-årsåldern men åldern för diagnos har sjunkit de senaste decennierna och allt fler män får sin diagnos före 65 års ålder. Detta beror förmodligen på en ökad medvetenhet hos befolkningen vilket har lett till ökad PSA-testning, trots vetenskaplig oenighet om värdet av denna testning.


**Syfte**


Det övergripande syftet är att ur ett livsvärldsperspektiv identifiera och beskriva hur medelålders (45-65 år) kvinnor med bröstcancer och män med prostatacancer upplever sin sexualitet efter diagnos och/eller behandling. Syftet är också att belysa och tydliggöra kontexten samt likheter och skillnader i upplevelserna mellan grupperna ur ett genusteoretiskt perspektiv.

**Metod och analys**

Resultatet bygger på fyra studier med totalt 46 informanter:

1. Fenomenologiska, individuella intervjuer med sex kvinnor i åldern 38-48 år. Alla utom en var gifta eller sambor.
2. Intervjuer i tre fokusgrupper med totalt tolv kvinnor, 39-54 år. Åtta av dessa var gifta eller sambor.
4. Intervjuer i fyra fokusgrupper med totalt 19 män mellan 53 och 76 år. 14
av dem var gifta eller sambor.


Majoriteten av informanterna rekryterades från föreningar för cancerpatienter i södra och mellersta Sverige.

I de individuella intervjuerna uppmanades informanterna att berätta om sina erfarenheter av att vara kvinna/man diagnostiserad med bröst/prostatacancer och hur detta hade påverkat deras sexualitet.

I grup pintervjuerna lade forskaren fokus på gruppdiskussioner för att dialogen främst skulle föras mellan grupppmedlemmarna i stället för mellan forskaren och informanterna. Visst material – bilder och en film – användes för att underlätta samtalen om sexualitet, intimitet och lust.

Avhandlingen har en kvalitativt beskrivande ansats. Forskaren har använt sig av en fenomenologisk, delvis tolkande metod, som heter EPP (Empirisk Fenomenologisk Psykologisk). Resultatet försöker beskriva fenomenets meningsstruktur, d.v.s. vilken betydelse i det här fallet sexualitet har för informanterna. Poängen med fenomenologisk forskning är att påvisa möjligheter, inte att kartlägga existensen av tillfälliga fakta.

Data från fokusgrupperna har analyserats med kvalitativ innehållsanalys som dock använts på delvis olika sätt för kvinno- respektive mansgrupperna. Detta har att göra med att forskaren hade en annan förståelse när det gällde kvinnorna; hon har i sin 20-åriga erfarenhet som onkologisjuksköterska haft betydligt fler kvinnliga patienter med bröstcancer än män med prostatacancer. Dessutom är hon kvinna. Förståelsen som cancersjuksköterska kretsar kring tre väsentliga begrepp, livsvärld/levd kropp, genus och sexualitet. Den levda kroppen med dess viktigaste drag, närvaro och kroppslig avsikt, formar basen för kunskapen i de fenomenologiska studierna.

**Resultat**

**Studie 1.** Den gemensamma innebörden för kvinnorna kunde liknas vid metafören av en vingklippt fågel oförmögen att flyga. Kvinnorna upplevde att de inte längre kände igen sig själva och att de hade blivit tvingade in i ett existentiellt vakuum. Det som var övervägande positivt var att de upplevde ny styrka i intima situationer trots att den erotiska delen av sexualiteten var förändrad.

De kände att deras kropp hade förändrats på ett dramatiskt sätt. De kände inte igen sig själva vilket påverkade dem i deras sociala kontakter. Att komma in i klimakteriet i deras ålder var inget naturligt och freståde på, eftersom de inte visste hur den medicinska behandlingen skulle påverka dem och vilka konsekvenserna skulle bli på lång sikt.

I det existentiella vakuum där kvinnorna befann sig kunde de inte skapa en identitet som kändes säker och välbekant. Den existentiella basen för kunskap var borta. Efter det att cytostatikabehandlingen var avslutad väntade sig kvinnorna att de skulle bli friska och starka igen. De kämpade för att leva upp till dessa förväntningar samtidigt som de kände att ingen förstod vad de gick igenom. Partnern och andra nära vänner spelade, liksom medlemmarna i cancerföreningen, en viktig roll för kvinnornas välbefinnande. I cancerföreningen kunde de bli bekräftade i sina känslor av utanförskap och förlust av sin kvinnlighet.

De kände det som att de måste övervinna hinder för att bli sexuellt upphetsade. De var inte heller säkra från gång till gång om de verkligen skulle ”tända till” så att de kunde njuta av samlaget. Samtidigt ökade deras behov av kramar och närhet. Kvinnorna kunde också uppskatta andra saker partnern gjorde för dem på ett nytt sätt. Detta ledde till att de intima relationerna förstärktes.

**Studie 2.** I fokusgrupperna identifierades fyra subteman: **att känna sig annorlunda, den oregerliga kroppen, erotiken är inte vad den brukade vara** och omvärdering. Kvinnorna hade svårt att tala om positiva känslor kopplade till kvinnokroppen och visste, liksom kvinnorna i studie I, inte vem de skulle identifiera sig med. De två först nämnda teman symboliserar de kroppsliga förändringarna till följd av menopausen och här stämmer resultatet överens med det som kom fram i de individuella intervjuerna i studie I.

Erotik kopplat till attraktion, längtan och kärlek diskuterades under de olika sessionerna. Temat, **erotiken är inte vad den brukade vara**, illustreras av att kvinnorna drog sig ifrån sina partners, attraktionen för partnern minska och det tog längre tid att bli upphetsad. Det var som om de inte längre kunde
hänge sig åt sina erotiska känslor. Majoriteten av kvinnorna levde i harmoniska förhållanden. De kände stor förståelse från sin partner vilket ökade intimiteten och stärkte kärleken, men inte den erotiska delen.


**Studie 3.** Den gemensamma inneböden för männen var att förlora sitt livselixir. Kännetecknen för detta var: något som inte längre finns, hotet mot manligheten, intimitet och slutligen spelad manlighet.

Temat, något som inte längre finns, belyser informanternas upplevelser av minskad lust och/eller impotens. Den minskade sexuella förmågan kunde i viss mån kompenseras med piller och/eller tekniska hjälpmedel men för många var detta inte något alternativ. Männen kände sig också obekväma med att behöva arrangera allt i förväg, vilket minskade deras motivation för att ha samlag.

Att ha fått prostatacancer och genomgått behandling innebar ett hot mot manligheten. Att ha fått minskad sexuell förmåga var bara en del av problemet, istället kände männen det som om hela deras existens var hotad. Att inte ha kontroll över sin sexualitet gjorde dem mer sårbara och kunde ge upphov till skamkänslor.

En del av männen upplevde sig vara stymade, att de bara var en halv man jämfört med tidigare. För dem var cancer omgärdad av mystik, de förstod inte hur den påverkade deras sexuella förmåga eller livet i stort, och de uppmuntrades inte heller av sjukvårdspersonalen att ställa frågor om detta.

**Intimitet** symboliserar den erotiksa delen av patientens livsvärld. Före diagnosen hade samlag med partnern varit ett sätt för männen att uppnå intimitet. Då detta inte längre var möjligt påverkades deras självkänsla och relation med partnern ibland negativt. När förmågan att genomföra samlag minskade, utvecklade de nya sätt att ha samlag eller också blev de mindre
sexuellt aktiva. Intimitet kunde då också uttryckas genom dagliga omsorger om varandra.

*Den spelade manligheten* symboliserar svårigheterna för mannen att leva upp till manliga ideal i samhället. Detta är kanske mest tydligt i rent manliga miljöer.

**Studie 4.** Här identifierade forskaren 16 subteman och fyra teman. De fyra teman var: när kroppen sviker och känslor och relationer förändras, prostatacancerns effekt på manligheten, sex med tekniska hjälpmedel och piller samt att gå före och ha modet att prata.

Majoriteten av informanterna levde i ett fast förhållande där man hade utvecklat sexualiteten på sitt eget sätt. De sexuella behoven undertrycktes när den sexuella förmågan blev den huvudsakliga stressfaktorn. Under sjukdomsprocessen omvärderade dock en del män sitt sexualliv och ändrade sitt samband mellan deras livssituation och sexuallivet.


**Genusperspektivet.**
Tiden efter cancerbeskedet upplevde både män och kvinnor ett hot mot den egna existensen. De kände ett slags främlingskap gentemot omgivningen och

Både männens och kvinnornas partner var ett stöd men för båda grupperna kunde man se att det fanns underliggande känslor av sorg och samvetskval gentemot sina partners. Känslan av skam och motvilja var djupare hos männen eftersom deras potens hade förändrats och denna upplevelse var helt annorlunda mot alla tidigare erfarenheter. Det var svårt att prata om detta med partnern och fokusgrupperna blev här ett forum för sådana samtal.

**Utmaning för vården**

Genomgående för alla delstudierna är att män och kvinnor har svårt att prata med sin partner om sexualitet. Eftersom sexualitet är en av flera dimensioner i en helhetssyn på patientens liv är det viktigt att det finns en beredskap i hälso- och sjukvården för att ta upp sådana frågor.


faktakunskaper eller är det istället mer emotionellt stöd som han eller hon är i behov av.
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