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Sexuality in the aftermath of breast and prostate cancer

Gendered experiences

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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 (Word 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; Word 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; Word 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; Word 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 & Chamberlain 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

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